

**INCREASING THE  
UPTAKE OF BOWEL  
CANCER SCREENING IN  
BME COMMUNITIES IN  
NOTTINGHAM CITY**

**EVIDENCE FROM THE LITERATURE  
JULY 2014**

**DR JATINDER SANDHU  
DR LINDA GIBSON  
DR JASON PANDYA-WOOD  
& C3 COLLABORATING FOR HEALTH**

# **Increasing the uptake of Bowel Cancer Screening in BME communities in Nottingham City: Evidence from the literature**

Dr Jatinder Sandhu, Research Fellow in Sociology

Dr Linda Gibson, Senior Lecturer in Public Health

Dr Jason Pandya-Wood, Reader in Social Policy

Nottingham Trent University

With c3 Collaborating for Health

July 2014

# Contents

<b>Introduction .....</b>	<b>4</b>
<b>Literature Review Methods .....</b>	<b>4</b>
<b>Barriers and challenges to uptake of bowel cancer screening amongst BME communities .....</b>	<b>5</b>
Cultural and language barriers .....	5
Patient factors .....	5
Process issues .....	7
Awareness issues .....	7
System related barriers .....	8
<b>Interventions .....</b>	<b>8</b>
Health professionals interventions .....	9
Patient navigation and support interventions .....	10
Process interventions .....	10
Individual directed interventions .....	10
<b>Campaigns .....</b>	<b>11</b>
<b>Pilot studies .....</b>	<b>13</b>
<b>Learning from other countries .....</b>	<b>15</b>
United States .....	15
Australia .....	15
European Union .....	16
<b>Public health risk and change .....</b>	<b>17</b>
Intrinsic personal factors: .....	17
Extrinsic factors .....	18
<b>References .....</b>	<b>19</b>

## Introduction

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. Between 2009 and 2011, an average of 57 per cent of these bowel cancer deaths occurred in people aged 75 and over (*ibid*).

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 in 2011. 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 (Cancer Research UK, 2014).

The **NHS Bowel Cancer Screening Programme (BCSP)** (NHS Bowel Cancer Screening Programme, 2014) is rolling out a nationwide campaign to screen the population aged between 60 and 69 every two years. Screening for bowel cancer is a test designed to be done at home, in an attempt to make the 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 the cancer – these groups of people include black and minority ethnic (BME) groups, the socially and economically deprived and, for some campaigns, men and younger people.

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. Work has been done surrounding the identification of barriers faced by individuals and has tried to address ways to breakdown these obstacles and encourage more people to take part in the possible life-saving process. This review will consider some approaches taken by charities and advocacy groups, as well as NHS pilots and examples to consider from other countries.

## Literature Review Methods

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.

The standard approach to systematic reviews was deployed including an assessment of whether any existing systematic reviews offer insights. Thus, a thorough search of appropriate databases was undertaken. 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.

A range of databases and search engines were used to find relevant academic and non-academic literature on bowel cancer campaigns and grey literature.

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, Afro-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.

## **Barriers and challenges to uptake of bowel cancer screening amongst BME communities**

A number of studies and evaluations of relevant initiatives were found to evidence of a range of barriers to the uptake of screening for cancers amongst BME communities. These are summarised below.

### **Cultural and language barriers**

- Research from other countries on barriers to uptake of CRC screening by ethnic minorities 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 FOBT uptake, both of which may be related to cultural and language needs.
- Certainly, **language** has been identified by more than one source 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<sup>1</sup> (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. Additionally, 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 reported that screening information leaflets are not available in all the BME languages and where translations are undertaken, the translation is not always adequate. While African people speak and understand English, the importance of screening was not conveyed owing to terminology and nuances of the language used.
- Austin et al (2010) also uncovered other important culturally specific barriers, which may be applicable to understanding the low uptake of FOBT 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.

### **Patient factors**

- **Being busy** – 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.
- **If they felt healthy, why should they attend a health check-up?** – men who perceived themselves as healthy may not be 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 the flexible sigmoidoscopy screening test unless told to go by the general practitioner (GP). In Damery, Clifford and Wilson (2010) study of GP attitudes to 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%), and 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',

- **Screening is ineffective** –In Damery, Clifford and Wilson (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 and almost a quarter of GPs thought it to be a major factor (18.9%).
- **Travelling** – the third most common reason for women not attending their breast-screening appointments in one study was that they were away travelling, sometimes for extended periods of time. This was the patient navigation study that looked at African Caribbean women; the report identified them as very transient individuals who were often difficult to contact (Betterdays Cancer Care, 2011)
- **Fear of the result:** Austin et al (2010) found that across all ethnic groups except the Pakistanis (who did not comment), fears centred on the results of the flexible sigmoidoscopy 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 CRC screening, 24% reported fear of the result to be a major barrier and 65.6% reported it 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 barrier by Javanparasat et al (2010) in nine of 27 studies reviewed by them.
- **Embarrassment and anxiety** – In Damery, Clifford and Wilson (2010) study of GP attitudes to CRC screening, half of GPs reported embarrassment and anxiety as being a major barrier to CRC screening (49.9%) and 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.
- **Fear of isolation and social exclusion** – this barrier was identified in the NICE (National Institute for Health and Clinical Excellence) public health guidance on increasing the uptake of HIV testing among black Africans, and so is related to HIV testing, although there is scope for this to be applicable to bowel cancer too. There is evidently still stigma surrounding a positive diagnosis of HIV, with some people reporting a fear of social exclusion and isolation if a positive result is returned; stigma is also faced by cancer sufferers. The NICE public health guidance could offer more insight into improving the uptake of screening for stigmatised diseases, such as HIV and cancers – a further study of this document could be useful; and
- **Threat to masculinity** – Although reporting on the Perceived barriers to flexible sigmoidoscopy screening, Austin et al. (2009) found that the test was considered to be a threat to masculinity by Afro-Caribbean males. However, a recent study 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, 2008; Galdas, Cheater and Marshall, 2005).
- **Doubt about the personal relevance of CRC screening** has been identified as a female specific barrier in a study undertaken by Friedemann-Sanchez et al. (2007).
- Other patient related factors identified by Javanparasat et al (2010) in their review of 27 relevant studies included **Lack of trust in Drs** (five of the 27 studies reviewed), **cost implications** (5/27), **doubt about test accuracy** (4/27), **lack of time** (3/27 studies), **inconvenient for FOBT** (8/27), **not being at risk** (6/27), **screening as low priority** (2/27) and **lack of social support** (2/27).

## Process issues

- **Difficult to keep people engaged in the process that requires them to have such an active role** – the FOBt is done individually, in your own home and over a period of time (usually within one week). The test must then be posted back to the laboratory. 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 posting 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 to CRC screening in Javanparast et al. (2010) review of relevant CRC studies (six of the 27 studies reviewed).
- **A messy and unsavoury process** – 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.

