Exploring reasons for low uptake of bowel cancer screening within South Asian communities in London: a ‘key informant’ approach

Cecily K Palmer¹, Mary C Thomas¹*, Lesley M McGregor², Christian von Wagner², Rosalind Raine¹

¹ Department of Applied Health Research
² Department of Epidemiology and Public Health, Health Behaviour Research Centre
* mary.thomas@ucl.ac.uk

BACKGROUND

Bowel Cancer Screening

- Bowel cancer is the second most common cause of cancer death in the UK
- In 2006, the NHS Bowel Cancer Screening Programme (BCSP) was launched in England to reduce bowel cancer mortality through early detection of the disease
- Screening uptake is considerably lower in Muslims (31.9%), Sikhs (34.6%), Hindu-Gujarati (42.6%) and Hindu-other (43.7%) compared with non-Asians (63.7%)

AIM

To explore reasons for low uptake of bowel cancer screening among South Asian communities, and to elicit methods by which uptake might be improved.

METHODS

Due to their position and immersion in a particular community, ‘key informants’ (KIs) can provide an invaluable source of information and insight into the experiences and needs of their community.

We recruited KIs who held ‘embedded’ roles within South Asian communities (e.g. faith leaders, community workers, GPs) across London. KIs were purposively sampled to ensure representation of the three dominant South Asian faith backgrounds (Islam, Hinduism and Sikhism).

CKP conducted semi-structured interviews with 16 KIs in English in community settings. All but one KI was of South Asian origin.

In each interview, the BCSP process was explained, and the KI was asked how they thought their community would respond to the screening invitation, and how low uptake could be addressed.

Interviews were audio-recorded and transcribed verbatim. We undertook an inductive analytical approach where themes were generated from the data.

Key Informant details

<table>
<thead>
<tr>
<th>ID</th>
<th>South Asian community represented</th>
<th>Role of KI</th>
<th>Sex</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Hindu</td>
<td>Faith leader</td>
<td>F</td>
</tr>
<tr>
<td>2</td>
<td>Hindu (Older community)</td>
<td>Community group leader</td>
<td>M</td>
</tr>
<tr>
<td>3</td>
<td>Hindu (Hindi speakers)</td>
<td>Faith leader</td>
<td>M</td>
</tr>
<tr>
<td>4</td>
<td>Hindu (Gujarati speakers)</td>
<td>Faith leader</td>
<td>F</td>
</tr>
<tr>
<td>5</td>
<td>Muslim (Bangladeshi)</td>
<td>Community project worker</td>
<td>F</td>
</tr>
<tr>
<td>6</td>
<td>Muslim (Bangladeshi)</td>
<td>Health worker (charity org.)</td>
<td>F</td>
</tr>
<tr>
<td>7</td>
<td>Muslim (Bangladeshi)</td>
<td>Community group leader</td>
<td>M</td>
</tr>
<tr>
<td>8</td>
<td>Muslim (Bangladeshi)</td>
<td>Community group leader</td>
<td>F</td>
</tr>
<tr>
<td>9</td>
<td>Sikh</td>
<td>Social group coordinator</td>
<td>M</td>
</tr>
<tr>
<td>10</td>
<td>Sikh</td>
<td>Social group coordinator</td>
<td>F</td>
</tr>
<tr>
<td>11</td>
<td>Sikh</td>
<td>Health worker</td>
<td>M</td>
</tr>
<tr>
<td>12</td>
<td>Sikh</td>
<td>Faith leader</td>
<td>M</td>
</tr>
<tr>
<td>13</td>
<td>Indian (Gujarati speakers)</td>
<td>GP</td>
<td>F</td>
</tr>
<tr>
<td>14</td>
<td>Muslim (Bangladeshi)</td>
<td>GP</td>
<td>F</td>
</tr>
<tr>
<td>15</td>
<td>Indian (Gujarati speakers)</td>
<td>GP</td>
<td>F</td>
</tr>
<tr>
<td>16</td>
<td>Indian and Pakistani</td>
<td>GP</td>
<td>M</td>
</tr>
</tbody>
</table>

RESULTS

In terms of letters and stuff they won’t read them. They’ll get the kids to read it. (11)

I think they would probably get lost in these words. (16)

They don’t function in a written way… they don’t do writing, written information does not give people the ability to go and do what needs doing. (14)

Our people are more visual learners, sorry to say that! When I say visual they rather see and hear before they make any decision. (8)

Most people think if they find they have the cancer, that’s it, that’s the end of the story. They’re too scared to know the word, hear the word. (10)

Everyone regards cancer as, once you get it you get it, that’s end of… you can’t do anything about it. (5)

I’d be fairly confident in saying I’m not sure people know screening is available. (4)

How to improve bowel cancer screening uptake within South Asian communities in the UK

Provide information about screening face-to-face, and via demonstrations

Inform people about screening and cancer in familiar places (e.g. faith settings, GP surgeries, community settings)

Convey screening messages via local South Asian TV and radio

Simplify the screening test, preferably to involve providing just one sample

LIMITATIONS

- We had a small sample, and were unable to recruit informants representing the Pakistani-Muslim community
- KIs spoke on behalf of others, rather than from personal experience, and most were <60 years, and therefore screening naive

CONCLUSIONS

- All the South Asian faith communities sampled gave similar reasons for low uptake of bowel cancer screening
- The way in which bowel cancer screening is delivered in England (written materials via post) is not effective in reaching South Asian communities
- Locally targeted efforts using face-to-face approaches delivered in community settings, and backed up with local ethnic media, should be developed

LIMITATIONS

- Exploring reasons for low uptake of bowel cancer screening within South Asian communities in community settings. All but one KI was of South Asian origin.
- We undertook an inductive analytical approach where themes were generated from the data.
- Due to their position and immersion in a particular community, ‘key informants’ (KIs) can provide an invaluable source of information and insight into the experiences and needs of their community.
- We recruited KIs who held ‘embedded’ roles within South Asian communities (e.g. faith leaders, community workers, GPs) across London.
- KIs were purposively sampled to ensure representation of the three dominant South Asian faith backgrounds (Islam, Hinduism and Sikhism).
- CKP conducted semi-structured interviews with 16 KIs in English in community settings. All but one KI was of South Asian origin.
- In each interview, the BCSP process was explained, and the KI was asked how they thought their community would respond to the screening invitation, and how low uptake could be addressed.
- Interviews were audio-recorded and transcribed verbatim. We undertook an inductive analytical approach where themes were generated from the data.
- Key Informant details

How to improve bowel cancer screening uptake within South Asian communities in the UK

- Provide information about screening face-to-face, and via demonstrations
- Inform people about screening and cancer in familiar places (e.g. faith settings, GP surgeries, community settings)
- Convey screening messages via local South Asian TV and radio
- Simplify the screening test, preferably to involve providing just one sample