

Increasing the uptake of Bowel Cancer Screening in BME communities in Nottingham City

A qualitative study

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Introduction

Bowel cancer is the fourth most common cancer in the UK. In 2011, there were 15,659 bowel cancer deaths recorded: 7,139 women and 8,520 men (Cancer Research UK, 2014). In women it is the second most common cancer after breast cancer; for men, it is the third most common after prostate and lung cancers. More than 8 out of 10 bowel cancers are diagnosed in people aged 60 or over.

Bowel cancer is a predominantly curable disease, especially when it is caught in its early stages (Beating Bowel Cancer, 2012). The mortality rates of bowel cancer have been falling in the UK over the past few decades.

The mortality rate for women more than halved over a period of 40 years, falling from 26 deaths per 100,000 people in 1971 to 12.6 deaths per 100,000 in 2011. This figure increased slightly in 2012 to 13.0 deaths per 100,000. The rate for men has also shown a significant decline, with 33.5 deaths occurring per 100,000 in 1971 falling to 20.3 deaths in 2011 (20.5 in 2012). (Cancer Research UK, 2014).

The NHS Bowel Cancer Screening Programme (BCSP) rolled out a nationwide campaign to screen the population aged between 60 and 74 every two years, with those over this age group able to obtain home screening kits. Screening for bowel cancer is a test designed to be done at home, in an attempt to make the perceived unpleasant nature of the process as agreeable as possible. People are sent a kit in the post that requires them to add faecal samples and then send back for laboratory testing; this is called a faecal occult blood test (FOBT). There are, however, limitations surrounding the engagement of certain community groups in the uptake of screening for cancer, and perhaps more so where there is active engagement required. These groups of people include black and minority ethnic (BME) groups, those facing social and economical deprivation and men.

In the UK and many other countries globally, there are initiatives and campaigns to help raise awareness of bowel cancer screening in the community; these are run both in collaboration with governments and by charities and advocacy groups. Extensive work has been done surrounding the identification of barriers faced by individuals and to identify the ways to breakdown these obstacles and encourage more people to take part in the possible life-saving process.

Aims of this study

Despite a growing and significant body of research that has enabled health academics and professionals to develop better identification of, and responses to, the incidence of bowel cancer, there remain a number of gaps. In the context of this study, Nottingham faces particular challenges both in terms of higher rates of incidence (of all cancers) for men, when compared to the East Midlands. Whilst mortality rates have declined, premature mortality in Nottingham (for all cancers) is higher than the national average and higher than most comparator cities (Nottingham City Council 2010). Finally, it is now

largely accepted that early deaths can be better prevented through better prevention, behavioural change and addressing structural, social and cultural health inequalities. In Nottingham, there is evidence of significant differential rates of health screening uptake with the BME population less likely to engage in bowel cancer screening.

This study therefore aimed to:

- Investigate the barriers to bowel cancer screening uptake amongst Nottingham's BME communities.
- Identify opportunities for increasing uptake, including drawing on good practice.

The study draws on two significant phases of work:

- A literature review, designed to capture and assess a wide range of evidence from academic work and 'grey literature' encompassing policy reports and good practice.
- A participatory action research project, utilising community researchers drawn from Nottingham's BME population to undertake qualitative fieldwork with a total 226 participants.

The study was undertaken between March 2014 and May 2015.

Methodology

Stage 1 – Literature review

A review of the literature was undertaken to establish: (i) what is known about the barriers and challenges to encouraging uptake of bowel cancer screening amongst BME communities; (ii) evidence of good practice and solutions that have demonstrable results in increasing uptake and (iii) what strategies have been used to increase uptake or participation in other public health issues that might provide additional insights.

A quasi-systematic review was deployed including an assessment of whether any existing systematic reviews offered insight. A search of grey literature and details about relevant campaigns to increase uptake in cancer screening was undertaken through Google and DARE CDSR NIHR databases.

In terms of finding academic literature, NTU One Search, Google Books and Scholar were used to find relevant articles. Exclusion criteria were limited to any reports not concerned directly with the uptake of a form of cancer screening and initiatives. Relevant academic literature was found using a range of search terms including: barriers or challenges and bowel cancer screening, faecal occult blood test, BME, Black, African, Afro-Caribbean, Caribbean, Chinese, Indian, Pakistani, good practice, increasing uptake, solutions, results, participation and public health issues, UK, USA, Australia.

In terms of finding relevant non-academic literature (i.e. grey literature and practical initiatives), Google was used as the primary search tool, and returned the vast majority of the research results, while some references from

documents found on Google Scholar were also used. Relevant non-academic material was identified through use of a range of search terms, including the cancers for which screening can take place, terms for BME communities, various specific geographic locations, and words relating to participation. Search terms included: bowel cancer, cervical cancer, breast cancer, mammography, faecal occult blood test, screening, rates, uptake, participation, ethnicity, ethnic minority groups, black and minority ethnic / BME, marginalised communities, UK, USA, Australia, NHS, charity and advocacy.

Over a 100 relevant academic articles, websites and other reports were identified from literature searches. Those that had no direct relevance to Bowel Cancer Screening or lessons to be learnt from an increased participation in other cancer screenings were not included. Searches also uncovered articles from Eastern countries and were included in the literature review because of the barriers recorded or proven initiatives to increasing participation in Bowel Cancer Screening. A total of 85 articles, websites, reports and grey literature were included in the review.

Stage 2 – Participatory Action Research

This study adopted a Participatory Action Research (PAR) approach to data collection, analysis and verification that draws on the philosophy and methods of social action (Mullender, Ward & Fleming 2013). In doing so, it provides an original contribution to knowledge around bowel cancer screening uptake in Nottingham, both in terms of the methodological approach used and the findings obtained through peer-led research.

Patient and public involvement is now seen as a central component of funded health and social care research ‘where service users are part of a team undertaking the research’ (NIHR RDS East Midlands, online¹). PAR yields a number of benefits:

- 1) Peer-led approaches can help to encourage discussion on sensitive or taboo health subjects (as in Wood et al’s (2011) work on BME groups and mental health).
- 2) Language, cultural and power barriers are often mitigated by recruiting local people to research health issues (Ledwith & Springett 2010).
- 3) Social action approaches enable groups to take action as the research unfolds, resulting in possible changes to attitudes and/or behaviour as a result of engagement.
- 4) Recruiting local researchers can result in a successful ‘snowball’ sampling strategy. This was particularly evident in this study where our researchers were able to access places of worship and community settings that they were familiar with in order to widen their participant reach.

In practice, the study followed a number of set stages:

¹ See: <http://rds-eastmidlands.nihr.ac.uk/ppi.html#sthash.HyOMDetO.dpuf>

Recruitment and training of 'community researchers'

We recruited 15 local residents through our known community and faith networks to act as community researchers in the study – representing a convenience sample approach. Between the initial training workshop and the commencement of fieldwork, two participants left the project, resulting in 13 working with us for the duration of the study. Seven participants were female and six were male. Researchers came from a number of different backgrounds in terms of previous engagement with health services/health research and their own ethnic, religious and cultural identities:

- 3 Indian Sikh Punjabi speaking
- 1 Indian Hindi speaking
- 1 Indian Gujarati speaking
- 3 Pakistani Mirpuri/Urdu speaking
- 2 Bengali Sylheti speaking
- 2 African –Caribbean (English)
- 1 White British (English)

They completed two days of training on approaches to research, qualitative interviewing techniques, ethics and data protection. Alongside this, a significant proportion of time was devoted to the co-production of research instruments. A draft qualitative interview schedule was presented by the research team and re-drafted, piloted and finalised working with the community researchers. This approach was necessary to ensure that the questions used were appropriate within the context of interviewing different BME groups.

Fieldwork and analysis

The community researchers completed 226 qualitative interviews, against a target of 200. However, some interviews were not analysed on account of falling too far outside of the age band (80+), poor quality or judged by the research team not to have proceeded – for example, a participant misunderstanding and withdrawing part of the way through. Exclusions accounted for, a total of 178 qualitative interviews were analysed.

Interviews were semi-structured, driven by the aims of the study and were design to explores the perceptions and experiences of participants in depth and in context (Miller and Crabtree 2004). Interviews explored:

- Individual biographical information.
- Awareness questions of cancer generally and bowel cancer specifically.
- Awareness of and engagement with the bowel cancer screening programme.
- Perceptions and experiences of barriers, including an assessment of what common barriers might exist within their community.
- Suggestions for how uptake might be improved.

