# <u>The Evaluation of the British Islamic Medical</u> <u>Association (BIMA) Intervention for Bowel</u> <u>Cancer Screening in Muslim Communities in</u> <u>the East of England.</u>

## **DISSEMINATION EVENT & STAKEHOLDER FORUM**

# REPORT

Faizan-E-Madina Mosque, Peterborough

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## Background

The British Islamic Medical Association (BIMA) has developed a culturally adapted, "faith-placed" educational intervention aimed at increasing the uptake of bowel cancer screening in the Muslim community. Our feasibility study explored the acceptability and accessibility of the intervention along with its impact on screening uptake.

The stakeholder dissemination event, which celebrated the completion of the study, was aimed at showcasing our preliminary findings for key stakeholders and thanking our community partners for their support and insight. Our goal was to raise the profile of the study and to highlight the potential of the intervention in addressing health inequalities.

Selected members of the research team presenting included Professor Daksha Trivedi, the Project Lead; Dr Salman Waqar, the President of BIMA; Dr Claire Thompson, a Qualitative Data Researcher; Julia Varnes, Screening & Immunisation Coordinator and Project Lead from NHS England; and Sadia Begum, a Senior Research Assistant.

Key areas covered by the presentations:

- Inequalities in bowel cancer screening uptake
- Study design, its limitations and strengths
- Data analysis
- Barriers to cancer screening access
- Recommendations for future studies engaging with Muslim communities

## Inequalities in bowel cancer screening uptake

Cancer screening programmes play a key role in early disease detection and prevention. They allow for early identification of persons who are at a higher risk of developing cancer and help to detect early-stage cancer, thus increasing the effectiveness of treatment. They contribute to saving 10,000 lives in England every year (1). In the case of bowel cancer, early detection and treatment markedly improves survival outcomes – 9 in 10 people survive bowel cancer for five years or more when diagnosed at an earlier stage compared to 1 in 10 when diagnosed at a later stage (2). However, inequalities in access and uptake of such preventative services result in avoidable disparities in health outcomes for certain population groups, in particular ethnically diverse communities (3) and/or low-income groups (2). As a result, members of those groups are more likely to receive a late diagnosis of bowel cancer and, consequently, have poorer survival (2, 3).

The bowel cancer screening test, routinely offered by the NHS to all people aged 54 to 74 registered with a GP and living in England, has lower uptake rates among Muslim and South Asian populations. Its uptake is also consistently lower among those living in areas of high deprivation. These factors influenced the selection of Luton and Peterborough as the study sites – both towns have low levels of bowel cancer

screening uptake (3). Also, both are ethnically diverse, have a significant proportion of Muslim residents, and contain areas of high deprivation (3).

To address health inequalities, there is a need to develop health initiatives tailored to the needs of and culture of specific communities. Faith institutions, such as mosques, could play a vital role in promoting health initiatives as they have a wider reach and can be perceived as more approachable when compared with traditional healthcare settings.

## The intervention

The intervention is an hour-long, face-to-face group session on bowel cancer screening. It covers benefits, risks, and practical information; and features elements adapted to the target audience. It is based on a slightly modified presentation from Cancer Research UK, with alterations including a slide motivating attendees through Islamic health principles as well as local data on cancer diagnosis and survival rates in the mosque community. It also features graphics tailored to Muslim culture such as women wearing hijabs.

The intervention is delivered by clinicians who either practice in or hail from communities of interest. Their cultural competencies help establish a better rapport with participants and deliver the intervention in a culturally sensitive and appropriate manner. It also helps reduce any language barriers and encourage attendees to better engage with the session.

The group sessions are gender-concordant (male clinicians for men and female clinicians for women) to accommodate Islamic gender norms.

The approach is described as "faith placed" rather than "faith based" because it uses faith settings (mosques) to target specific communities without mixing religious and health messages together.

The intervention has been recognised by the Royal Society for Public Health (RSPH) for its dedication to reducing health inequalities: it was one of the finalists of the 2019 Health and Wellbeing Awards as well as receiving a 2019 Public Health England Commendation for Reducing Inequalities at Community Level (4).