## Awareness issues

- **Awareness of bowel cancer screening.** 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..
- **Awareness of Bowel cancer as a disease and perceptions of susceptibility.** 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 12 of the 27 studies reviews lack of knowledge of bowel cancer was stated as a barrier to CRC screening.
- **Low health literacy** – this refers to patients struggling to understand health information that could be key to their involvement in screening programmes; if individuals are unaware of the benefits of such tests they may not be as keen to participate (Health Day, 2013). 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%).
- **Lack of symptoms** was a reason given for not participating in people aged 50–69 years old (Hoffman-Goetz et al., 2008)

## System related barriers

- **GP attitudes.** Previous research has implied that South Asian GPs are more likely to have negative attitudes towards FOBt screening, however research by Damery, Clifford and Wilson (2010) suggest that this is not a group requiring targeted interventions to increase their support. A study examining GPs' attitudes in relation to colorectal cancer screening and the use of FOBt in routine practice reports some important findings in relation to GP attitudes to recommending FOBt to their patients. Responses gained from 960 GPs in the UK through use of a postal survey, shows Positive attitudes were associated with personal experience of CRC screening and Asian or Asian British ethnicity. GPs from practices located in more deprived locations were also more likely to have positive attitudes towards FOBt and its recommendation to patients.
- Chow Choi et al. (2013) also found that some Chinese Honk Kong older residents cited 'the Dr did not suggest the test' as a reason for not participating in FOBt screening. This coupled with the awareness issues around bowel cancer and screening practices resulted in large numbers of older participants not participating in screening for bowel cancer.
- **Not receiving a letter to attend screening** – the patient navigation evaluation identified that 33 per cent of their participants had not received the invitation letter to their breast-screening appointment and this was why they had not attended (Betterdays Cancer Care, 2011)
- Damery, Clifford and Wilson (2010) identify a number of system related barriers to CRC screening. These include: **screening costs too much** (minor barrier: 38.8%; major barrier: 48.5%), **GPs do not actively recommend screening** (minor barrier: 44%; major barrier: 40.1%), **shortage of training providers to conduct screening** (minor barrier: 34.8%; major barrier: 57.8%) and **shortage of trained providers to investigate positive FOBt** (minor barrier: 34.9%; major barrier: 55.2%).
- Javanparast et al. (2010) also identified a number of 'system barriers' to CRC screening in their review of relevant CRC studies. **Lack of GPs recommendations** was found to be a barrier in 14 of the 27 studies reviewed, **lack of availability of the FOBt kit** in 5 of the 27 studies reviewed **and lack of patient-provider communication** in five of the 27 studies reviewed.
- Analysis of focus group data revealed that **unhelpful attitudes of health professionals** to be important barriers to effective cancer screening among BME groups (Thomas et al., 2005)

## Interventions

From the review of non-academic literature, it has been possible to identify a number of solutions that have been used and/or recommended, following campaigns and pilots:

### Information and awareness

- **Empowering patients with more high-quality information:** good-quality information is seen as one of the greatest tools to increase both awareness and uptake of cancer screening (Bowel Cancer UK, 2013). This information, which can come in different forms, can empower patients and educate them on the advantages of such procedures;
- **Gender- and age-specific, simple and easy information with memorable slogans:** 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).
- **Follow-up with non-respondents, including with the use of informative materials:** 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)
- **Outreach events:** this is built into the PN model and many such events are held by charities to raise awareness and funds for further advocacy and research;



- **Word-of-mouth information:** this can be a useful way of disseminating information within the community, although it is important to make sure that such information is both correct and up-to-date (Gordon-Dseagu, 2006).
- **Traditional and social media:** 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).
- 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 Imam and Pastors as key in delivering the message by identifying aspects of the Qur'an or Bible 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. Similar culturally targeted interventions could help to increase FoBt screening amongst BME communities.
- Other suggested solutions to increase colorectal cancer screening awareness by BME communities include: (Austin et al. 2009)
  - **Group discussions within communities:** All ethnic groups were in favour of this approach. A variety of community locations were suggested including 'mosque ladies circles', and 'rum shops'.
  - **Use of ethnic community media:** The Gujarati Indian, Pakistani and African- Caribbean groups suggested the benefits of this in overcoming language barriers and reaching more people (e.g. Zee TV, Star Plus etc, BBC Asian Network)
  - **Use of celebrities and community leaders as role models.** Indian, Pakistani and African-Caribbean groups endorsed the use of role models

Participants also made a number of recommendations as to the required *message content*: increase awareness, to emphasize the severity and to emphasize the preventative nature.

### Health professionals interventions

- **The personalised touch** – a few of the campaigns and pilots have suggested a personalised approach from health professionals improves the uptake of cancer screening: the PN model is very personalised with each individual being assigned a patient navigator (Better Days, 2011) 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.
- Training of GP reception staff has also been found to be a noteworthy intervention and has increased uptake of breast screening amongst BME populations (Atri et al, 1997).

## Patient navigation and support interventions

- **Patient navigation (PN)** – the pilot run using the PN model showed good results with regards the uptake of cancer screening amongst African Caribbean women (Betterdays Cancer Care, 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 organizations, and other components of the health care system (Oncology Service Line. 2013). 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.
- **Involvement of partners/husbands/wives/families** – men identified their wives and partners as being a big influence on their engagement with health services, and women saw this as an important influence in many cases as well (Wilkins, 2011)

## Process interventions

- In two review studies on CRC screening participation and adherence by Vernon (1997) and Vernon and Peterson (2000), the adherence rate to programmatic offers of FOBT, even with intensive efforts, was rarely exceed above 50%. Most of the studies reviewed used Hemoccult kit, which requires stool handling, diet restriction, and sending stool samples back for diagnosis.. Vernon and Peterson concluded that, in general, FOBT adherence was lowest when persons were asked to pick up a test kit or to mail in a reply card to receive a kit. Those randomized trials reported near 50% FOBT screening adherence to program efforts used strategies that ranged from using a physician-signed letter along with FOBT kits in the mail out, to intensive follow-up with instructional phone calls [Myers et al. 1994; Myers et al, 1994; Myers et al., 1991; Lewis et al, 1994; Hardcastle et al. 1983]. Hou and Chen (2004) in their study which assessed the perceived acceptance, difficulty level, and screening efficacy of home-administered fecal occult blood test (FOBT) among a Chinese population, found use of the innovative screening strategy using the home-administered kit called EZ DETECT increased participation in FOBT screening. This type of home-administered kit requires no stool handling or diet restriction. Test results can be obtained immediately through observing color changes in test tissues. The convenient, sanitary, and easy-to-use nature of the procedure gained not only high acceptance but also high screening efficacy among the participating Chinese people. However it must be noted that another factor that possibly contributed to the high follow-up and screening completion rate could be the support obtained from managers and leaders at each worksite, which may have contributed to more people participating than if they hadn't been involved. It is important to note that the intervention also included provision of educational brochures.
- **Maintaining motivation** – this was identified as a hugely important part of the process throughout the screening campaigns; how this should be done is not explicitly outlined, however (Weller et al. 2006).

## Individual directed interventions

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)

## Campaigns

There are a number of charities based in the UK that concentrate specifically on bowel cancer, raising awareness and campaigning for better research, screening and treatments. Two of the biggest and most influential are *Bowel Cancer UK* (Bowel Cancer UK, 2014) and *beating bowel cancer*, (Beating Bowel Cancer, 2014) both of which have active campaigns in the public domain; other cancer charities, such as *Cancer Research UK*, also run campaigns on bowel cancer.

**Champs** is a public health network and ran a campaign to increase the uptake of bowel cancer screening in GP practices by 5 per cent in three months (Tiffany et al. 2012). 16 GP practices were approached and 80 of their patients, who had most recently not responded to FOBT tests, were targeted and followed up; these surgeries were in Halton and St Helens, Knowsley, Liverpool, Warrington and the Wirral. Researchers sent packs containing a reminder letter, information leaflets, a DVD and a bookmark to 1,280 patients. GPs were also asked to flag these individuals so they could discuss it with them when they next came into the surgery. To establish if these non-respondents were encouraged to partake in the screening process by the packs, they were asked to call a number provided in the pack to receive a new FOBT. The campaign aimed to increase screening uptake rates by 5 per cent; it achieved and surpassed this goal, **increasing uptake by 11.87 per cent in the three months** (*ibid*, p.14). The campaign found that a more personalised touch from GPs produced higher rates of uptake in the general population, for example by signing the reminder letters

and talking to patients about screening when attending the surgery for other reasons. However, the project also found there to be serious issues with obtaining up-to-date data and information on patients to contact them and engage them effectively – this would need to be addressed to make this a more viable option for further action.