This report draws primarily on the voices of participants. Where we have used quotations, we identify the participant by as many characteristics as they volunteered during the interview. A typical quotation will feature:

[Gender, Age, Ethnic Origin, Religion]

For example:

[M68, Indian, Sikh]

Qualitative data was transcribed for analysis in two ways, using an iterative process of describing, classifying and connecting data (Dey 1993; 1998) within a framework of adaptive grounded theory (Layder 1993; 1998). The first approach was participatory analysis through two structured analysis workshops with the community researchers. Working with NTU academics, the community researchers reviewed data, identified emerging themes and identified commonalities and differences across their datasets. In addition to providing a distinctive analytical contribution, this in itself provides new data and throughout this report, quotations from these analysis workshops end with:

[Community researchers]

Verification and participant validation

Participant validation (PV) is a key element of effective policy orientated research, advocated as a good technique for enhancing the quality of inferences in qualitative research (Lincoln and Guba 1985), to check with participants 'the accuracy of the themes, interpretations and conclusions' (Tashakkori and Taylor 2008: 109) and to make recommendations more grounded in everyday practice. The third stage of the study attempted to use verification and participant validation techniques in two ways: through focus groups with community and faith leaders, and through a learning workshop with policy makers and practitioners locally. The latter was a successful event held in January 2015 where emerging findings were deliberated and the recommendations that feature in this report arise both from analysis of the data and the discussions at this event. The former – focus groups – proved more challenging, not least in the repeated difficulties in bringing together faith and community leaders. In two cases, focus groups were arranged where no participants attended. Three groups were subsequently held where emerging findings were reviewed. We do not refer directly to either of these validation events in the substance of the report, but they do inform the final section – the way forward.

Section 1: Barriers to uptake

Cultural and language barriers

There's a lot of reasons why people won't do it. You've got the Asian, you've got the blacks, they won't do it. They won't do it because it's like a taboo to them. I would encourage all of those to take part in the bowel cancer because for a culture or a nationality, and also the food that we eat, and we need to look at our diet because that as well can cause the cancer. When there are too many chemicals in the black body as well trigger all these things. So something we eat as well can trigger bowel cancer.

[F73, Indian Sikh]

Research from other countries identifies older age (Powe, 1995; Weinrich, 1990; Boring, Squires and Heath, 1992; Hoffman-Goetz, Breen, Meissner, 1998) and shorter acculturation or length of residence (Lindholm, 1995; Theuer et al, 2001a; Theuer et al, 2001b) as significant predictors of low screening uptake, both of which may be related to cultural and language needs. Acculturation refers to the process of psychological and cultural change that occurs when individuals or groups from one cultural engage with another. In the context of studies such as this one, acculturation might refer to new migrants adapting to cultural or structural systems that are different to the ones they are used to.

We did not find strong evidence of shared cultural beliefs, expressed by participants, which would account for any one particular BME group not engaging with screening.

Rather, across all groups and in most cases, a longer period of acculturation provided people with more awareness of the health systems and in some cases, the treatment options for cancer. As one community researcher observed, many people from the Caribbean community had close contact with the NHS having worked within hospitals:

[An interviewee] has been here since the fifties, the Caribbean people have been here a very long time and a large portion have worked in the health service. And when it comes to health they have a very good understanding and the language. Its common threads in terms of why they perhaps will integrate under the national agenda, because cancer affects everybody irrespective of race, gender, religion.

[Community Researcher]

Certainly, language has been identified across the literature as being a significant barrier to screening for some BME groups. A campaign run by *Breast Cancer Care* found that around three-quarters of BME women would like access to healthcare information in their own first language (Gordon-Dseagu, 2006). Austin et al (2010) also found evidence of language difficulties failure to meet religious sensitivities and the expression of culturally

influenced health beliefs as specific barriers to uptake of flexible sigmoidoscopy screening for colorectal cancer amongst ethnic minority groups.

Thomas et al. (2005) in a study that observed factors that act as barriers to effective uptake of breast and cervical cancer screening services amongst different BME groups (Indian- Gujarati, Pakistani (Urdu), West African, African Caribbean, Arabic Muslim, Greek) found language barriers to be important barriers. Language was the most commonly reported barrier among the Gujarati and Muslim communities. The groups in that study reported that screening information leaflets were not available in all the BME languages and where translations are undertaken, the translation is not always adequate. While African people spoke and understood English, the importance of screening was not conveyed owing to terminology and nuances of the language used.

Language was a barrier commonly identified throughout the Nottingham study, across all groups. Community researchers reported that those with good levels of spoken and written English were better able to articulate an understanding of cancer and the possibilities for treatment, and that this was a stronger factor than say, religion or cultural norms:

A lot of issues are through ethnic minorities, I think they need to understand it because I think a lot of people in this country have issues with reading and writing and the message is not coming through to them.

[Community researcher]

However, it is important to state that although language may prevent an understanding of cancer and treatment options, in some cases this did not prevent people from participation. The case of one Pakistani woman, aged 66, who moved to the country 7 years ago and whose language was Urdu, demonstrates this. During the interview, she reported low levels of understanding of cancer generally and no knowledge of bowel cancer, but she had taken part in the screening process. In this case, having a daughter who could access the internet to find out more about the screening process had been invaluable. The use of family members and other supporters was key to helping people access the right information, for example in this exchange:

Participant: We don't understand how to put it in, because normally I take [my mum] to the doctor and they give us a bottle if we send a urine sample. That paper, we didn't know that, we had difficulty.

Interviewer: And with regards to the instructions did you have any information that told you a bit more about bowel cancer?

Participant: That I don't know because I didn't read because my English is not good. My sister in law she read it and she found out.

Interviewer: So when it came to dealing with the process you took over the ...

Participant: If I don't understand something I take my letters to my sister in law or somebody else who can explain it.

[F66, Pakistan, Muslim]

The reverse was the case for a Pakistani male, aged 62, who had good levels of spoken English. Although he had lived in Nottingham since 1967 with a long history of working here, he could not read or write in English. During the interview, he expressed low levels of understanding about cancer and the screening process but upon being shown the kit, recognised it. He had not participated on account of he and his wife (whose language was Urdu) not being able to read the instructions:

Interviewer: ...would you go to anyone else to ask how to use that?

Participant: Yes but I didn't find anybody because downstairs the lady, she has just been...has been off for a couple of weeks being sick so I can't ask that lady.

Interviewer: Would you feel comfortable asking the lady?

Participant: No

Interviewer: [...] Who would you feel comfortable with to talk about that?

Participant: Some men

[M62, Pakistan, Muslim]

Here, language, access to help and the issue of gender were identified as issues during the interview. The issue of discussing this with people of the same gender was certainly a theme. When asked about how the screening process could be better promoted, one participant suggested:

By speaking... with ladies we Muslims don't really go to the male, we go to the male doctors but it's quite embarrassing when they show the pictures of bowels, and the females show pictures and then they tell us the signs and explain the things, that can be helpful.

[F66, Pakistan, Muslim]

Most participants called for the instructions that accompany the kit to be in the languages they would be able to read:

I have seen in lots of papers they do write in Punjabi, Hindi and Urdu as well...they can do that.

[F66, Indian, Sikh]

However, some recognised the practical challenges of this. There were suggestions to improve the visual guides:

... lots of ladies don't read English they don't know and you should show them a picture of what happens and what you have to do, what can save you from it.

[F68, Indian]

Religion was occasionally identified in terms of people's attitudes towards cancer, with some expressions of fatalism. However, it was more strongly identified as a potential source of support for promoting the screening process. Many people identified the importance of their local places of worship and the faith leaders who could act as a 'role models' in challenging some perceptions:

I'm not very sure but I think it is more a cultural thing that they need because they think well if God wants me to suffer that way I'll go and suffer. It's a sad thing but people do. And the Hindu religion is very calm and if something happens they think if God thinks, God is right.

[F64, Indian, Christian]

Austin et al (2010) also uncovered other important culturally specific barriers, which may be applicable to understanding the low uptake of screening amongst certain ethnic minority groups. For example, female Pakistani participants spoke about their attitudes to cancer treatment where some women in the group were reluctant to seek treatment believing that the treatment itself would cause the cancer to advance. Austin et al (2010) also reported that African-Caribbean participants stated cancer as a 'taboo' subject within their community. Both of these factors, within the context of this study, are further discussed below.

