NIHR | Applied Research Collaboration East of England

# Working with Muslim Communities to Increase Bowel Cancer Screening

## Changes, Benefits and Learning from Public Contributors: Public Involvement Impact Case Study


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# Introduction

The UK National Standards of Public Involvement are used as a framework for the ARC EoE Public, Community, Involvement, Engagement and Participation (PCIEP) Strategy and includes 'impact'. We define 'impact' as "**the changes, benefits and learning,** gained from the insights and experiences of patients, carers and the public when working in partnership with researchers and others involved in NIHR initiative's" (*NIHR Patient and Public Involvement Impact Working Group, 2019*). Through this, we seek improvement by identifying and sharing the difference that public involvement makes to research.

The ARC EoE PCIEP Impact Case Studies are used to evaluate the impact of PCIEP on ARC EoE research and to highlight the changes, benefits and learning gained from partnership working and public involvement in ARC EoE.

Public contributors have been invited to co-produce the case studies and the perspectives of public contributors are included in the case study.

# **Public Involvement Impact Case Study:** Increasing Bowel Cancer Screening in Muslim Communities

## Project Title:

Supporting efforts to increase bowel cancer screening in Muslim communities in the East of England.

## What problem is this research addressing?

Bowel cancer screening uptake is approximately 28% lower in people of South Asian ethnicity compared to the general population. Lower rates of screening uptake have also been reported overall among the UK Muslim population. In the East of England, Luton Borough Council has a large Muslim population (2021 census data) while Luton CCG has the lowest uptake of the bowel cancer screening among Black, Asian, and Minority Ethnic groups in the region. This inequitable access to preventative services leads to significant and avoidable inequalities in health outcomes for those communities. To increase the awareness of the importance of participation in the free NHS bowel cancer screening among Muslim communities, the British Islamic Medical Association (BIMA) designed a “faith placed” educational intervention which was delivered in selected mosques with the support of local community partners. Luton and Peterborough were chosen due to the high proportion of Muslims (2021 census data) and low uptake of bowel cancer screening.

The project aims to evaluate the effectiveness of the BIMA intervention and to increase awareness of bowel cancer screening among the Muslim community.

The benefits of the research include:

- increasing awareness of bowel cancer symptoms and the importance of bowel cancer screening among the Muslim communities in the East of England and thus working on improving health outcomes within the target group;
- assessing the impact of a public health intervention tailored specifically to a Muslim community;
- addressing health inequalities in ethnically diverse (and often marginalised) populations;
- the intervention and evaluation will generate evidence that informs national practice in the long term.

References:
Office for National Statistics, 2022. *Census 2021*, [online] Available at: https://www.ons.gov.uk/census [Accessed 02/08/23].

## How were the public involved in this research?

Working together with public and community contributors and partners has been central to the project from the start. Initially, we held a stakeholders' event to launch the study – we invited clinicians, BIMA members, NHS professionals, public health officials, community leaders and academics. The aim was to discuss the implementation of the project, generate ideas on prospective approaches as well as to identify potential challenges and possible ways of overcoming them.

As the intervention was delivered in mosques in Luton and Peterborough, its success depended on the engagement of mosque leaders and volunteers from within the Muslim community (including local GPs) who spread the word about the intervention, encouraged people to attend, and hosted the delivery. Peer researchers supporting data collection were also recruited from the community.

As the project is ending, we are planning to organise an end-of-study stakeholder event where we will share the initial findings with the BIMA representatives, NHS professionals, clinicians, religious and community leaders, public contributors and some of the participants, among others.

## What were the outcomes of public involvement in this project?

- The fact that the intervention was delivered in local religious venues and had the support of both local community figures and religious leaders acted as a way of creating trust and credibility among the Muslim community; it helped convince people to attend the intervention and to take part in the study;

- The involvement of health professionals and doctors from within the Muslim community was important in terms of the success of the study as it allowed for the health message to be delivered in a way that was tailored to participants' religious and cultural background; it also allowed the participants to relate better to the clinicians and to align health promotion with the values of their community – this is particularly relevant when research projects focus on ethnic or religious minorities;

- Dr Salman Waqar, a BIMA representative and a co-investigator in the project, was key in linking the academic researchers with other public contributors (from BIMA clinicians to peer facilitators) from within the Muslim community.