**Bowel Cancer UK** runs a number of campaigns both to advocate for better approaches to treating and diagnosing the disease, and raise awareness of the disease among the general public. Its most recent campaign is concerned with making sure the correct endoscopic test is offered to those who have been identified as either being at risk or whose FOBt has returned abnormal results (Bowel Cancer UK, 2013). In September 2013, a qualitative survey was run with 708 participants, all of whom had undergone an endoscopic procedure, with the aim of understanding more about their experiences. The report found there was a need to **empower** patients with better-quality information surrounding the diagnostic processes; the report concluded this could both improve the experiences of patients and reduce any anxieties they may have. ‘Good quality information is one of the main ingredients for a good patient experience’ (Bowel Cancer UK, 2013, p27), as well as increasing adherence and reducing the possibility of cancellations.

*Bowel Cancer UK* has also run campaigns specifically targeting certain groups of people in a bid to improve awareness and uptake of screening: one campaign targets men and the other raises awareness of bowel cancers in younger people. ‘**Spotlight on Men**’ found that nearly half of men questioned would not seek advice from their doctor if they suspected they were suffering with a bowel-related illness. The campaign also identified a socioeconomic gradient, with more men from deprived backgrounds dying from bowel cancer than their more affluent, male peers (Bowel Cancer UK, 2013).

**Men’s Health Forum** conducted a survey and interviews and subsequently compiled a report on encouraging male participation in the BCSP; its findings could help to explain the lower uptake of men in bowel screening (Wilkins, 2011). An unforeseen barrier to uptake was identified by the report – many of the men felt that if they were fit and healthy they did not think a bowel cancer screening process was necessary or relevant to them. This finding highlights the need for further information surrounding the preventative nature of the screening process, as well as an awareness of gender differences. Participants also reported finding the FOBt to be a ‘messy’ and ‘unsavoury’ process, which they identified as a reason why they may not participate in the testing (Wilkins, 2011, p. 7). Men reported an interest in more gender-specific information on the bowel screening process, with simple and easy-to-digest information; they also mentioned a preference for the use of memorable slogans.

The *Bowel Cancer UK* and *Men’s Health Forum’s* reports on men’s participation in the BCSP are documents to look to for guidance on group-specific campaigns and recommendations. Men have been identified as a group that has faced barriers to participation in bowel cancer screening, much like many BME communities. *Bowel Cancer UK* has not run a campaign specifically targeting these communities to date, and has not responded to an email requesting further information on the topic. There has also been no response to a similar request sent to *beating bowel cancer*.

**Cancer Research UK** has also run campaigns on the importance of screening for cancers; its most recent and topical campaign was ‘**Screening Matters**’ (Cancer Research UK, 2014). The aim of this nationwide campaign, started in 2008, was to get at least 3 million more people screened for cervical, breast and bowel cancers over five years. The programme also aimed to reduce the variation of uptake of screening across the country and encourage those who are eligible and not taking part to engage. The campaign was government-backed, with the health minister in 2008, Ann Keen MP, committing to widen the age range for cancer screening so as to make the goal of testing 3 million more people an achievable one. Evaluation of this campaign is limited, despite the fact it should have finished in 2013. Raising awareness of screening and preventative measures of bowel cancer does seem to be a priority of many of the charities, although they have not concentrated specifically on BME communities.

**Breast Cancer Care** ran a campaign to better understand the needs of BME women with regards to awareness of and information about breast cancer screening, diagnosis and treatment (Breast Cancer Care, 2005). This campaign revealed a high proportion of women did not know enough about breast cancer (32 per cent) and had not attended a breast cancer screening appointment regardless of being the correct age (45 per cent). Involving men in breast cancer campaigns was identified as a good way to encourage women

to attend as they may have the ability to encourage their loved ones to attend screenings, as well as other solutions such as media campaigns.

**Beating bowel cancer** has also run campaigns to raise awareness of the disease and how to recognise it, and to encourage participation in screening programmes. The charity's main campaign is '#LiftTheLid' and it concentrates on making more people aware of the disease and how it can be recognised (Beating bowel cancer, 2014). A #LiftTheLid day was organised on 16 April 2014 and people have been encouraged to run their own events both to fundraise and continue the campaign's awareness raising. It does not focus specifically on involving more marginalised groups, but the campaign does raise some questions surrounding ethnicity in other ways. An interactive message wall invites people to write about their experiences of bowel cancer, any advice on screening/treatments and how it has impacted them and their families; this wall is predominantly white people (see: <http://liftthelid.org/messagewall/>). This trend continues on the *beating bowel cancer's* website where there is a section with videos of patients' experiences of the disease – and all the videos offer the stories of white people. BME individuals are heavily underrepresented on this website and others (the *Bowel Cancer UK's* 'voices of bowel cancer' are also all white) (Bowel Cancer UK, 2014b).

Smaller charities in the UK have also shown that the health inequalities faced by BME communities are having a visible impact – an example of a small charity acting on its own merit is the case of a hospice in Birmingham. **John Taylor Hospice** was seeing terminally ill young men with prostate cancer from BME communities all too often, and decided to begin an initiative with the aim of slowing this trend. It has raised £3,000 to begin its efforts to engage and educate the community with outreach events; this money was raised through a crowdfunding website, to which members of the public give their own money. This is an example of how care workers have been able to see the impact of such health inequalities and have felt inspired to take action.

There have also been examples of individuals who have campaigned for greater awareness of bowel cancer screening in the wider community. Lynn Faulds-Wood, a television journalist in the UK, is a bowel cancer survivor and has produced a number of short films on screening processes, including the FOBt and endoscopic procedures. These have been created to raise awareness of bowel cancer and the importance of the screening process (Youtube, 2011). For reference, Lynn is a good friend of C3 and if it is considered useful we can engage her further.

## Pilot studies

There have been a number of pilots, conducted on behalf of the **NHS**, of various bowel screening programmes run across the country, which have reported on the uptake of testing and the variation between different groups. One report, published in 2003 following the UK colorectal cancer screening pilot, concentrated on **ethnicity** and its influence over the rate of uptake of bowel screening (Szczipura, 2003), and found there were considerably lower uptake rates amongst BME communities than in non-BME communities in Coventry and Warwickshire. The Muslim community had a particularly low uptake rate (31.9 per cent) compared with 63.7 per cent for non-Asian communities (Szczipura, 2003, p.4). Prior to being sent the screening kit, Asian participants were asked about their willingness to do the FOBt – no reluctance was reported, although this finding was not reinforced by the low rates of uptake. A low rate for completion of the screening process was also found amongst Asian communities, with only 32 per cent of Muslims and 35 per cent of Sikhs completing (Szczipura, 2003, p. 46). Multivariate analysis showed that these low uptake rates cannot and should not be explained by factors such as deprivation, age or gender. This report notes that **diverse solutions** are needed to address the diversity of barriers affecting the BME communities. The study was effective in showing that rates for BME communities were significantly lower than for the non-BME population, but it did not offer possible explanations of or solutions to this problem.