Better not to know: fear and embarrassment

[I'm] terrified, shaking [that] I'm going to drop dead from cancer. No cure for cancer. And I think knowing about cancer will kill you off quicker than the disease itself because the worrying will kill you off, not the cancer.

[F, Caribbean]

The relationship between the perceived threat of illness, levels of self-efficacy and levels of fear is well documented in the health promotion literature. Where perceptions of efficacy are low but a perceived threat is high, people respond by controlling their fears rather than addressing the problem. Fear itself becomes a justifiable reason for not taking action:

People engage in fear control processes when they do not think they can adopt an effective response to avert a serious and relevant threat because the response is too hard, too costly, takes too much time, or they think it will not work...as a result people focus on how frightened they feel and try to eliminate their fear through denial [e.g., "I'm not at

risk...”], defensive avoidance [e.g., “This is just too scary; I’m simply not going to think about it”] or reactance [e.g., “They’re just trying to manipulate me; I’m going to ignore them”].
(Witte et al 2011)

Individual interviewees, from across all groups, identified fear as a key barrier to participation in the screening process, especially in relation to obtaining a result. Perhaps unsurprisingly, this fear was often described in relation to *others* – i.e. it was externalised in response to a general question about why the ‘community’ might not be participating.

People are scared but they don’t realise [it can be treated]. But maybe some do and they go to the doctors and have the treatment...they are scared.

[F61, Indian, Sikh]

I think that the only reason is, when I think I think that they’re afraid they might get the result but they’ve no idea. So it’s better they don’t know and then tomorrow your light’s out and you’re gone

[M59, Caribbean, Rasta]

...a lot of people can complain they will never go forward because it’s too private to them, they prefer to die, they wouldn’t go forward to get help. So a lot of people with bowel cancer they say I am not going because they might say it’s cancer, I am not going. That timidity will keep them away from getting help.

[M75, Caribbean, Christian]

Mostly because they are scared, they want to know and they don’t want to know. If they know they are frightened and if they don’t know it doesn’t bother them. They are scared and they want to know they don’t want to know. Well I did want to know and that’s why I went through all that. People are very scared, frightened.

[F89, Caribbean, Christian]

Generally, participants agreed that early detection and prevention could result in better outcomes. However, the two strongest mitigating factors were the problem of screening in the absence of symptoms (discussed later) and the fear of participating:

We know that some people are just scared of this. I know my son is one of those people he does not want to go to hospital for fear he will be told of the diagnosis which will then stress him. Some people say let nature take its course and they only want help when they come to the extreme. So it’s just a fear of maybe hospitals, a fear of what happens. Some people definitely have a fear and therefore when they are told come and do an investigation they fear maybe it’s already confirmed, just because they are invited it means there is a suspicion they have it so they have it, in their mind that’s what they think. And that alone can

keep people away from having regular screens because they have the fear.

[F59, African, Christian]

The other thing as well, especially in the BME community, we don't talk about it so we leave it until it's too late before anything can be done. But if we pick up the pride and said yes, go and check with the doctor, yes it can be treated early instead of leaving it too late.

[F, Caribbean]

In responding to this, some participants again talked about the need to meet or hear from people who could act as role models. This was particularly common among the Punjabi Sikh participants, most of who suggested that better promotion could be undertaken through the Gurdwara. People doing the promotion (such as medical professionals) could give specialist lectures and talks to enlighten people on the process and allay fears. In some cases, it was suggested that this could be done by those who have had direct experience of cancer:

Participant: I would say someone who has got...knowledge of cancer or who has been through cancer.

Interviewer: They have already experienced it themselves?

Participant: Yes, at least that way you wouldn't have that fear then. So that person can show the old person look I have got courage you can have courage as well.

[M63, Indian]

Personal exposure to cancer, often through relatives or friends experiencing it, was a powerful factor that shaped attitudes towards screening and early help. We were told powerful stories about the impact of seeing dying friends or relatives and how this affected individuals and their own fears:

So I went after about 3 years and I was in pain and I'm not telling anybody about it because I was so terrified that it would be cancer...[I also had a lump on my breast...] But I knew in my heart it wasn't cancer...That was the most terrifying thing of my life, I didn't tell anyone.

[M, Caribbean]

Our findings certainly endorse the work of previous literature in this area. Austin et al (2010) found that across all ethnic groups except the Pakistanis (who did not comment), fears centred on the results of the screening test and what they might mean. Similar fears have been reported by other studies. For instance, in Damery, Clifford and Wilson (2010) study of GP attitudes to screening, 24% reported fear of the result to be a major barrier while 65.6% reported fear of the result to be a minor barrier to patient participation in screening practices. Chapple et al. (2008) reported that fear or dislike of

colonoscopy also influenced people's decisions about participation in screening. Fear of cancer was also identified as a barrier by Javanparasat et al (2010) in nine of 27 studies reviewed by them.

Although not commonly expressed, for some the issue of stigma or shame was raised. One interviewee **[F63, Indian, Sikh]** indicated that people might not take a test due to the potential for feeling *'ashamed...not wanting to tell anyone in the community'*. Another: *'...they could be ashamed, I am not going to tell anyone I have got cancer'* **[M63, Indian]**.

During our analysis day, one of the community researchers noted:

I had a really interesting comment by the African Caribbean lady I was speaking to, it wasn't until afterwards when the tape was turned off, but she said cancer had the same stigma as AIDS. She said everyone thought that everyone died from cancer but now it's not like that any more.

[Community researchers]

Interestingly, the idea of shame in one interview was linked to seeing cancer as firmly linked to behavioural choices: people *'not paying attention to their health and eating whatever they can'*. Expressed in this way, cancer was a consequence of poor choices.

We were reminded too that health is a very personal issue:

But I do feel that people don't wish to talk about it because it's very personal, emotions and psychological effect it has on them as well as the impact on the family, they don't know how to deal with it. So educating the mindset.

[F, Indian]

And one connected to personal pride:

Sometimes the embarrassment to tell people, you know, if they find out they've got that some people don't want to, you know. In our culture people don't like to say to the guy, oh he's got cancer, or anything like that but if one person can do that it can save another ten people's lives because it can catch up to other persons as well.

[M62, Indian, Sikh]

In Damery, Clifford and Wilson's (2010) study of GP attitudes to screening, half of GPs reported embarrassment and anxiety as being a major barrier to Colorectal Cancer (CRC) screening (49.9%) while over two fifths of GPs reported it to be a minor barrier (44%). Embarrassment was also identified as barrier by Javanparasat et al (2010) in seven of 27 studies reviewed by them. We had some people in our study describing their embarrassment with the process and this was also unsurprisingly manifested in some of the interviews,

which were categorised by shorter responses to the questions. The issue of 'disgust' with the process was also highlighted (see page 20).

If they felt healthy, why should they attend a health check-up?

Encouraging people to screen in the absence of symptoms, as a normal process, poses a real challenge to the success of the BCSP. The obvious difficulty is in shaping a message that convinces people to take part when they might otherwise feel healthy (a theme we return to in the final section). In most cases, people subscribed to the view that cancer could be treated successfully if caught early enough. We also found there to be a general lack of awareness about the specifics of bowel cancer but good awareness of other types. However, what was most stark in the questions around awareness was the clarity of some messages about what to look for and when to take action versus the commitment to engaging in screening when symptom free.

Some participants questioned the value of screening when healthy, exemplified by this quote:

...If you have got any symptoms you should talk to your doctor. If you haven't why should you bother...I never bother about anything like that.

[M57, Indian, Sikh]

We are mindful of the many reasons why people might avoid screening – not least in relation to the ideas of fear, embarrassment and taboo discussed above. Other factors such as time, pride and 'process confusion' are discussed below but some participants (and our community researchers) felt that there may be a bigger issue about the value of prevention more generally:

I think people still feel in most of the Asian and black community that when it comes we'll take it but they don't go for prevention. I am different, I say no, prevention is better than cure.

[F64, Indian, Christian]

As stated above, it was evident from the study that many people could describe the early warning signs and symptoms that would necessitate a visit to the GP – which in itself is a form of preventive action:

...when you go to the toilet you must always look in the bowl if blood is in your faeces, it could be a blood vessel burst, you must always look and see what you see.

[M76, Caribbean]

There was evidence though of being aware of the combination of these two prevention messages. For instance, a married Black Caribbean couple had both participated in the screening process and could tell the interviewer about

the difference between this and the need to proactively seek further help if and when symptoms arise.

