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

DISSEMINATION EVENT & STAKEHOLDER FORUM

REPORT

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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 took place on Saturday 2nd March 2023 in Faizan-E-Medina, Peterborough, and celebrated the completion of the study. Our goal was to present our preliminary findings to key stakeholders and thank our community partners for their support and guidance. We wanted 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 who presented at the event include Professor Daksha Trivedi, the Project Lead; Dr Salman Waqar, the President of BIMA; Dr Claire Thompson, a Qualitative Data Researcher and the Lead for the NIHR ARC East of England Prevention and Early Detection in Health and Social Care Theme; 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 are a key factor in early disease detection and prevention. They enable 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 significantly improve survival outcomes – 9 in 10 people survive 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 cancer screening result in avoidable disparities in health outcomes for certain population groups, particularly ethnically diverse communities (3) and low-income groups (2). This results in members of those groups being more likely to receive a late diagnosis of bowel cancer and, consequently, facing poorer survival (2, 3).

Bowel cancer screening kits are routinely offered by the NHS to all people aged 50 to 74[1] who are registered with a GP and living in England. The screening 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), 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 specific communities as the "one size fits all" approach does not appear to bring the desired results. Faith institutions, such as mosques, can play an important part in the promotion of health initiatives at a community level given that they have a wider reach and can be viewed as more accessible and welcoming when compared with traditional healthcare settings.

The intervention

The intervention developed by BIMA is an hour-long group session covering benefits, risks, and practical information about bowel cancer screening. Based on a slightly modified presentation by Cancer Research UK, the slide deck used features elements culturally adapted to the target audience e.g. a mention of Islamic health principles and local data on cancer diagnosis and survival rates. It also features graphics tailored to Muslim culture such as women wearing hijabs. These alterations help increase the relevance of the health message.

The intervention is delivered by clinicians who either practice in or hail from communities of interest. The shared background helps establish a better rapport with attendees and deliver the intervention in a culturally sensitive manner.

The group sessions are gender-concordant (male clinician lead sessions for men while female clinicians lead women's sessions) to accommodate Islamic gender norms.

The approach is described as "faith placed" rather than "faith based" because it uses faith settings – in this case 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 featured a two-group non-randomised mixed-methods design to evaluate the accessibility and acceptability of the intervention along its impact on screening uptake. We gathered the views of participants who were divided into an

[1] The NHS Bowel Cancer Screening Programme has been expanded to include people aged 50 and over. The phased roll out is to be completed in 2025. At the time of the study, the minimum eligibility age was 56.

intervention group (91 individuals) and a control group (55 individuals) – the former participated in an intervention session, while the latter received standard NHS leaflets on bowel cancer screening. Of those, 135 participants were eligible for bowel cancer screening (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 and May 2022, took place in selected mosques in Luton and Peterborough and were conducted by trained NHS clinicians who were themselves members of South Asian Muslim communities. As mentioned earlier, women and men attended separate sessions.

To explore the long-term effects of the intervention on participants' behaviour, we accessed Bowel Cancer Screening Hub records for 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

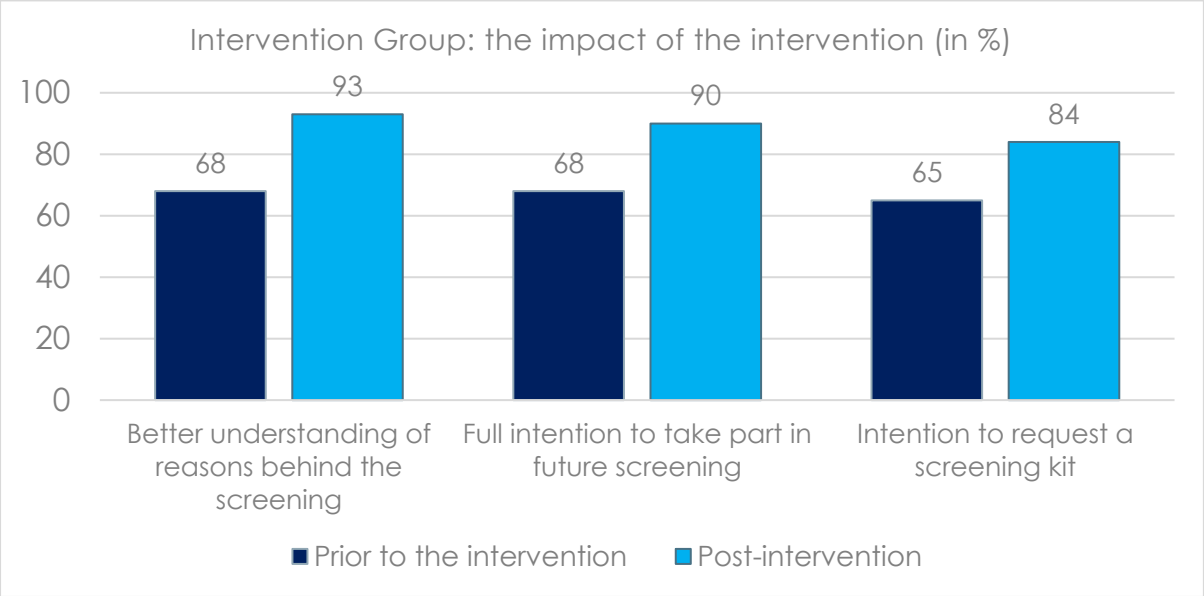
	Intervention group	Control group
Number of participants (aged 56 and over)	83	52
Gender	59% male 41% female	62% male 38% female
Average age	67	66
Ethnicity	Pakistani (82%), Bangladeshi (11%), Indian (4%)	Mostly Pakistani (51 out of 52 individuals)
Preferred language(s)	Urdu (37%), English (35%)	Punjabi (56%)
Previous screening	42% took part in previous screening; 9% too young to participate at the time	31% took part in previous screening; 6% too young to take part at the time.