**Bowel Cancer UK** has worked with six junior GPs in the London boroughs of Lambeth and Southwark (areas with high levels of social deprivation and low uptake of screening) on a small programme to deliver teaching sessions about screening, aiming to improve screening uptake among both British/Irish and ethnic minority (particularly Chinese) populations. The sessions, which were run over a three-month period, were attended by 36 people aged over 50, and covered information on bowel cancer and the importance of

screening and a demonstration of the bowel cancer screening test kit. Pre- and post-session questionnaires were carried out to assess the level of awareness of bowel cancer and willingness to participate in the screening. It found that before the sessions less than a fifth of the target population were aware of the symptoms and risk factors of bowel cancer; this then rose to 95 per cent. Even after the sessions, only 23–42 per cent expressed a willingness to change lifestyle factors (e.g. smoking cessation) – but 95 per cent said they would be willing to participate in a screening test (up from just 39 per cent before the sessions). Further research is needed to see if these changes can be sustained.

Another pilot project run for the NHS involved ‘**patient navigation**’ (PN) as a way of keeping patients involved and engaged in the process of screening, diagnosis and through to treatment (Betterdays, 2011). This pilot was run in the South East London area, concentrating specifically on African Caribbean women and their attendance at breast screening. The PN study identified barriers to breast screening uptake amongst the African Caribbean women (outlined in the section below on barriers). The pilot produced some positive results: patient navigators made mammography appointments for 39 per cent of women living in Southwark and 36 per cent of women in Lewisham who had not previously responded to invitations for mammograms – the attendance rates for these appointments were 66 per cent and 63 per cent respectively. Feedback from **outreach events** suggested they were effective in conveying important information to the community; these consisted of breast-health education and community awareness, in the form of presentations and radio broadcasts. Results show an improved rate of uptake amongst these women, suggesting the patient navigation approach is beneficial. There is no information on the costs of such an approach, although it could be assumed they would not be low. The report provided **some recommendations** to improve the uptake of screening, including: making sure GPs’ contact information for patients is up-to-date; introducing more follow-up (in the form of PN) for those who did not attend; introducing more flexible screening times (in the case of endoscopic procedures); and running more community-outreach events (Betterdays, 2011, p.27). This PN model could be thought of as a useful first step in a process of engaging communities – not only to participate in screening, but also to feel more comfortable with the health care system more generally.

Patient navigation is an intervention developed to address inequalities that exist in healthcare; it aims to achieve the reduction of inequalities by breaking down any possible barriers to care a patient may have. This approach was developed by a US surgeon, Dr Harold Freeman, and was first used in a deprived neighbourhood of Harlem, New York. Patient navigators are individuals who are assigned to a patient and are there to guide them through the healthcare system, offering advice, tips and guidance throughout the patient’s process. In this pilot, patient navigators were from the same cultural background as the study participants and spoke the same language (if English was not a first language); this allowed them to communicate effectively with and understand the participants. The **PN model is split into four sections**: outreach navigation; diagnostic navigation; treatment navigation; and financial navigation.

The third pilot of note was this second-round pilot study of the BCSP with 127,746 individuals; it had a response rate of 52.1 per cent, with 51.7 per cent completing all phases of the screening (Weller, 2011). The evaluation found that uptake was lower amongst men than women and in areas with a higher proportion of South Asians (40.4 per cent, compared with 54.0 per cent in areas with lower proportions of South Asians) (Weller, 2011, p37). This report formed part of the evidence base for rolling out the BCSP nationally; it also contains recommendations for consideration with regards to improving the uptake of such screening. **Maintaining motivation** is identified as an important part of the screening process, since it requires an active role on the part of the patient. Keeping these participants engaged in the process every two years is thought to be one of the hardest parts of the screening (Weller, 2011, p.174).

## Learning from other countries

### United States

In the United States there have been some excellent campaigns and approaches to increasing the uptake of cancer screening; US approaches have differed slightly to the United Kingdom's, although there are some lessons to be learnt. The **American Cancer Society** has published guidelines to increase the uptake of preventative screening of cancers in primary care (American Cancer Society. 2008). There are **four guiding principles** to the strategy:

- GPs and nurses should recommend to patients that they take part in screening, making it clear that the process is important and could have a big impact –one of the main reasons people do not participate in screening is because it was not recommended personally by their doctor;
- produce a screening policy within practice – a standardised procedure will make it easier for both staff and patients;
- keep reminding those who do not attend – this may need to be done a few times to improve uptake considerably. This can be an inbuilt part of the screening policy – tracking those who have attended, those who have been diagnosed and those who have not attended is important; and
- evaluate the progress of the practice – set a goal for screening uptake and watch uptake rates grow from the baseline; this can be rewarding for staff (American Cancer Society. 2008, p.1).

These guidelines are all about implementing changes within the GP practice and would require support from the whole team, including GPs, nurses and administrators. Less emphasis is given here to the education of patients and no acknowledgement is given to involving groups who are less likely to participate, perhaps in the form of outreach work.

There is evidence to suggest that BME communities are less likely to participate in bowel cancer screening – in 2013, a study found that 42 per cent of white people were screened, while only 36 per cent of black people, 31 per cent of Asians and 28 per cent of Hispanics participated in such screenings, between 2000 and 2005 (Health Days, 2013). The study suggested a number of reasons why these disparities could exist and outlines a number of barriers:

- money and lack of access;
- transportation issues;
- poor health literacy (unable to understand and use health information); and
- trouble getting time off work and losing pay (manual, low-paid labour, for example).

These barriers are more to do with having endoscopic tests, although the poor health literacy is also relevant to FOBt screening. Solutions to deal with such barriers are sometimes not translatable to the UK system – for example, it was suggested that doctors are incentivised to perform cancer screens in underserved areas.

The US government has also funded campaigns with the aim of raising awareness as well as encouraging uptake of screening. There is a bowel cancer campaign run by the Centers for Disease Control and Prevention called '**Screen for Life**' (Centers for Disease Control and Prevention, 2014a) that has two prongs – an awareness-raising element and inbuilt evaluation. Public Service Announcements (PSAs) have been used to answer important questions about the screening process and have been fronted by famous American actors, such as Meryl Streep and Morgan Freeman; there are also PSAs in Spanish to target the large Hispanic population (Centers for Disease Control and Prevention, 2014b). The television PSAs were estimated to have been seen 1.2 billion times (Centers for Disease Control and Prevention, 2014c). Telephone surveys have shown that screening uptake has increased in the last decade, although rates still remain low. This campaign is also active on Twitter (Centers for Disease Control and Prevention, 2014d).

### Australia

A campaign run in Australia has taken a different approach to all other strategies discussed in this report. The '**Love my family**' campaign, run by *Bowel Cancer Australia*, uses emotional attachments to hammer



home important messages on bowel cancer and its prevention (Bowel Cancer Australia. 2014). A television campaign was broadcast in 2009 showing an Australian celebrity talking about her father who died from bowel cancer, and how it could have been preventable if he had caught it early through screening (YouTube, 2010); this video uses emotion to encourage uptake. It also suggests that the campaign believes that family and friends can have a big influence over the actions of loved ones with regards to health. Another video on the campaign's website (that was broadcast in 2010) shows average Australian people saying which of their loved ones have or had bowel cancer; this video highlights how the disease affects ordinary people (Bowel Cancer Australia. 2014).

There is no evaluation available on the effectiveness of this campaign, but the approach differs to others within the UK and it could be considered as a possible strategy for raising awareness; attaching **emotional ties** to an issue can increase the impact it can have.