Interviewer: And do you know what happens about the screening process, how that works?

Participant – Man: Yes they send you a pack and ask you to take samples of your poo and after three or four days you post it back to them. And then they analyse it and see if you are ok. Actually what they are looking for is any blood in it. ... If there is any blood in your poo, when you have a wee you really should look at it because if you are passing blood you need to report it to your doctor because there is something wrong. It could be a one off but report it. Once you start to pass that blood, showing signs of passing blood, you have to be aware and careful.

Participant – Woman: Go straight to your doctor.

Participant – Man: Take notice and report it and get help.

[MF, Caribbean, Christian]

In keeping with much work around prevention and screening uptake, our study has found a widespread perception that men are less likely to engage when compared to women:

Well the point is this, especially the men, I think the men are afraid to go. The women will have more opportunity to go but men they think its something and they are ashamed and they will hide it until it's too late.

[F70, Black British, Christian]

Austin et al. (2009) found that screening was considered to be a 'threat to masculinity' by African-Caribbean males. However, studies examining screening uptake figures indicated no significant difference between African-Caribbean men and women and research has suggested this reluctance is not exclusive to African-Caribbean men (Robb et al, 2008; Galdas, Cheater and Marshall, 2005).

We would concur with these studies insofar as whilst a particular gender issue was highlighted, this was across all BME groups. Some participants suggested targeting women through campaigns:

I think they should get the women, women listen more than men...they are interested more than men

[F65, Indian, Sikh]

Family dynamics were seen to be important with women taking a more active leadership role in relation to family health and wellbeing, whereas men were often portrayed in these examples as quite passive. Another participant described having all of his interactions with medical appointments and family events mediated by his wife.

Men who perceived themselves as healthy may not see why they should screen for a cancer (Wilkins, 2011). Austin et al also found that Pakistani participants held a very biomedical view of the health-care system, refusing to attend tests unless told to go by the GP. In Damery, Clifford and Wilson's (2010) study of GP attitudes to colorectal cancer (CRC) screening just over a quarter of GPs stated that patients do not perceive CRC as a serious threat, thus did not attend screening was a major barrier (25.2%), while almost half of GPs thought it was a minor threat (47.5%). Chapple et al. (2008) in a study which sought to understand why some people decided to participate in screening for bowel cancer while others did not also found some evidence of participants stating that they felt healthy, thus did not feel the need to participate in the FOBt screening. Further in a study examining gender differences in the use of colorectal cancer tests among older Chinese adults, Chow Choi et al. (2013) found the most commonest reason for not participating in the FOBt test, for both genders, was that they perceived the test was not necessary and that they believed they were 'healthy all along'.

There were plenty of strong views expressed about people's unwillingness to take responsibility or action for their health. We have highlighted some of the context of this above, but it is also important to signal the issue of 'time' when set against the levels of active engagement and sustained motivation required for screening, especially when it takes place in the private sphere of people's homes.

They don't want to go and waste their time to go and they don't want to waste the time in the house doing things like that. So they just don't bother, some people are like that. Because I went through, I knew, and touch wood they have not been through and that's why they are saying these things.

[F68, Indian, Sikh]

The Patient Navigation evaluation found that some patients (21 per cent of participants) said they did not attend breast screening appointments because they were busy. This could suggest people are not prioritising their health screens (Betterdays Cancer Care, 2011). Chapple et al. (2008) also found some evidence of people stating that they did not have time to participate as a barrier to FOBt screening.

I guess one will be because of ignorance, two a letter comes and sometimes if it's not urgent or if you don't think it's applicable you tend to ignore it. So there are a number of reasons why people don't do it. I don't think there is any one reason; I just think sometimes its ignorance, laziness, and other things like that.

[M, Caribbean, Christian]

In Damery, Clifford and Wilson's (2010) study of GP attitudes, over half of GPs thought patients believing screening was ineffective was a minor barrier (52.8%) to them participating in CRC screening while almost a quarter of GPs thought it to be a major factor (18.9%). This was not found to be a factor in the

present Nottingham study, with most participants agreeing that cancer can be treated if detected early enough.

Other patient related factors identified by Javanparasat et al (2010) in their review of 27 relevant studies included:

- lack of trust in doctors (five of the 27 studies reviewed),
- cost implications (5/27),
- doubt about test accuracy (4/27),
- lack of time (3/27 studies),
- inconvenient for FOB (8/27),
- not being at risk (6/27),
- screening as low priority (2/27)
- and lack of social support (2/27).

Process issues

The nature of the test means patients must be actively engaged and maintain motivation (Szczepura et al., 2003). Chapple et al. (2008) found that some people were concerned about positing samples back in the post and there was a case for instructions to be clearer as some had misunderstood them. Inability to follow instructions was also found to be a barrier in Javanparast et al's (2010) review.

We found in Nottingham that, amongst those who had undertaken the screening, most people had understood and followed instructions but that language and accessibility of information were still significant barriers. In cases where this was overcome, the support of family members, friends and support workers ensured uptake.

A minority of respondents reported not having received the kit in the post. One particular case concerned a son whose father had died from bowel cancer. Whilst the circumstances of course cannot be verified, it is important to note:

Interviewer: He didn't receive any kit in the post?

Participant: Not at all. And I think this should have been important that he, because he has got a medical issue he should have had somebody to say we can give you this. But he wasn't told about any of this information. I think if he was told earlier about this information and maybe they could have done something earlier on than wait for the last moment.

Interviewer: So he didn't take part in this screening programme because he wasn't aware of it.

Participant: Yes and he wasn't given any information by his GP, he wasn't given any information by anybody. I think it's important that anything like this comes up I think people should know about it.

[M, Indian, Sikh]

We did identify cases where people described confusion over the process, captured in this example:

Interviewer: Are you aware of the bowel cancer screening programme?

Participant: I have heard of it but I haven't got time, I don't have time to go to the clinic.

Interviewer: What they do is when people turn 60...

Participant: They must go to the doctors and they must have tests and stuff like that to clarify that they are fine.

Interviewer: This screening programme, what they do is when people turn 60 they send them a letter.

Participant: Leaflets yes.

Interviewer: At home asking them to put a sample in and send back to the doctors so they can test and see if they have any symptoms. Have you heard of this?

Participant: I have not heard of it and we have not got it, we haven't got anyone 60 in the house so obviously we are not going to get anything.

Interviewer: So you have just turned 61 so you have not received anything?

Participant: No nothing.

[M61, Indian]

Others, even when prompted, could not accurately identify (or recall) the specific bowel cancer screening kit. Many people also wrongly attributed screening to a process that takes place through contact with the GP

Some men involved in the *Men's Health Forum* survey described the process of the FOBt as messy and suggested this could be a reason why they put off taking part in the bowel cancer screening. Women did not have as strong feelings about the process being unpleasant (Wilkins, 2011). In O'Sullivan and Orbell's (2004) focus groups, a minority of participants said they found the idea of doing the FOBt test disgusting. Chapple et al. (2008) also reported some participants who were deterred from undertaking the FOBt test due to disgust at the idea of handling stools, however relatively few stated this as a factor for not doing the test.

I received a letter but I haven't sent it because I can't do it, my husband did. I think there should be another option to go to the hospital and

they do it. I find it hard; I start vomiting, when I put the toilet on the paper. I have to put it in three or four days and I can't do that, I find it hard.

[F, Indian, Hindu]

Awareness issues

When we asked the question what types of cancers there are that was also interesting, they could name quite a few. I had to at one point say ok that's enough; they went through breast cancer, throat cancer, cervical cancer. And they seemed to have a really good knowledge of the very different types of cancers that there were in the public information, which I thought was interesting they could name quite a few.

[Community researchers]

Unsurprisingly, general awareness of cancer including the ability to name different cancers was found to be reasonably high in our Nottingham study. There were some instances of confusion about what constitutes the early symptoms to watch out for. Some people conflated the signs of undergoing treatment (e.g. hair loss) as a symptom of cancer itself. Whilst knowledge about bowel cancer was generally limited, it was more common for participants to identify warning symptoms that might warrant medical attention.

Robb et al (2010) in a study examining ethnic disparities in knowledge of cancer screening programmes in the UK found that awareness of the bowel cancer screening programme was less than 30% in both white and ethnic minority groups. From a sample of 1500 adults from the six largest ethnic minority groups in England (Indian, Pakistani, Bangladeshi, Caribbean, African and Chinese) Bangladeshi respondents (53%) reported the greatest awareness of the bowel screening programme and Chinese respondents (0%) the least, with Caribbean (51%), Indian (46%), African (31%) and Pakistani (18%) falling between.