Compared with the intervention group, the comparison group had more missing socio-economic data covering 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.

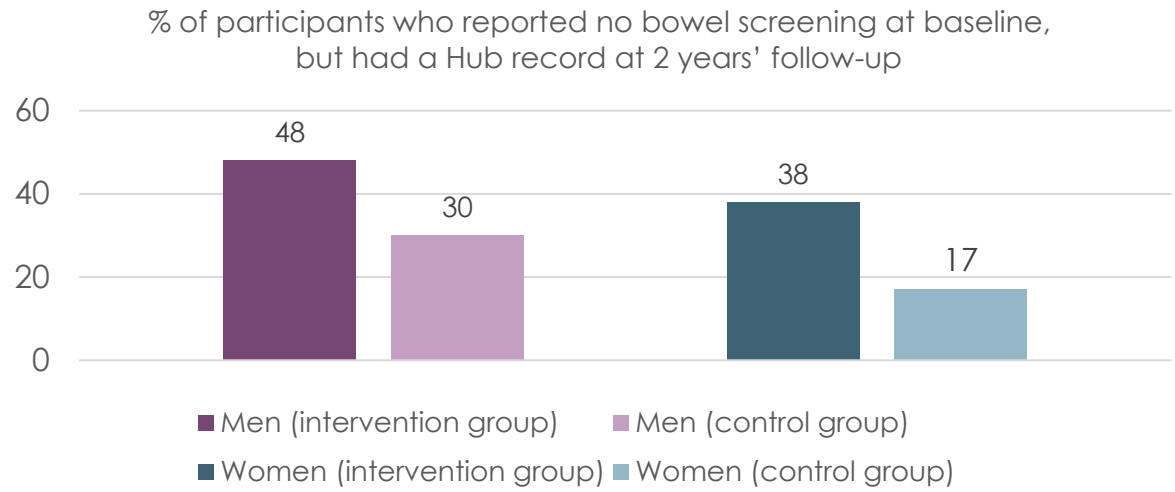
Preliminary data analysis

We used quantitative and qualitative data collection methods to generate a detailed picture of how the intervention was perceived and what impact it had on the participants. We also accessed the regional Bowel Cancer Screening Hub records for a 2-year follow-up as the NHS screening kits are offered every 2 years. This allowed us to compare participants' screening uptake before and after the intervention.

Quantitative data: a comparison of the surveys completed by participants at baseline and immediately post-intervention shows that attending the session has had an immediate positive impact on attendees' understanding why screening is important and their attitudes towards taking part in it.



Hub data: those who attended the intervention and reported no prior participation in screening were more likely to undertake it in the 2 years following attendance at an intervention session. This was the case for both male and female participants, with the difference in uptake being close to 20% compared to the control group.



There was no significant difference in screening uptake between male participants who reported taking part in screening prior to the study – this was the case for both groups. Our data suggests that women were less likely than men to undergo bowel cancer screening – this was true for both the intervention and control groups.

Qualitative data:

