Exploring the Views and experiences of British Bangladeshis regarding digital interventions to support self-management for long term conditions, and the capture and use of patient feedback

e-Research

Recent policy and research focused on self-management and patient feedback has increasingly focused on the extensive potential for digital interventions to enhance support and services for people with long-term conditions. This is the focus of multiple studies within the 'Co-Produced health' theme within HeRC (e.g. ClinTouch/ Careloop in relation to severe mental illness; REMORA for rheumatoid arthritis; DEPEND for digital capture and analysis of patient feedback on services). Previous Patient and Public Involvement (PPI) work within these projects has indicated a need to consider the views and experiences of diversity and marginalised groups, such as those from Black and Minority Ethnic (BME) groups, and non-English speakers to enable culturally appropriate interventions that will ultimately enable more

equitable service delivery and self-management support. We aimed to conduct a public engagement event with an exemplar BME population, namely British Bangladeshi. The aim of the public engagement event was to explore the views and experiences of British Bangladeshis on self-management of long term conditions and patient feedback on healthcare use, and on levels of digital engagement to explore

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potential for enhancing self-management and capturing feedback..

We conducted two workshops with British Bangladeshis, one with men (#18) and one with women (#12) to adopt culturally appropriate gender segregation.

The workshop

Participants were recruited via the Bangladesh High Commission and a local British Bangladeshi community organization GMBA (GMBA is a registered charity, working

and run by the British Bangladeshi community in greater Manchester). Total

18 male and 12 female have participated.

Participants were divided into small groups for discussions focusing on the issue of 'self-management' and any views and experiences of providing feedback on their use of health services and digitalisation of health service.

A Benagli topic guide was prepared with the community partners' prior to the discussion. Which included general views about 'self management' from both who have chronic condition and who do not have. It took sometimes to explain the term 'self management' as the participants were not very familiar with the term.

Instant translation from Bengali to English was done by an interpreter. Simultaneous visual minutes were taken by visual report artists. The participants became especially engaged in the workshop as they could see the visual production of their discussion.

Key messages

(health care and beyond).

- CULTURALL WHY do WE GIVE FEEDBACK Few participants were familiar with the term 'self-management'. However when this was explained participants recognised its similarity to the term 'self-care' which they were aware to include all types of care
- Gender was viewed to have a major influence on practicing care within the family as women take the larger burden.
- In order to develop a culturally appropriate awareness program to promote 'self-management' a dialogue with the target population is necessary.
- Most participants had no experience of giving or being asked to provide feedback on their healthcare experiences.
- Those who had experience of giving feedback reported giving positive feedback only as they thought negative feedback would affect their future treatment.
- Those who gave feedback felt that structured questions were inadequate and limited their ability to express their experience in detail.
- Both men and women were dissatisfied with the appointment system for primary care as they found it difficult to get appointments and were not sensitive to lifestyle of this community.
- They felt that a bi-lingual feedback system would be useful
- Both men and women were generally in favour of digitisation however, they suggested that before implementation any intervention must be community tested.
- Remote monitoring was seen as one way to increase awareness if self-management.
- Participants felt that giving digital feedback was a useful option and that younger generation could support the older generation in doing this. Therefore, joint family living was seen as a positive factor in regard to digital literacy and language barriers.

Future plans

To conduct further research and co-design a culturally sensitive digital tool to support feedback and self-management.

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