Austin et al (2009) in a study examining perceived barriers to flexible sigmoidoscopy screening for colorectal cancer among UK ethnic minority groups, conducted focus groups with 53 participants from African-Caribbean, Gujarati Indian, Pakistani and white British communities. Findings show that most participants (regardless of ethnic background) expressed limited awareness of bowel cancer and cited this as a barrier to screening attendance. Two of the Pakistani focus groups felt they did not know anything about susceptibility, and lack of awareness about bowel cancer also led the white British men to infer it was rare. While bowel cancer was thought to be common in the UK, both the Indian and African-Caribbean groups considered it to be less common among their communities. Both Pakistani and African-Caribbean women commented they thought it was a disease that affected men only. In another study Asian groups were identified as having unrealistic perceptions of their risk of getting cancer, believing their risk was low (Szczepura; 2003). Javanparasat et al (2010) in a study reviewing published literature on the equity of participation in colorectal cancer screening amongst

different population subgroups, in addition to identifying factors identified as barriers and facilitators to equitable screening (studies were included in the review if they included FOBT as at least one of the screening tests), found that in 12 of the 27 studies reviewed, lack of knowledge of bowel cancer was stated as a barrier to CRC screening.

In Damery, Clifford and Wilson's (2010) study of GP attitudes to CRC screening over three fifths of GPs stated that patients being unaware of screening was a major barrier (64.8%), a further third of GPs thought it was a minor barrier (29%).

Section 2: Interventions to improve uptake

Improving information and awareness

Bowel Cancer UK (2013) argues that good quality information is seen as one of the greatest tools to increase both awareness and uptake of cancer screening. This information, which can come in different forms, can empower patients and educate them on the advantages of such procedures. The evidence from this Nottingham study suggests that some of the key campaigns around cancer have broken through and that participants are able to articulate when to seek help from health professionals. We are less convinced that the message around preventative screening has been as adopted – and we return to this in our concluding section.

In response to questions around what might increase uptake within communities, better information and more efforts at raising awareness were most commonly cited. Amongst the suggestions was the provision of good quality leaflets, easily accessible that set out the clear messages around bowel cancer. A minority of participants who had read about bowel cancer reported satisfaction with the quality and depth of information available to patients. However, many participants said that more leaflets needed to be readily available, covering the major languages and produced in a way that communicated key messages to enable action.

Leaflets on their own are not enough to lead to action, especially where health behaviours are concerned. As participants observed:

I've come across loads of leaflets in English, Urdu and Punjabi, even Hindi as well, but the leaflets are there, people if they don't actually read the leaflet, don't even have the courage to pick a leaflet up, who is going to read it.

[M, African]

And the information that comes has got to be something that makes people want to take notice and read. If you get lots of words and words and words, a leaflet in a GP surgery, how many people actually go and pick up leaflets in a GPs surgery, not too many.

[M, Caribbean, Christian]

The point made by the second participant highlights an issue related to what participants had described as information that was difficult to understand. It may be difficult to discern the key messages or instructions within leaflets that are too detailed – and this will certainly be cemented where language is already a barrier. The participant goes on to say that information needs someone to interpret it – a person to act as a message 'translator' (what does this mean?) or 'mediator' (how does this relate to you?):

But if it is given to you by your GP on entering the GP surgery or practice, then that would be a really good way. Because people around this sort of age tend to be concerned about their health and

when you hear about this cancer, it's when you basically will be quite open to your GP having a chat with you and giving you a leaflet for you to read.

[M, African]

The importance of accompanying written information with verbal messages of reassurance or further insight confirms what previous studies have said about the effectiveness of public information campaigns (e.g. Kemshall and Wood et al 2010).

In Kemshall and Wood et al's (2010) evaluation of the national public disclosure pilot scheme, the role of a information giver or mediator was critical to allaying fear and anxiety about the potential outcomes of a sensitive and taboo professional intervention – in this case a disclosure or non-disclosure to family members with the aim of reducing child sexual abuse. Parallels can be drawn with raising awareness around bowel cancer, especially given the suggestions that people do not act on account of fears. Information mediators (such as a GP) could set out the context of the issue, provide valued reassurance and guidance and close their engagement with a leaflet for further information and follow up. As a side note, a number of participants in this present study reported satisfaction to the community researchers for having the opportunity first to talk about bowel cancer and then to receive information at the end about the process.

The other suggested response was to deliver leaflets directly to people within the communities where uptake was lower, rather than simply leaving them at points of interest where we are reliant on people picking them up:

Like the man walks around with those pizza leaflets and shove through your letterbox, that's what they need to do with these... Yes, put these through the letterbox where black people can see these things.

[M59, Caribbean, Rasta]

Linking the leaflets to existing mailings was also suggested, for instance in this case through the local temple's newsletter:

I think if we had a leaflet we could post it in the newsletter to every household that would make them look at it, with some Indian pictures and people that have been patients or victims.

[MF, Indian, Sikh]

Our literature review found that the campaign run by *Men's Health Forum* found both sexes showed a preference for gender-specific, as well as age-specific, information on bowel cancer and screening processes (Wilkins, 2011). This was reflected in our study where individuals often called for focused targeting at BME media:

Other ways like telling them on the radio, you know, interviews on the radio and let people talk to you live on air as well, or on television, our Asian channels.

[F62, Indian, Sikh]

However, the issue of age appropriate targeting became apparent. One particular example was highlighted around targeting BME media that was not age appropriate. In this case, health messages were being communicated through a youth orientated station. As our community researchers noted:

[They said they] don't listen to that sort of stuff because the music on there is not for our age group. They said why not [BBC] Radio Nottingham or the heart thing because the perception is its because its pigeonholed into a black section because it's a black problem. Bowel cancer affects everyone but they are trying to target the community by doing [targeted BME media] and the community is not listening.

[Community researchers]

Some participants highlighted the TV as an important medium, citing the success of particular health focused documentaries on helping to change attitudes:

You put it on the TV that would help, everybody watches TV...when you have got cancer on telly and you see how they come out and you have got young kids and they will come and show you that, and it does hit when you see that they had cancer.

[F62, Pakistan, Muslim]

Others were less convinced, even when using targeted approaches through BME focused media outlets:

There is a lot of Asian television now as well. There are so many programmes on health but hardly anybody watches it, all the programmes are there but hardly anybody watches them, they watch dramas. I have never seen anybody watching health programmes to the end, so I don't know how to deal with that.

[M69, Indian, Hindu]

The more general, and perhaps more useful consensus was around the use of video and projectors within community and faith settings where people could see and hear information, discuss it with others and follow up as required. A number of people who signalled that their place of worship would be a good place to promote bowel cancer awareness suggested that short videos could be shown there (see below).

The use of media to disseminate health information and advice has been identified as beneficial for raising awareness of screening and the disease more generally (Breast Cancer Care, 2005).

Outreach and education sessions in the community

Every community gets together.

[F61, Indian, Sikh]

In an analysis of focus groups with BME communities, Thomas et al. (2005) found that in terms of strategies for effective intervention, the most popular strategy for improving uptake of cancer screening services was community-based cancer awareness education that is sensitive to religious and cultural needs.

They especially identified religious leaders as key in delivering the message by identifying aspects of religious texts that endorse health promotion and health-seeking behaviour. In a study examining perceptions and barriers to uptake of cervical screening among Somali women in Camden, Abdullahi et al. (2009) suggests providing education and information orally, as well as improving access to a more culturally appropriate screening service, could lead to improved uptake among this group. This certainly seems to be the case in this present study.

Places of worship were seen as a vital place through which to communicate key messages, indeed on other topics this was commonplace for some:

Sometimes, you know we have [invited speakers or groups] at our temple, you can set up a group that will arrange with the management committee, we want to come over to talk in general to the centre. When the divan finishes then there is an announcement on the stage that a gentleman or a group of people come here to question and answer your questions openly, or even in confidence if you want to.

[M, African]

One Sikh participant reflected on the practices that she perceived were more common in a Hindu temple:

[I'd recommend the] temple myself, in the Hindu temple, they call people like that and they always have a new subject every time...one hour before everybody sits in the hall, have a little tea, have their talk about it, then they go upstairs. Or after the ceremony they let people say can you stay behind today, we need to talk before you go. Only for a period of half an hour or whatever they can give.