Currently, there is another awareness-raising campaign running in Australia called '**Don't be a fool, test your stool**', run by *Bowel Cancer Australia*, *Bowel Screen Australia* and *Let's Beat Bowel Cancer* in collaboration. The campaign, which started at the beginning of 2014, has been described as 'attention-grabbing' and using a 'light-hearted approach' (Testyourstool.org, 2014). This public-awareness campaign has used traditional and social media to get the message across; a video uses a simple, catchy approach to disseminate the key information (YouTube, 2014). Other reports, such as those discussed in earlier sections, have highlighted the desire for memorable slogans to retain the interest of the general public. There does not, however, appear to be any evaluation on its effectiveness to date.

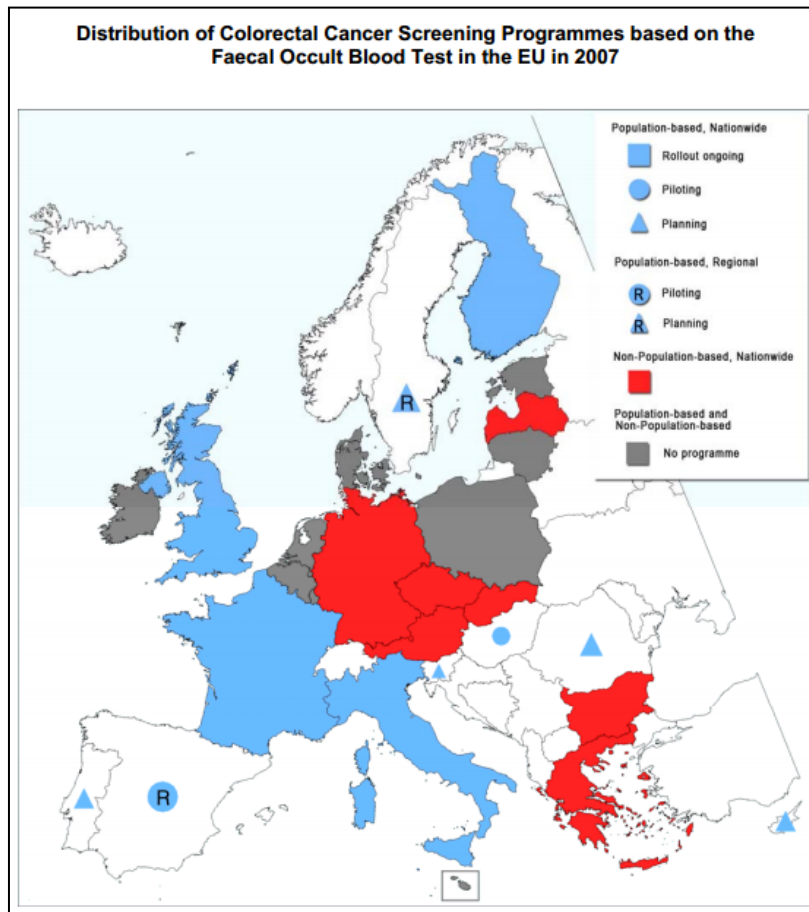
There does not appear to be any non-academic information, for example campaigns or outreach events, directed at engaging BME or Aboriginal populations in the country.

## **European Union**

The first European Union set of **guidelines** for bowel cancer screening were published in 2011; they were drawn up by more than 90 experts from 32 countries (Cancer Research UK, 2014c). These guidelines offer principles on various topics that need to be considered when implementing an effective screening programme in a country; topics include communication, organisation and testing procedures (Segnan, Patnick, and von Karsa, 2010). Within the communication section of this document there was a recommendation suggesting the use of the **patient navigation** model; this was particularly based on improving outreach to underserved patients. It explicitly states that if patients are from ethnic minority groups the patient navigators should be from a similar background or even the same community (Segnan, Patnick, and von Karsa, 2010, p.302). More recommendations on communications are given in this particular document on pages 301–303.

The European guidelines favour the use of **nationwide, population-based bowel cancer screening** programmes, as opposed to regional and non-population-based programmes; this is because they are more inclusive and require each eligible person to be personally invited to screening. These types of programme do require a high-level of organisation, however. As of 2008, 12 EU countries had population-based programmes and seven had non-population-based programmes, with the remainder not offering screening (Von Karsa et al., 2008) some of these programmes were in the planning or piloting phase at the time of publication of this report, but they may now be fully in place. It may also be the case that some countries that did not have a programme at all in 2008 will now have one in place. Below is the map presented in the EU report on the distribution of bowel cancer screening programmes, which shows a lack of uniformity across the region:





Source: European Commission (taken from Von Karsa et al. 2008, p 54)

## Public health risk and change

In a study examining research evidence of factors influencing access to health care by ethnic minority groups, Szczepura (2005) found that explanations offered by relevant research literature for reported disparities in access to health services fall into two main groups. The first group are linked to intrinsic or “*personal*” factors; these include the particular needs of ethnic minority people that must be met as part of ensuring equitable access. The second group are associated with extrinsic or *organisational factors* – the focus of these are on the organisation itself and its healthcare delivery and planning systems.

### Intrinsic personal factors:

- **Cultural differences:** This explanation recognises that people identify themselves with a social group on cultural grounds, and that diverse racial and ethnic groups may respond differently because of their particular health beliefs and behaviours (Broch and Fraser, 2000). Cultural dimensions include religion that may affect compliance or access to services; sex, which is commonly mentioned as an obstacle to service access by women; differential presentation including “*somatisation*” of symptoms, which is reported to lead to misunderstandings, misdiagnosis, or incorrect referrals; “*fatalism*” or shyness, which may also lead to a reluctance to seek help resulting in late presentation; and other cultural factors such as family dynamics may mean people cannot easily attend or take up services without the support of family members (Atkinson et al, 2001).

It is recognised that health professionals need to take into account these types of cultural beliefs and values when communicating with patients or users

- **Language and literacy.** Poor linguistic competence is an important barrier to access for many with high levels of need among older ethnic minority adults. In cases of poor linguistic competence, interpreting services are required to diagnose, consent and treat those people adequately. Differences in literacy levels may also be an issue. Although people may be able to speak English, they may not be able to

read it (Johnson et al, 2000; Rudat, 1994). Additionally despite the translation of letters and patient information sheets and leaflets, some people may not be able to read their own language (Rudat, 1994).

- **Newness or user ignorance.** This factor is related to the migrant status of people (and taking account of older generations) in the BME population, and shows itself through unfamiliarity with the NHS and limited knowledge of available services (Lindesay et al, 1997; Iqbal, 1994; Penso and Hill, 1995; Powell, 1999).

#### **Extrinsic factors**

- **Differential needs and provision.** In some cases, barriers to access may be linked to poor provision of certain services required specifically for ethnic minority groups.
- The **location** of health services may result in poor access for certain mobile populations (e.g. refugees, gypsies). Also as settled ethnic population move (through suburbanisation - there may be a lag in providing appropriate services in the new locations. Isolated minorities in areas not equipped to meet their language needs may also experience barriers in accessing routine services (e.g. poor levels of interpreting services)
- **Staff training needs.** Healthcare staff with stereotypical views, lack of cultural awareness and an ability to manage patients from a diverse background in an unsuitable manner – can create barriers and resentment and lead to a lower uptake of healthcare services. Literature suggests that institutional racism should be tackled as part of any intervention to improve access for ethnic minority users. Improving diversity in the workplace is not the answer, but integrating diversity training for existing staff is also important. Training in the use of interpreters is also important.