- One of the peer facilitators organised the follow up session on a day when there was another popular event happening at the local mosque, thus increasing the chances of more community members attending the project session.

## How did public involvement influence the project overall?

For this project, public involvement dictated our overall approach to engaging with communities. Public involvement contributors advised on how best to contact community gatekeepers and how to frame the intervention and its benefits when discussing involvement with mosques. Public involvement guidance also helped us to appropriately tailor data collection activities (separate sessions for men and women). The benefit of public involvement can be summarised, for this project, as having insight and guidance on how best to communicate with communities, and this was invaluable. Our learning about public involvement on this project is not new, but bears repeating: community involvement from the planning stages of research projects onwards is an asset. Even with public involvement support, a great deal of time needed to successfully collect data (as is explained in the next section). Without public involvement support we may have had to abandon data collection in some sites.

## What was the feedback from public contributors involved in this project?

Feedback from Dr Choudhry, a Peterborough-based GP, involved in the study:
*"I actively participated in a collaborative study titled "Testing a faith-placed education intervention for bowel cancer screening in Muslim communities (Luton & Peterborough)" conducted by NHS improvement, University of Hertfordshire and BIMA. As part of the study, I played a voluntary role in identifying study locations, engaging with the local community, and planning intervention deliveries. I recruited two peer researchers [from the community] who helped me to complete the questionnaires. I organized and delivered talks in two local mosques for the intervention group and completed questionnaires for the non-intervention arm in the third mosque.*

*To promote the talks, I designed flyers and posters and advertised them on social media platforms of the local community leaders, councillors, a local radio, and the Joint Mosque Council. Additionally, I displayed the posters on notice boards at all the local mosques and sent messages to Muslim patients registered with my practice regarding the talks.*

*I sought help from community volunteers to fill out questionnaires on the talk days, particularly for the intervention group, where pre- and post-talk responses were needed.*

*However, I faced several challenges during the study. Convincing people to complete the questionnaires proved difficult as it was a new concept for them. Cultural factors also played a role as seeking medical advice was often associated with being unwell and preventive measures were not widely understood despite my efforts in conducting various health awareness programs in the community for almost five years.*

*Completing the questionnaires for the non-intervention group posed a struggle with only three participants showing up on the designated date. This required multiple visits to the mosque on different occasions to complete the questionnaires, making the process time-consuming for me. Furthermore, people were hesitant to grant consent to the peer researchers and unfamiliar health professionals, leading me to handle most of the arrangements and questionnaire completion myself."*

## What are the reflections and learning from public involvement in this research?

**What went well:**

- The engagement of community and religious leaders was key in the progression of the study: Imams in participating mosques promoted both our interventions and follow-up sessions after prayer times and put-up posters advertising them.

- The involvement of BIMA representatives and clinicians from within the Muslim community supported the promotion of the study and the recruitment of participants and peer facilitators; it also allowed for a better engagement with participants.

**Key challenges:**

- public involvement input is an asset, but it is not a solution in and of itself. Engaging with under-served communities is still difficult, even with public involvement support from those communities. It is unfair to expect our public involvement contributors to be able to 'fix' this for us or to assume that they can automatically guarantee engagement success for us. We had to build time into the project (by applying for extensions) to allow us to collaboratively build solutions to the challenges we faced. The extra time everyone put in was largely uncosted and relied on good will.

**What can we learn from this experience:** As stated in earlier sections: our learning about public involvement on this project is not new, but bears repeating. Community involvement from the planning stages of research projects onwards is an asset.

**What would you do differently?** Possibly spend more time and resources in preparation (although this is not always possible) by applying for a series of small grants to inform a larger programme of work.

## Example poster advertising the project:


The case study template is informed by GRIPP 2-SF (Staniszewska et al., 2017)

For more information, visit the project webpage

Visit our website: arc-eoe.ninhr.ac.uk

Contact: ARCoffice@cpft.nhs.uk

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