[F62, Indian, Sikh]

The role of faith leaders was often cited as important in helping to spread more positive health messages:

We need to go into churches as well. Let the pastor tell them about it, more and more black and Asian community are dying of cancer. Nobody knows how much a week has died but you go round the church on the corner every week, and then you can guarantee five funerals a week, prostate cancer, breast cancer.

[F, Caribbean]

The pastor gives you just a short time before he preaches to talk about these things. Because health is regularly linked to Christianity...A

church is not only a place to go and pray its also a place to go and promote what is good for the people. And this is working for the people to help them understand and to help them alleviate the fears they tend to have.

[F59, African, Christian]

As was featuring health professionals as part of the programme of activities:

If [people] can't arrange a time with their GP or the GP has got no appointments or the doctor or whoever is going to talk about cancer come in the [temple] and speak to that person one to one in private.

[M63, Indian, Sikh]

I would say a GP from our culture coming in and explaining things or somebody in the medical profession probably come in, somebody who has done research on this. Somebody that knows a lot about it and wants to get through to different cultures at that sort of age group to make sure that it's not happening to them, and maybe we can do something before it does happen to them. Because it's a really serious illness and it maybe could save your life if you took ten minutes to do something.

[F61, Indian, Sikh]

Amongst the Punjabi Sikh community, the Gurdwara was almost unanimously recommended as a place to focus community engagement activities, again built around the programme of faith activities and with the involvement of those running the temple:

You have got to ask for a few moments please you have to listen to us for 5 or 10 minutes, do you have 15 minutes for us. It's not going to cost you money just a bit of time. Get together for 10-15 minutes and see what I am going to say to you and you have to listen to us. If you go to any [other] place they don't want to know, they don't have the time, it's just here they have plenty of time.

[F61, Indian, Sikh]

I think it would be good if somebody came in on a day that the community are together and speak to them about it and speak to, it would be somebody from the community or somebody from that religion that could speak their language and make them understand more...And then tell them downstairs we have got leaflets that we can hand out to you. And if you are 60 and you are supposed to be getting a kit and they haven't sent it to you because of so and so, we are going to issue the kits to you. And then we need you to do this and send it off and it's important that you do it because it's a life saving thing. And the only way it's going to help you and your health is if you catch it at an early stage. The only time you are going to catch peoples attention is when they are upstairs and after they pray altogether so you are not talking to individual people you are talking to a whole group.

[F63, Indian, Sikh]

The idea of group discussions within community settings was also suggested and was thought to be a positive way of bringing people together:

To encourage more people they should have a meeting and invite lots of people and show them how it's done, and show them the effects on having it done and how they can prevent or they can know if they have it and can cure it in the early stage.

[F70, Black British, Christian]

Participants who had been through the screening process recognised the potential value of being able to explain this to other people to allay fears:

Talking, people like myself who have been through it talk to them and tell them my experience. Because it's not that difficult, it might be a little bit uncomfortable but not difficult, so talking to people that's the only way you can do it. But now that I have done it I can address it. So there are a lot of things that we put aside that we shouldn't do, face it head on, find out what it's all about and deal with it.

[M71, Caribbean, Christian]

This participant referred to the value of the meeting having a supportive function for people experiencing bowel cancer but her suggestion may equally apply to a group focused on prevention:

The people have got the same problem they should sit together and talk to each other and that's how they can reduce the embarrassment and they can share their problems with each other.

[F66, Pakistan, Muslim]

The rationale for community-focused activities was put forward to address the potential of poor attendance at health appointments and also to enable people to engage in collective discussion about the problem:

Yes, I think the way you are doing it is one good thing [*the interview*] because people won't come to surgery, people won't come, we have to go to people and that's the main thing.

[M64, Indian, Christian]

I think if somebody spoke about it and put it into people's heads how important it is and then brought the kits in to say you are 60 you need to do it. I think if it gets through to one person the word of mouth will get round to the community and they will say right we need to go down here and sort that out or you need to ring up somewhere and get it sorted out.

[M74, Indian]

The call for community-based activities reflects previous work by Austin et al (2009), which found all ethnic groups were in favour of this approach. A variety of community locations were suggested including 'mosque ladies

circles', and 'rum shops'. The resulting benefit of increasing 'word of mouth' could also contribute to 'normalising' discussions about bowel cancer and screening. Some participants reported that they valued the research interview for this very purpose:

Thank you for this privilege to understand a little bit more about it, and I will myself go and have it done, a check out.

[M60, Caribbean, Christian]

It's like you are having a meeting with me now and we want to have meetings with other people that's a way you can get them to come in. Because the way you talk to me now is encouraging. So you need more people like you to go and get groups and have talks and then you will know what to do from there. Nottingham is a big county so we need a lot more of you people to go round and get in groups and make more investigation or whatever, that will help.

[M, Caribbean, Christian]

We look later at the concept of 'social currency' – the idea that key messages are received, discussed and collectively understood within social groups. Rather than seeing messages as delivered and received, we take account of the various ways in which people (in groups) will receive information, talk about it, try to make sense of it and that this process either reinforces myths or challenges them.

Outside of continuous messages transmitted through the mainstream media, community focused interventions can lead to greater discussion and deliberation, and ultimately alternative perspectives on common norms around a particular topic. This in turn might enable people to feel confident to support each other. The role of peers in tackling embarrassment, for instance, was a recurring theme:

One of my friends she was bleeding from the bowel and when she goes for a wee even that time she was bleeding from the bowel as well. But she was really embarrassed to go to the doctor and we pushed her to go to the doctor. And she went and they did the check ups and they give her medicine. And after a year she got better...

[F66, Pakistan, Muslim]

The example cited above is one that would be expected to be seen – the role of friends and family in encouraging people to take action on health. The role of wives in encouraging men to take positive action was highlighted in our section on barriers, a finding that reflects work by Wilkins (2011). Throughout our study we had various examples of relatives providing help with interpretation and advice on how to use the screening kit. Some older people with particular vulnerabilities had relied on their support workers to assist:

At one particular place it was a warden sheltered housing there was one man who was actually helped to do his kit. But that was because he had taken it to the warden to say what does this mean what do I do

and he showed him. [A different resident] was practically blind, couldn't see, couldn't hear very well [and] he didn't know any thing about the kit, didn't even know if he had received it in the post. It may well have been in the post but he couldn't see whether he had got it, he had got no one to check it. And yet the same warden had obviously missed him and not been able to give him help with the sample...he just got completely missed because of this disability he had.

[Community researchers]

There were situations where people shared their unwillingness to discuss health issues with their peers and family on account of not wanting to cause alarm or distress, or not wishing to discuss what they perceived to be very personal matters even with those closest to them. More generalised messages delivered in a targeted way may offer a more helpful approach of enabling people to talk about bowel cancer and screening. Shaping health dialogue within communal spaces enables large numbers of people to hear a common message and begin the process of interrogating it and applying it to their own lives, comforted by the lack of focus on their own individual and specific circumstances. Some people, for instance, will not get to a point where they can comfortably talk about the issue but are still within the place where they can receive messages:

[Translator] She said was that she doesn't go to the GP much, she is not involved with talking to anybody much. Most of the time she spends at home or at the community centre but not talking much about anything.

[F, Indian, Hindu]

On suggesting that the Gurdwara was the best place to focus energy, one participant said:

Its where we are getting together like a wedding, there are so many meetings, where we meet...It's the most important because people are there and they listen to you, if you go to someone's house [you don't have the chance] in here you can talk to everyone. And people say... but I know him and I know what he is saying.

[M73, Indian, Sikh]

The additional point to note here is the importance of authority, trust and authenticity. Role models are important in helping people to take decisions and faith leaders obviously occupy some privilege here, alongside health professionals. However, as the quote demonstrates (and it is representative of many other views), people also place faith in their fellow community members and listen to the stories of people that they respect. This can be positive in the sense that clear messages can be reinforced but in the absence of these, myths or misunderstanding can gain ground.

Community champions can provide benefits here since they can act as role models outside of the health service. Several participants had benefited from engaging with an advocate for taking action on prostate cancer.

I found from speaking to the people I interviewed that they were very aware of cancer in terms of breast cancer, prostate cancer, there is a big drive on at the moment about prostate cancer, there is a real push on it. Someone ...has been doing fantastic work in relation to raising awareness of cancer. So in the community the people I have spoken to seem to have a real understanding of cancer and what it means and they have been touched by it in some way.