Healthcare organisations and their staff need to be culturally and linguistically competent when delivering services. Improved responsiveness to the health beliefs, practices, and cultural needs of patients is required to provide equitable access to health care for diverse populations. Such provision should also recognise that the provider and the ethnic minority patient each bring their own individual learned patterns of language and culture to the healthcare experience.

## References

- Abdullahi, A., Copping, J., Kessal, A., Luck, M and Bonell, C. Cervical screening: Perceptions and barriers to uptake among Somali women in Camden. *Public Health*. Volume 123, Issue 10, October 2009, Pages 680–68. Available: <http://www.sciencedirect.com/science/article/pii/S0033350609002662> [accessed 10th June 2014]
- American Cancer Society. 2008. 'How to increase preventive screening rates in practice: an action plan for implementing a primary care clinician's evidence-based toolbox and guide' [online] Available: <http://www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-029276.pdf> [Accessed 6<sup>th</sup> June]
- Atkinson M, Clark M, Clay D, et al. Systematic review of ethnicity and health service access for London. Coventry: Centre for Health Services Studies, University of Warwick, 2001.
- Atri, J/, Falshaw, M., Gregg, R., Robson, J., Omar, R. and Dixon S. 1997. Improving uptake of breast screening in multiethnic populations: a randomised controlled trial using practice reception staff to contact non-attenders. *British Medical Journal* 315, pp.1356–9.
- Austin, K., Power, E., Solarin, I., Atkin, W., Wardle, J and Robb, K. 2009. Perceived barriers to flexible sigmoidoscopy screening for colorectal cancer among UK ethnic minority groups: a qualitative study. *Journal of Medical Screening* 16, 174. [online] Available: <http://msc.sagepub.com/content/16/4/174> [accessed 10th June 2014]
- Beach, M.L., Flood, A.B., Robinson, C.M., et al., 2007. Can language-concordant-prevention care managers improve cancer screening rates? *Cancer Epidemiology, Biomarkers & Prevention*. 16, pp.2058–2064.
- Beating Bowel Cancer. 2012. 'Equity and excellence for bowel cancer' [online] Available: <https://www.beatingbowelcancer.org/sites/default/files/images/Equity%20and%20excellence%20for%20bowel%20cancer%20FINALfrontcover.pdf> [accessed 20<sup>th</sup> June 2014]
- Beating bowel cancer. 2014. Website '#LiftTheLid' [online] Available: <https://www.beatingbowelcancer.org/liftthelid> [Accessed 22<sup>nd</sup> June 2014]
- Beating Bowel Cancer. 2014. Website. Available <https://www.beatingbowelcancer.org/> [accessed 20<sup>th</sup> June 2014)
- Beeker C, Kraft JM, Goldman R. 2001. Strategies for increasing colorectal cancer screening among African Americans. *Journal of Psychosocial Oncology*, 19, pp.113–32.
- Betterdays Cancer Care, 2011. Patient Navigation Project Pilot Report. [online]. Available at: <http://www.cancerscreening.nhs.uk/breastscreen/patient-navigation-pilot-july2011.pdf>
- Boring C, Squires T, Heath C. 1992. Cancer statistics for African Americans. *A Cancer Journal for Clinicians* 42, pp.7–17.
- Bowel Cancer Australia. 2014. 'Love my family' Website [online] Available: <http://www.bowelcanceraustralia.org/lmf/> [Accessed 6<sup>th</sup> June 2014]
- Bowel Cancer UK, 2013. 'Right test, Right time' [online] Available: <http://www.bowelcanceruk.org.uk/campaigns-policy/latest-campaigns/right-test,-right-time/read-our-report/> [Accessed 12<sup>th</sup> June 2014]
- Bowel Cancer UK. 2013. 'Spotlight on men', [online] Available: [http://www.bowelcanceruk.org.uk/media/264986/1758\\_bcuk\\_mensreport\\_web.pdf](http://www.bowelcanceruk.org.uk/media/264986/1758_bcuk_mensreport_web.pdf) [accessed 20<sup>th</sup> June 2014)
- Bowel Cancer UK. 2014. Website. Available: <http://www.bowelcanceruk.org.uk/> [accessed 20<sup>th</sup> June 2014)
- Bowel Cancer UK. 2014b. 'Voices of bowel cancer'[online] Available: <http://www.bowelcanceruk.org.uk/voices-of-bowel-cancer/> accessed 20<sup>th</sup> June 2014)
- Brach C, Fraser I. 2000. Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Medical Care Research and Review*, 57, pp.181–217.

- Breast Cancer Care, 2005. Same difference: Breast awareness is for everyone [online] Available: <http://tinyurl.com/qfxlcog> [Accessed 20th June 2014]
- Cancer Research UK. 2014a. 'Bowel cancer mortality statistics', [online] Available: <http://www.cancerresearchuk.org/cancer-info/cancerstats/types/bowel/mortality/uk-bowel-cancer-mortality-statistics> [accessed 20<sup>th</sup> June 2014]
- Cancer Research UK. 2014c. 'New European guidelines on bowel cancer screening and diagnosis', February 2011. [online] Available: <http://www.cancerresearchuk.org/about-us/cancer-news/news-report/new-european-guidelines-on-bowel-cancer-screening-and-diagnosis> [Accessed 22<sup>nd</sup> June 2014]
- Cancer Research UKb. 2014. 'Screening Matters'. [online] Available: <http://www.cancerresearchuk.org/support-us/campaign-for-us/our-campaigning-successes/screening-matters> [accessed 20<sup>th</sup> June 2014]
- Centers for Disease Control and Prevention, 'Screen for Life: 2013 Year-End Report' [online] Available: [http://www.cdc.gov/cancer/colorectal/pdf/CDC\\_SFL\\_2013\\_Year\\_End\\_Report.pdf](http://www.cdc.gov/cancer/colorectal/pdf/CDC_SFL_2013_Year_End_Report.pdf) Accessed 6<sup>th</sup> June 2014]
- Centers for Disease Control and Prevention. 2014a. 'Screen for Life: National colorectal cancer action campaign'[online] Available: <http://www.cdc.gov/cancer/colorectal/sfl/> [Accessed 6<sup>th</sup> June 2014]
- Centers for Disease Control and Prevention. 2014b. 'Screen for Life Television Public Service Announcements' [online] Available: [http://www.cdc.gov/cancer/colorectal/sfl/tv\\_psa.htm](http://www.cdc.gov/cancer/colorectal/sfl/tv_psa.htm) Accessed 6<sup>th</sup> June 2014]
- Centers for Disease Control and Prevention. 2014d] 'Screen for Life – twitter' [online] Available: [https://twitter.com/cdc\\_cancer](https://twitter.com/cdc_cancer) Accessed 6<sup>th</sup> June 2014]
- Chapple, A., Ziebland, S., Hewitson and McPherson, A. 2008. What affects the uptake of screening for bowel cancer using a faecal occult blood test (FOBT): A qualitative study. *Social Science & Medicine* 66, pp. 2425 – 2435
- Chow Choi, K. et al. 2013. Gender differences in the use of colorectal cancer tests among older Chinese adults. *European Journal of Oncology Nursing* 17 (2013) pp.603-609
- Clavarino, A., Janda, M., Hughes, K., Del Mar, C., Tong, S., & Stanton, W., et al. (2004). The view from two sides: a qualitative study of community and medical perspectives on screening for colorectal cancer using FOBT. *Preventive Medicine*, 39, pp.482-490.
- Cole, S., Smith, A., Wilson, C., Turnbull, D., Esterman, A., Young, G., 2007. An advance notification letter increases participaiton in colorectal cancer screening. *Journal of Medical Screening*, 14, pp.73–75.
- Cole, S., Young, G., Byrne, D., Guy, J., & Morcom, J. (2002). Participation in screening for colorectal cancer based on a faecal occult blood test is improved by endorsement by the primary care provider. *Journal of Medical Screening*, 9, pp.147-152.
- Cole, S., Young, G., Esterman, A., Cadd, B., Morcom, J., 2003. A randomised trial of the impact of new faecal haemoglobin test technologies on population participation in screening for colorectal cancer. *Journal of Medical Screening* 10, pp.117–131.
- Correspondence with Gail Curry, Bowel Cancer UK, 19 June 2014.
- Damery, S., Clifford, S. and Wilson, S. 2010. Colorectal cancer screening using the faecal occult blood test (FOBT): a survey of GP attitudes and practices in the UK. *BMC Family Practice* 2010, 11:20 doi:10.1186/1471-2296-11-20
- Dietrick, A.J., Jonathan, N.T., Cassells, A.N., et al., 2006. Telephone care management to improve cancer screening among low-income women. *Annals of Internal Medicine*. 144, pp.563–571.
- Douglas CY. 2001. Community-based screening interventions for colorectal cancer. *Journal of Psychosocial Oncology*, 19, pp.133–46.