- The intervention produced positive outcomes: it appeared more effective in delivering the health message than the traditional bowel cancer screening information campaign. Participants noted that they found the cultural tailoring of the intervention helpful as it made the information more approachable. They also appreciated the opportunity to ask questions.
- Mosques were viewed as more accessible venues which were able to reach a wider audience.
- Clinicians delivering the intervention shared their ethnic and religious background with the attendees – this helped build a better rapport with the audience as the health professionals were able to align the health message with community values by drawing on their cultural knowledge. Also, the clinicians' high social standing within the target communities gave them credibility and increased participants' trust and confidence in the importance of given health recommendations.
- The intervention was delivered verbally and on-the-spot translation in participants' preferred language was provided. This eliminated any language and literacy barriers that may have hindered attendees' 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: given that English was often not their first language, some participants found health-related communication (e.g. during GP appointments) difficult as they struggled to express their symptoms or to understand doctors' advice. They also struggled with accessing health information if it was only available in English.
- Dependency on others: some participants relied on others (e.g. children, relatives) to help them access information in English or to accompany them to health appointments (reasons mentioned included transportation issues, a lack of self-assurance, or a need for a chaperone). Participants often felt uncomfortable asking for assistance as they did not want to be a burden – this frequently led to delaying health appointments.
- A lack of understanding of the importance of screening as a preventative measure.
- Fatalism – a belief that outcomes in life are pre-determined by a higher power and that our actions cannot alter them – could impact on one's willingness to proactively look after one's health (5). This notion was highlighted by some respondents as a potential explanation why some members of their community may seem unbothered by cancer screening (as one interviewee put it: *"if it [cancer] is going to happen, it will come anyway."*). During the focus group discussion, however, this idea was countered by participants' emphasis on the need to look after one's health because current medical advances in cancer screening and treatment were "God-given" and meant the disease was becoming increasingly treatable. Arguably, raising awareness of cancer curability and the benefits of early diagnosis can encourage positive health behaviours and address fatalistic beliefs and fears (6).

The perspectives of interviewed healthcare professionals:

- We gathered feedback from two NHS clinicians who delivered intervention sessions. We wanted to know their opinions on the intervention itself and the delivery.
- The interviewees highlighted the wider reach of health awareness interventions held within community settings such as mosques. They also discussed the impact of cultural tailoring on participants' engagement with the session.
- In terms of challenges linked to the faith-placed approach, the clinicians noted the amount of planning and organisation required. They also mentioned the need for realistic expectations when collaborating with faith-based settings as they operated in a different way to, for example, community centres.

Strengths and challenges

Strengths:

- Comprehensive demographic data: age and gender reported by all participants, ethnicity reported by nearly all participants (96% of the intervention group and 100% of the control group disclosed their ethnic background)
- Immediate post-intervention assessment limited the risk of participants' responses being influenced by external factors. This helped us understand more accurately the immediate impact of the intervention.
- Long-term follow-up data: 97 participants (approx. 72%) consented to us accessing their Bowel Cancer Screening Hub records and were followed up for 2 years after their attendance at an intervention session. This gave us insight into the potential for the intervention to lead to a long-term behavioural change.

Challenges:

- Recruitment context: the study took place during the recovery phase of the COVID-19 pandemic which may have affected community engagement and the recruitment of participants. Our close relationship with clinicians and their networks mitigated this to an extent.
- Socio-economic data: a proportion of the comparison group declined to provide data on education, employment, and living circumstances.
- Bowel Cancer Screening Hub record access: approx. 28% of the participants did not grant permission for us to access their Hub records.
- Follow-up response rate: participant retention, particularly within the control group, proved more challenging than anticipated.

Recommendations for similar future health research within underserved communities

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

• The initial findings of our project are promising, however, a scaled-up study exploring the acceptability, accessibility and impact of the intervention would help generate more robust evidence to inform potential policy and practice strategies.

• To improve community engagement and recruitment, studies need to factor in the time necessary to build deep connections within the target population. Community engagement was at the heart of our project and our research would not have been possible without it.

- Strategies to minimise participant drop-out rates are an important part of the project planning. While we anticipated challenges with retention, our strategies struggled to maintain the long-term involvement of participants, particularly in the control group.

- To resolve the issue of a language barrier, questionnaires could be provided in participants' preferred languages. Our research team managed this issue by having clinicians and support staff (peer facilitators and volunteers) provide on-site translation. However, in larger participant groups this could prove unfeasible.

- Funding plays a key role in ensuring that sufficient resources are available to support research in underserved communities – this may mean that, to achieve desired outcomes, additional resources may be needed.

References:

1. Richards, M., 2019. *Report of the Independent Review of Adult Screening Programmes in England*. [PDF] Available at: https://www.england.nhs.uk/wp-content/uploads/2019/02/report-of-the-independent-review-of-adult-screening-programme-in-england.pdf

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

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

4. RSPH Awards 2019: championing the public's health. *Perspectives in Public Health*. 2020;140(1), pp. 6-10. doi:10.1177/1757913919888592

5. Dharni N., Armstrong D., Chung-Faye G., et al, 2017. Factors influencing participation in colorectal cancer screening – a qualitative study in an ethnic and socio-economically diverse inner City population. Health Expectations (20), pp. 608–17.doi:10.1111/hex.12489

6. Palmer C.K., Thomas M.C., McGregor L.M., et al, 2015. Understanding low colorectal cancer screening uptake in South Asian faith communities in England--a qualitative study. *BMC Public Health* (15) 998. doi:10.1186/s12889-015-2334-9

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