[Community researchers]

Interventions by health professions

GPs were highly regarded as an important source of information and guidance for making appropriate health decisions. Participants identified the problems with the current BCSP process being detached from their engagement with a GP:

I guess one of the important things, because people actually do listen to their GPs, and with their GPs they could send letters out at the time which coincides with this kit being sent. I think people are more likely to actually go into their doctors with their letter and with the appointment that's made. I think that would make life a lot easier for a lot of people because to most people the GP knows everything about your health, whether they do or not.

[M, Caribbean, Christian]

I think it's better if doctors explain to people, if they take a little time and talk to their patient and they explain and talk to them.

[F66, Pakistan, Muslim]

Some have benefited from targeted interventions through their GP. For example, one participant described engaging with a specific group:

I did have ABC cancer team, that check, the surgery invited me so I did go

[F64, Indian]

Educational courses along with clinics and drop in services were suggested as a way to encourage preventative interventions located within the GP practice:

I think there should be a drop in clinic where anyone can come if they feel anything. And it's taking that first step to that direction because they are thinking why should I be thinking about this. And you get those people who go constantly, always conscious of their health.

[MF, Indian, Sikh]

If GPs were to run a well person's clinic, even if it's once a month that will also encourage people to come in and get a check up, even if it's

just the nurse going through the basic things. And if it includes testing or screening for these things then we're at a better position because what it means is that all you're doing is making sure that everything is working well and you're in good health. Similar to something that you do for a car, an MOT type sort of thing.

[M, Caribbean]

A few of the campaigns and pilots reviewed as part of our study have suggested a personalised approach from health professionals improves the uptake of cancer screening: the *Patient Navigation* model is very personalised with each individual being assigned a patient navigator (Better Days, 2011). Patient Navigators are trained, culturally sensitive health care workers who provide support and guidance throughout the cancer care continuum. They help people "navigate" through the maze of doctors' offices, clinics, hospitals, outpatient centres, insurance and payment systems, patient-support organisations, and other components of the health care system. This model could be considered for more widespread use, although cost-benefit analysis would be useful to assess its applicability (ibid). PN has also been used in an American study (Lasser et al. 2008) to investigate whether PN helps to increase uptake of colorectal cancer screening amongst minority ethnic groups (patients who spoke Portuguese, Spanish or Haitian Creole as well as English). The objective was to determine the feasibility and effectiveness of a patient navigator-based intervention to increase colorectal cancer screening rates in community health centres. Findings show that a patient navigator-based intervention, in combination with a letter from the patient's primary care provider, was associated with an increased rate of colorectal cancer screening at one health centre as compared to a demographically similar control health centre. The study adds to emerging literature supporting the use of patient navigators to increase colorectal cancer screening in diverse populations served by urban health centres in the USA.

The *Breast Cancer Care* campaign suggested GPs and nurses talking about screening with patients helps (Breast Cancer Care, 2004) and the *Champs* campaign pointed towards similar suggestions (Tiffany et al. 2012). Mant et al. (1992) also found that compliance with colorectal cancer screening in general practice in the UK improved when the invitation letter was 'personalized', and when the FOBt test kit was sent with an invitation to attend a nurse-managed general practice health check.

More recent studies have also found a higher uptake of FoBt due to a personalised approach (Cole et al. 2002; Clavarino et al. 2004). Cole et al. (2002) found a higher rate of participation from the group who received a letter from their GP (40.1%) than those in the group that received support from a named practice (38%) and the control group (32%). Fitzgibbon et al. (2007) reported a 7% increase in the CRC recommendations by GPs who attended feedback sessions and 9% increase in completed CRC screening. Responses gained from BME participants in a series of focus groups led Thomas et al. (2005) to suggest that it is essential to plan concurrently to educate GPs and other health professionals in cultural beliefs and customs, language needs, racial awareness and communication skills.

The *Champs* campaign highlighted the effectiveness of handing out packs to people who did not originally respond to invitations to attend cancer-screening appointments (Tiffany et al. 2012) - an approach that we would strongly endorse.

Javanparast et al. (2010, p.170) also reviewed a number of studies that evaluated the effectiveness of particular interventions or facilitated the actual utilisation of the screening services. The authors reviewed fourteen articles which addressed the equity of access to colorectal cancer screening by implementing interventions targeting specific population sub-groups. A number of 'individual related interventions' were identified to have increased participation in CRC screening. These are summarised below:

Interventions	Effectiveness
Telephone support intervention (Dietrich et al., 2006)	Increase in CRC screening of 0.24 (60% over baseline)
Novel communication modality (storytelling methods) (Larkey and Gonzalez, 2007)	Increased intention to CRC screening in intervention groups
Targeted and tailored interventions (Myers et al., 2007)	Higher CRC screening in intervention groups (33% in control group, 46% in the SI group, 44% in the TI group, and 48% in the TIP group)
Language appropriate telephone support (Beach et al., 2007)	Higher CRC screening in intervention group (53% vs. 38%)
Novel invitation strategies (Cole et al., 2007)	Significantly increased screening rate by advance notification. No improvement in screening after risk or lay advocacy strategies
Psycho-educational intervention (Wardle et al., 2003)	3.6% increase in attendance for screening in intervention group, less negative attitudes and higher priority for screening
Structured risk information tool (Stephens and Moore, 2007)	Significant increase in seeking screening advice in intervention group (56% vs. 37%) but no significant increase in screening test uptake (6% vs. 8%)
Communication social comparison information model (Lipkus and Klein, 2006)	Higher rate of FOBT in intervention groups (38% in control, 42% in absolute risk only and 64% in absolute plus comparative risk group)
Removal of dietary restrictions for FOBT and simplification of faecal sampling (Cole et al., 2003)	28% increase in screening participation by removal of dietary restrictions and 30% increase by simplification of sampling (66% increase by using both strategies)

Section 3: Taking forward Bowel Cancer Screening

It is not surprising that much of the qualitative work undertaken for this study supports the strong messages found within the literature. There are common and consistent barriers found within any discussion about BME groups, older age and health, and many of these can be addressed by thinking differently about what appropriate non-clinical strategies can be deployed. The challenges of designing healthcare towards a more preventative model require us to think differently about issues of identity, community, the spaces people occupy and the networks they are part of. The literature points towards the success of various community-based initiatives and to the value of bespoke targeted message giving. However, we are also aware of the potential resource implications of doing this right, in a context of restricted funding.

When considering how the BCSP might be improved to reach and impact upon high numbers of older BME people, there are some clear messages. Crucially, the arrival of a kit on the doorstep outside of any accompanying conversations or engagement with health practitioners ultimately requires an increased active role and continued motivation on the part of individuals. The broader literature on health inequalities and inequality more generally finds that people who experience poverty and disadvantage may experience chaotic and unstructured lives. These issues are compounded when the twin dynamic of culture and age is taken into account.

Many interviewees described the important role that health practitioners, especially GPs, play in helping people to make positive decisions about health. Indeed the 'authoritative' role of GPs was identified strongly within certain interviews. However, we recognise the pressures that GPs are under and are acutely cognisant of the disjointed relationship between the screening programme and the everyday work of GPs. We therefore recognise the limited value that would be placed on any recommendations targeted at a structural change to the operation and funding of the national bowel cancer screening programme.

Nonetheless, there is obviously a greater role for GPs to play in generalised prevention. They can reinforce key health behaviour messages, send targeted follow up messages to non-participants and provide valuable personalised reassurances about bowel cancer and the BCSP. We are mindful of the work that the CCG has already done in this area and continues to invest in ensuring better levels of GP engagement.

Therefore, our attention is turned to those strategies that can be deployed outside of the traditional GP/patient encounter. In particular, we were drawn to three strands that came out of the qualitative work and are supported by the literature. These are:

- Shaping the message
- Creating a community focus
- Personalising the process

Shaping the message

There are two key public health messages that we would argue require urgent prioritisation as part of any strategy going forward:

- Raising awareness about bowel cancer
- Normalising 'screening for healthy people'

Our study is in line with previous research that has found minimal awareness of bowel cancer amongst the older age group. There is evidence in our qualitative work that many people were aware of the general campaigns, had seen posters around town and were able to provide general insights into what might cause cancer and the symptoms to look out for. This was overshadowed by generally low levels of awareness – and certainly only a very small number of participants recognised the importance of routine screening in the absence of symptoms.