- Fitzgibbon, M.L., Ferreira, M.R., Dolan, N.C., et al., 2007. Process evaluation in an intervention designed to improve rates of colorectal cancer screening in a CA medical center. *Health Promotion Practice*. 8, pp.273–281.
- Friedemann-Sanchez, G., Griffin, J.M., Partin, M.R., 2007. Gender differences in colorectal cancer screening barriers and information needs. *Health Expectancy*. 10, pp.148–160.
- Galdas PM, Cheater F, Marshall P. 2005. Men and help seeking behaviour: a literature review. *Journal of Advance Nursing*. 49, pp.616–23
- Gordon-Dseagu, V. 2006. Cancer Research UK, 'Cancer and health inequalities: an introduction to current evidence'. [online] Available: [http://www.cancerresearchuk.org/prod\\_consump/groups/cr\\_common/@nre/@pol/documents/generalcontent/crukmig\\_1000ast-3344.pdf](http://www.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@pol/documents/generalcontent/crukmig_1000ast-3344.pdf), p. 8 [accessed 19<sup>th</sup> June 2014]
- Hardcastle J.D., Farrands P.A., Balfour, T.W., Chamberlain, J., Amar S.S. and Sheldon MG. 1983. Controlled trial of fecal occult blood testing in the detection of colorectal cancer. *Lancet*, 2,pp.1–4.
- Health Day. 2013. 'U.S. minorities less likely to get colon cancer screening: study', [online] Available: <http://consumer.healthday.com/cancer-information-5/colon-cancer-news-96/u-s-minorities-less-likely-to-get-colon-cancer-screening-study-672439.html> Accessed: 10<sup>th</sup> June 2014]
- Hoffman-Goetz L, Breen NL, Meissner H. The impact of social class on the use of cancer screening within three racial/ethnic groups in the United States. *Ethn Dis* 1998;8:43–51.
- Hoffman-Goetz, L., Thomson, M., Donelle, L., 2008. Reasons for declining colorectal cancer screening by older Canadians: a pilot study. *Journal of Cancer Education*. 23, pp.32–36.
- Hou, S.I. and Chen, P. 2004. Home-administered fecal occult blood test for colorectal cancer screening among worksites in Taiwan. *Preventive Medicine* 38, pp. 78– 84. Available: <http://www.sciencedirect.com/science/article/pii/S0091743503002354#>
- Iqbal H. 1994. Palliative care service use by black and ethnic groups in Leicester. Leicester: Leicestershire Health.
- Javanparast, Sara ; Ward, Paul ; Young, Graeme ; Wilson, Carlene ; Carter, Stacy ; Misan, Gary ; Cole, Stephen ; Jiwa, Moyez ; Tsourtos, George ; Martini, Angelita ; Gill, Tiffany ; Baratiny, Genevieve ; Matt, Michelle Ah. (2010) How equitable are colorectal cancer screening programs which include FOBTs? A review of qualitative and quantitative studies. *Preventive Medicine*, 2010, Vol.50(4), pp.165-172
- Johnson MRD, Owen D, Blackburn C, et al. 2000. Black and minority ethnic groups in England: the second health and lifestyles survey. London: Health Education Authority.
- Larkey, L.K., Gonzalez, J., 2007. Storytelling for promoting colorectal cancer prevention and early detection among Latinos. *Patient Educational Counselling*. 67, pp.272–278.
- Lasser K. E, Murillo J, Medlin E, Lisboa S, Valley-Shah L, Fletcher R. H, Emmons KE, Ayanian J. Z. A Multilevel Intervention to Promote Colorectal Cancer Screening among Community Health Center Patients: Results of a Pilot Study. *BMC Family Practice* 2009, 10:37.
- Lewis, R.J., Lerman, S.E., Schnatter ,A.R., Hughes J.I. and Vernon, S.W. 1994. Colorectal polyp incidence among polypropylene manufacturing workers. *Journal of Occupational Medicine*.36, pp.174– 81.
- Lindesay J, Jagger C, Hibbett M, et al. Knowledge, uptake and availability of health and social services among Asian Gujarati and white elderly persons. *Ethnicity and Health* 1997;2:59–69.
- Lindholm E, Berglund B, and Haglund E. 1995. Factors associated with participation in screening for colorectal cancer with faecal occult blood testing. *Scandinavian Journal of Gastroenterology*, 30, pp.171–6.
- Lindholm E, Berglund B, Haglund E, et al. Factors associated with participation in screening for colorectal cancer with faecal occult blood testing. *Scand J Gastroenterol* 1995;30:171–6.