## Study design

The project involved a two-group non-randomised mixed-methods design to evaluate the accessibility and acceptability of the culturally adapted bowel cancer screening intervention. We gathered the views of participants who were divided into an intervention group (91 individuals) and a control group (55 individuals) – the former participated in an intervention session, while the latter did not. Of those aged 56 years and more, there were 83 in the intervention group and 52 in the control group. We also spoke with 2 healthcare professionals who delivered the intervention to gather their views on the intervention and its delivery.

Intervention sessions, delivered between March – May 2022, took place in selected mosques in Luton and Peterborough and were conducted by NHS clinicians from the

Muslim communities served by those mosques. Women and men had separate sessions due to cultural reasons.

To explore the long-term effects of the intervention on participants' behaviour, Bowel Cancer Screening Hub records were accessed in a 2-year follow-up for 97 participants (71 individuals from the intervention group and 26 individuals from the control group who consented to have their records accessed).

### **Data collection**

Quantitative data – surveys at baseline for both groups (total completed by those aged at least 56: 135); the intervention group: post-intervention questionnaires completed immediately after the session (61); 6-month or 12-month follow-up (15).

Qualitative data – the intervention group: a focus group with 8 male participants, semi-structured telephone interviews with 3 female participants. Semi-structured interviews with 2 clinicians who delivered the intervention.

Hub records – data accessed for 97 participants in a 2-year follow-up to evaluate the long-term impact of the intervention.

## **Participants**

The intervention group: 59% men and 41% women, average age 67; predominantly of Pakistani ethnicity (82%) with a few participants being of Bangladeshi (11%) or Indian (4%) ethnicity. 42% reported taking part in the previous screening while 9% were too young to participate in it earlier. Participants' preferred languages were Urdu (37%) and English (35%).

The control group: 62% men and 38% women, average age: 66; almost all participants were of Pakistani ethnicity (51 out of 52 individuals). 31% took part in the previous screening while 6% were too young to do so. Over half of the group chose Punjabi as their preferred language.

Compared with the intervention group, the comparison group had more missing socio-economic data: living circumstances (40% answers missing in the comparison group v 4% in the intervention group), education (56% v 7%) and employment (58% v 5%). This made it difficult to compare the two groups on a socio-economic basis.

## Preliminary data analysis

Both qualitative and quantitative research methods were used to generate a nuanced picture of the impact and impressions the intervention created. Those findings were validated using Bowel Cancer Screening Hub data covering a period of up to 2 years after the intervention, as the NHS screening kits are offered every 2 years, this showed how many of the participants returned screening kits back before and after the intervention.

Quantitative data: based on the information provided in the baseline and postintervention surveys, there was an immediate positive change in both understanding of and attitudes towards bowel cancer screening following the educational session in the intervention group.

Hub data suggested that among participants from both control and intervention groups, out of those who reported not taking part in bowel cancer screening prior to the intervention, a higher proportion of members of the intervention group undertook the screening in the following 2 years. In terms of males who reported undergoing the screening prior to the study, there was no significant difference in screening uptake between the intervention and control groups in the following 2 years. Interestingly, the hub data highlighted that women were less likely than men to undertake bowel cancer screening – this was the case for both intervention and control groups.

## Qualitative data:

- The intervention was seen as more effective in conveying the health message compared with traditional cancer screening campaigns. Its content was culturally and religiously tailored to the South Asian Muslim communities it was delivered to, making it more approachable.
- Mosques were seen as more accessible and able to reach a wider audience.
- Having clinicians from their communities deliver the intervention allowed for a better rapport with the audience as they used their cultural knowledge to align the health message with community values. Also, the clinicians' high social standing within the communities in question gave them credibility and meant participants were more likely to trust them and adhere to their health recommendations.
- As the health message was delivered verbally and in the participants' preferred tongue, language barriers and/or issues with literacy no longer hindered their understanding.