One of the most powerful messages of cancer screening is the potential for the prevention of a disease before it manifests itself. Survival rates are therefore dependent on people investing in their health and taking action in the absence of symptoms. During our learning workshop with policy makers and practitioners, one participant captured the idea with this slogan: 'screening is for healthy people'.

However, this message is not cutting through as strongly as other more powerful messages around what to do if you detect early symptoms. For example, by far the biggest proportion of Punjabi Sikh participants could readily identify the main messages that could be associated with the *Be Clear on Cancer* campaign. This is a considerable success but brings with it problems. Many people talked about the bowel cancer screening programme as being something that had to be done if and when such symptoms arise. The theme explored earlier around not taking action when feeling healthy was prominent amongst people and is a considerable barrier to uptake. For women who have experienced a 'screening career' this was identified as less of a problem but men have no such screening history. Therefore, it is our recommendation that investment be made in finding snappy targeted messages that:

- Communicate the routine and normal nature of screening.
- Are culturally appropriate in relation to languages and imagery.
- Factor in how messages may need to shape according to gender and age.

Creating a community focus

The strongest message to come out from our discussions about barriers and opportunities to increase uptake was the need to focus on communal – not individual – activities. The links between poverty, class, 'race', culture, health

inequality and **place** are well documented in the literature with more sophisticated approaches to mapping health inequalities in a local context coming to the fore. Participants in this study routinely identified their places of worship, community centres and other meeting places as the key sites through which positive health messages could be delivered. People from all ethnic groups identified strongly with the notion of community, whether it be through organised meeting places or the more informal relationship networks that extend beyond their homes. Whilst many of these communal places are inevitably linked to cultural or religious identity (such as the church, mosque or temple), others such as day centres and supermarkets were seen as more general but equally applicable to reaching older people en masse.

During the analysis day, our community researchers identified four pressing themes that emerged from across all groups:

- The need for language and cultural specific information.
- The need for a personalised approach and someone to talk to about bowel cancer and the screening programme.
- The need for an overriding message of ‘screening for healthy people’.
- The difficulties some people had encountered in understanding how to use the kit.

The group explored the potential for using focused activities, built on established relationships and meeting points within a local context, as key to driving uptake. As one interviewee suggested:

There needs to be a much more of a targeted approach [to health promotion]. Whether its three times a year there is that drive at community centres, there is a physical presence where people become familiar with it, its normal. There is a health week when we know we can talk about these things and people can see it, get a leaflet. One person said to me it would be really helpful...they had a week of action at St Anns last week and he said if they delivered, hand leafleted, every house on St Anns some people would read it and some people wont. But if you get say 50% of the community reading it than that's more than what they had done before. Train up local people to do it and go round and deliver leaflets.

[Community researchers]

We start from a presumption that there are three separate but interlocking communities that most older people are part of. These are:

- Communities of place: the physical geographical location where people live.
- Communities of identity: the cultural and religious groups that people belong to.
- Communities of interest: the shared leisure, educational and work pursuits that people share with others.

In the case of many BME communities, the three interlock to provide a coherent whole. For example, people live alongside many others who speak the same languages, share their historical, cultural and religious identities and pursue similar leisure activities. Focusing on place therefore enables us to also undertake a concentrated focus on the identity and interest needs of a particular group. We accept that such an approach will not target the whole BME population of Nottingham City, since like any other group they are dispersed throughout the city. However, where uptake levels are lower (and many other health inequalities persist), there are the added dimensions of poverty and exclusion that require a concerted effort.

The final benefit of such an approach is that it is likely to contribute to a more positive 'collective' message about health behaviour, driven in part by 'social currency'. According to research that has examined risk communication, the importance of the social currency built around the circulation of 'everyday knowledge in routine conversations' is probably more important than any centralised or media managed message (see Hughes et al 2006: 262). Social currency is defined as the everyday interactions we have that help cement or confirm ideas, rightly or wrongly, about risk. As communicative strategies and interactive media continue to expand through, for example, the internet, yet more information and debates are in the public domain and these in turn help shape our social currency. Social currency triggers (i.e. positive messages about screening) can enable people to discuss with others, debate, decide on and take action. It also enables common myths to be challenged (Wood 2011).

Taking the idea above of a 'week of action', we recommend that a pilot approach to intensive place-based action be tested to determine whether it offers a model for increasing positive health literacy and behaviour. We would argue that a period of intensive action could take place over 1-2 weeks in each of the target communities, repeated if successful on an annual basis. The following offers some preliminary suggestions for such an approach based on the findings from this study.

Define the parameters and identify the networks. We recommend the first step to working locally is to take account of the existing fabric of the community. This requires, at the very least, a map of 'assets' – those things that are collectively valued in a community and often include religious places, community centres, groups, main meeting points, markets, shopping centres and so on. Alongside this are the 'people assets' – the network of key decision makers within communities who can provide support to any targeted campaign. As we have seen in the findings, faith leaders and champions have been cited as important role models. Put simply, who needs to be on board and how do we ensure that they are familiar with the key messages that need to be imparted.

Recruit and train local community champions. Nottingham has a rich history of community-based health interventions, not least in terms of successful programmes like Change Makers and the work of the BME Cancer Network. During this study, we recruited local community researchers

reflecting the diversity of language, religion and cultures of those we interviewed. This was critical to the success of the study and will be critical to promoting messages that are culturally appropriate. We would argue that people involved as community champions do not require extensive knowledge of bowel cancer and the associated health interventions. They should be lay advisers, able to provide general awareness, positive messages and signposting – the ‘patient navigation’ role described in the previous section.

Target places and people of religious and cultural significance. This recommendation came through strongly across all groups as the best way to reach large numbers of people within an environment and with people that they respect. During the mapping phase described above, there should be strong efforts put into securing the support of local faith leaders – and in the case of temples, the management committees – to ensure buy-in and to explore the possibilities for screening messages to be delivered during or after religious ceremonies.

Undertake a targeted doorstep modelled on a political campaign. If possible, data should be obtained that provides the addresses of all those within the age band for bowel cancer screening. It should be an aim of the team of community champions to undertake a targeted doorstep of each of these addresses. The doorstep would be primarily about delivering information about the programme but also provides the benefit of having a trained community champion on hand to answer general questions and offer reassurance about bowel cancer and the BCSP. Doorstep champions will have a script to work to and will record, in the same ways that political campaigners do, the ‘strength’ of response on the doorstep. This data can then be used to identify the most appropriate method of follow up. We recognise the potential data protection and sharing implications of this model but would encourage local partners to identify appropriate data sharing agreements. In cases where people do not answer, ‘out cards’ are left providing information about the screening process and valuable signposting information. By way of example, there are approximately 1462 people aged 60-74 living in St Anns (Census data 2011), meaning that the number of households to be knocked is certainly doable.

Be visible at local gathering points. As some participants indicated, it is as important to identify the factors of ‘age’ and ‘gender’ as it is to consider the specific cultural and language needs of the BME population. Identifying the more general local gathering points and being visible at them is likely to be a successful intervention. In Hyson Green, this might include a stall at the front entrance to ASDA, one in the market place and a targeted walkabout along Radford Road and Berridge Road.

Personalising the process

“Like when you go on holiday. If you don’t know the country very well then [...] the bus takes you to this place and there’s the tour guide, he’s telling you this place, this is what you can do here, this is what you can do there. People feel confident that somebody is there to help them.”

[M, Indian, Sikh]

The home screening process is detached from most people's experience of engagement with healthcare. As health services develop more and more preventative measures that are home and community based, rather than accessed through traditional primary or secondary care settings, the issue of personal responsibility and investment is likely to become more pressing. We understand from the particular model of this screening programme that there is limited scope to shift the responsibility for screening towards GPs and are not seeking to recommend something that cannot be changed. However, as our participants identified, there is a clear role for making the screening process more personal.

The targeted approach described above offers unique opportunities for personalisation – through community networks, interaction with champions and the engagement of faith and community leaders. Outside of this process, we recommend more targeting by GPs within each of the areas where uptake is lower. As a minimum standard, GPs should be empowered to write a personalised letter to all who do not participate in the test as the main mechanism for follow up. The bowel cancer screening process should become an explicit part of all consultations with people who fall within the age band and we would strongly encourage GPs and other health professionals to keep sample kits on hand to demonstrate.

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