- Lipkus, I.M., Klein, W.M., 2006. Effects of communicating social comparison information on risk perceptions for colorectal cancer. *Journal of Health Communication*. 11, pp.391–407.
- Mant, D., Fuller, A., Northover, J., Astrop, P., Chivers, A., & Crockett, A., et al. (1992). Patient compliance with colorectal cancer screening in general practice. *British Journal of General Practice*, 42, pp.18-20.
- Myers R.E., Ross, E., Wolf, T.A., Balshem, A., Jepson, C. and Millner, L. 1991. Behavioral interventions to increase adherence in colorectal cancer screening. *Medical Care*, 29, pp.1039– 50.
- Myers RE, Ross E, Jepson C, Wolf T, Balshem A, Millner L, et al. 1994. Modeling adherence to colorectal cancer screening. *Preventative Medicine*. 23, pp. 142– 51.
- National Institute for Health and Clinical Excellence. 2011. 'Increasing the uptake of HIV testing among black Africans in England' [online] Available: <http://www.nice.org.uk/nicemedia/live/13417/53591/53591.pdf> [accessed 6th June 2014]
- NHS Bowel Cancer Screening Programme. Website: Available <http://www.cancerscreening.nhs.uk/bowel/> [accessed 20<sup>th</sup> June 2014)
- Oncology Service Line. 2013. Navigation Program Resource Guide: Best Practices for Patient Navigation Programs [online] Available: [http://mdpnn.files.wordpress.com/2013/04/chi-navigation-program-resource-guide-final-012013 .pdf](http://mdpnn.files.wordpress.com/2013/04/chi-navigation-program-resource-guide-final-012013.pdf) [Accessed 19th June 2014]
- Penso D, Hill D. Opening doors: improving access to hospice and specialist palliative care services by members of the black and ethnic minority communities. London: National Council for Hospice and Specialist Palliative Care Services, 1995.
- Peterson, S. and Vernon, S. 2000. A review of patient and physician adherence to colorectal cancer screening guidelines. *Seminars in Colon and Rectal Surgery*. 11,1, pp.58– 72.
- Powe BD. 1995. Fatalism among elderly African Americans. Effects on colorectal cancer screening. *Cancer Nursing*,18, pp.385–92
- Powell B. Improving accessibility and information services for Asian communities, relating to cancer and palliative care. Leicester: Cancer Care— Ethnic Minorities Group, 1999.
- Price, C.L., Szczepura-A.K., Gumber A.K. and Patnick, J. 2010. Comparison of breast and bowel cancer screening uptake patterns in a common cohort of South Asian women in England. *BMC Health Services Research* 2010, [online] Available: <http://www.biomedcentral.com/1472-6963/10/103> [accessed 10th June 2014]
- Robb, K. Wardle, J., Stubbings, S., Marmirez, A., Austoker, J., Mcleod, U., Hiom, S. and Waller, J. 2010. Ethnic disparities in knowledge of cancer screening programmes in the UK. *Journal of Medical Screening* 17, 125. [online] Available <http://msc.sagepub.com/content/17/3/125> [accessed 10th June 2014]
- Robb, K., Power, E., Atkin, W and Wardle, J. 2008. Ethnic differences in participation in flexible sigmoidoscopy screening in the UK. *Journal of Medical Screening*. 15: 130. Available: <http://msc.sagepub.com/content/15/3/130.full.pdf+html> [accessed 10<sup>th</sup> June 2014]
- Rudat K. Black and minority ethnic groups in England: health and lifestyles. London: Health Education Authority, 1994.
- Segnan, N., Patnick, J. and von Karsa, L. (eds.) European Commission. 2010. 'European guidelines for quality assurance in colorectal cancer screening' [online] Available: <http://www.kolorektum.cz/res/file/guidelines/CRC-screening-guidelines-EC-2011-02-03.pdf> [Accessed 22<sup>nd</sup> June 2014]
- Shokar, N.K., Vernon, S.W., Weller, S.C., 2005. Cancer and colorectal cancer: knowledge, beliefs, and screening preferences of a diverse patient population. *Fam. Med*. 37, pp.341–347
- Stephens, J., Moore, J., 2007. Can targeted interventions in CRC patients' relatives influence screening behaviour? A pilot study. *Colorectal Disease*. 10, pp.179–186.

- Szczepura, A. 2005. Access to health care for ethnic minority populations. *Postgraduate Medical Journal* 2005; 81, pp/141–147. doi: 10.1136/pgmj.2004.026237
- Szczepura, A., Johnson, M., Orbell, S., O’Sullivan, I., Clay, D. and Owen, D. 2003. Ethnicity: UK colorectal cancer screening pilot. [online] Available: <http://www.cancerscreening.nhs.uk/bowel/ethnicity-finalreport.pdf> [Accessed 19<sup>th</sup> June 2014]. p. 17
- Testyourstool.org, 2014. Website: Don’t be a fool, test your stool. [online] Available: <http://testyourstool.org/> [Accessed 22<sup>nd</sup> June 2014]
- Theuer CP, Taylor TH, Brewster WR. 2001a. The topography of colorectal cancer varies by race/ethnicity and affects the utility of flexible sigmoidoscopy. *The American Journal of Surgery*, 67, pp.1157–61.
- Theuer CP, Wagner JL, Taylor TH. 2001b. Racial and ethnic colorectal cancer patterns affect the cost-effectiveness of colorectal cancer screening in the United States. *Gastroenterology*, 120, pp.848–56
- Thomas, N., Saleem, T, Abraham, R. 2005. Barriers to effective uptake of cancer screening among black and minority ethnic groups. Available: <http://www.brightideasnottingham.co.uk/wpcontent/uploads/2011/01/barriers-to-screening-in-BME-groups.pdf> [Accessed 10th June 2014]
- Tiffany, C., Perry, C., Thurston, M. Meredith, L. and Lee, A. 2012. ‘Evaluation of a bowel cancer screening awareness campaign for Cheshire and Merseyside Public Health Network’ [online] Available: <http://tinyurl.com/pr2an5m> [Accessed 22<sup>nd</sup> June 2014]
- Vernon S. 1997. Participation in colorectal cancer screening: a review. *Journal of the National Cancer Institute* 89,19 pp.1406– 22.
- Von Karsa, L. et al. 2008. European Commission, ‘Cancer screening in the European Union: report on the implementation of the council recommendation on cancer screening. First report’. [online] Available: [http://ec.europa.eu/health/archive/ph\\_determinants/genetics/documents/cancer\\_screening.pdf](http://ec.europa.eu/health/archive/ph_determinants/genetics/documents/cancer_screening.pdf)
- Wardle, J., Williamson, S., McCaffery, K., et al., 2003. Increasing attendance at colorectal cancer screening: testing the efficacy of a mailed, psychoeducational intervention in a community sample of older adults. *Health Psychology*. 22, pp.99–105.
- Weinrich S. 1990. Predictors of older adults’ participation in fecal occult blood screening. *Oncology Nursing Forum* 17, pp.715–20.
- Weller, D., Moss, S. Butler, P., Campbell, C., Coleman, D., Melia, J, Robertson, R. 2006. English Pilot of Bowel Cancer Screening: an evaluation of the second round. [online] Available: <http://tinyurl.com/m7abrgl>
- Wilkins, D. 2011. Slow on the uptake: Encouraging male participation in the NHS Bowel Cancer Screening Programme. London: Mens Health Forum [online] Available: [http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&cad=rja&uact=8&ved=0CCcQFjAB&url=http%3A%2F%2Fwww.menshealthforum.org.uk%2Fsites%2Fdefault%2Ffiles%2Fpdf%2Fmhf\\_bowel\\_cancer\\_project\\_report\\_2011\\_web.pdf&ei=0gyjU5qwOliW0AXqnoDYAQ&usg=AFQjCNE6CGt03EHxTxTDzdRv4JMOoXYzJg&sig2=vf8ae0WtO5JkkRXfbXNdDA](http://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&cad=rja&uact=8&ved=0CCcQFjAB&url=http%3A%2F%2Fwww.menshealthforum.org.uk%2Fsites%2Fdefault%2Ffiles%2Fpdf%2Fmhf_bowel_cancer_project_report_2011_web.pdf&ei=0gyjU5qwOliW0AXqnoDYAQ&usg=AFQjCNE6CGt03EHxTxTDzdRv4JMOoXYzJg&sig2=vf8ae0WtO5JkkRXfbXNdDA) [accessed 8<sup>th</sup> June 2014) p. 7
- YouTube, 2014. Don’t be a fool, test your stool video. [online] Available: <https://www.youtube.com/watch?v=Udp6clXF2N8> [Accessed 22<sup>nd</sup> June 2014]
- YouTube. 2010. ‘Love my family campaign’ [online] Available: <https://www.youtube.com/watch?v=mbTk66AZ2cY> [Accessed 22<sup>nd</sup> June 2014]
- YouTube. 2011. Bowel cancer screening video. [online] Available: <https://www.youtube.com/watch?v=Rj4IjkcOGpE>
-