During qualitative data collection, we were able to gather information on potential barriers to bowel cancer screening uptake. The barriers identified related to:

- A language barrier: as English was often not their first language, some participants found it difficult to communicate with health professionals and to access health information presented to them in English.
- Dependency on others: some participants required assistance from others (e.g. children, relatives) in accessing information in English (i.e. help with translation) or being accompanied to health appointments (this could be due to requiring help with transportation or due to a lack of self-confidence in attending alone). Participants often felt uncomfortable asking for help as they did not want to be a burden.
- A lack of understanding of the importance of screening as a preventative measure.
- Religious fatalism, i.e. a belief that outcomes in life are pre-determined by a higher power. This could impact on a person's willingness to take care of their health proactively (5).

## Strengths and challenges

Strengths:

- Comprehensive demographic data: age and gender reported by all participants.
- Immediate post-intervention assessment minimising the risk of external factors influencing participants' responses. This allowed for a more accurate measurement of the immediate impact of the intervention.
- Long-term follow-up data: Hub records obtained up to 2 years after the baseline questionnaire, coinciding with the recommended interval between screenings. All participants were followed up for at least 2 years after the date of their last self-reported screen. This allowed for the assessment of the potential for the intervention to create a long-term change in behaviour.

#### Challenges:

- Recruitment context: the study was conducted during the recovery phase of the COVID-19 pandemic which likely affected community and clinician engagement, resulting in lower-than-anticipated participant numbers.
- Socio-economic data variability: while many participants provided comprehensive information, a proportion of the comparison group had incomplete data on education, employment, and living circumstances.
- Selective Hub record access: a portion of participants exercised their right to privacy and declined to have their Hub records accessed.
- Follow-up response rate: the study experienced some attrition, impacting on the number of completed follow-up questionnaires.

#### Recommendations for similar future health research within Muslim communities

The presentations, along with the Q&A session and the ensuing discussion, identified recommendations for similar future projects:

• While the initial findings of our study are promising, there is a need to conduct a larger-scale study exploring the acceptability and accessibility of the intervention.

• Any future projects need to find ways to develop deep connections with the Muslim community to ensure that researchers can recruit widely from within the community, including persons who may be hard-to-reach.

• Ways of limiting drop-out numbers need to be established to ensure higher retention rates than was the case in the present study.

• To address the language barrier, surveys could be provided in the participants' preferred languages. While our research team navigated this matter by providing on the spot oral translations by the clinicians and support staff (peer facilitators and volunteers), in larger participant groups this could prove difficult.

• The discussion highlighted the importance of appropriate funding to ensure adequate resources are given to support research in underserved communities. The idea of health and research equity, where additional resources are required to achieve desired outcomes, is one that will be vital to ensure good quality research is conducted that can deliver improvements to health outcomes in those communities.

## References:

1. Richards, M., 2019. Report of the Independent Review of Adult Screening Programmes in England. [PDF] Available at: <u>https://www.england.nhs.uk/wpcontent/uploads/2019/02/report-of-the-independent-review-of-adult-screeningprogramme-in-england.pdf</u> [Accessed 27/09/2024].

2. NHS Digital. Cancer Survival in England, cancers diagnosed 2015 to 2019, followed up to 2020 – NDRS [online] <u>https://digital.nhs.uk/data-and-information/publications/statistical/cancer-survival-in-england/cancers-diagnosed-2015-to-2019-followed-up-to-2020</u> [Accessed 27/10/2024].

3. Carr, M., Thompson, C., Berger-Gillam, T., Freedman, J., Smeeton, N., Waqar, S., and Trivedi, D., 2024. Testing a faith-placed education intervention for bowel cancer screening in Muslim communities using a two-group non-randomised mixed-methods approach: Feasibility study protocol. *PLoS ONE* 19(3), pp. 1-15. 10.1371/journal.pone.0293339 [Accessed 11/12/2024].

4. RSPH Awards 2019: championing the public's health. *Perspectives in Public Health*. 2020;140(1):6-10. doi:10.1177/1757913919888592 [Accessed 11/12/2024].

5. Campbell, C., Douglas, A., Williams, L., Cezard, G., Brewster, D.H., Buchanan, D. et al, 2020. Are there ethnic and religious variations in uptake of bowel cancer screening? A retrospective cohort study among 1.7 million people in Scotland. *BMJ Open*. 10(10). <u>https://doi.org/10.1136/bmjopen-2020-037011</u> [Accessed 11/12/2024].

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