Co-producing a community event to raise awareness of mental health & dementia research

Project Background
Black and minority ethnic groups are under-represented in health research in the UK\(^1\). 22% of Oxford’s residents are from black or minority ethnic groups, and two of the largest non-white ethnic groups represented in Oxford are Pakistani and Indian\(^2\).

Oxford Health NHS Foundation Trust (OHFT) has an active Research & Development Department and, in partnership with the University of Oxford, hosts the NIHR Oxford Health Biomedical Research Centre and cognitive health Clinical Research Facility, with a focus on mental health and dementia research.

Through previous activities, we identified that Asian communities are under-represented in our mental health and dementia research. We approached two local organisations to co-develop a community engagement project:

- Oxford Asian Cultural Centre, a well-established community centre, which delivers regular events and activities for individuals and families living in and around Oxford.
- M&A Social Enterprise, a local voluntary organisation, set up to initiate, engage and support diversity related activities delivered in a fun and friendly format.

Project Aims
Our project co-produced an engagement event with Asian communities in Oxford that aimed to:

- Raise awareness of mental health & dementia research
- Increase understanding of community experiences of mental health & dementia
- Build relationships that support on-going engagement

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\(^1\) Andrew Smart & Eric Harrison (2017) *The under-representation of minority ethnic groups in UK medical research*, Ethnicity & Health, 22:1, 65-82 ; \(^2\) Data from [https://www.oxford.gov.uk/info/20131/population/462/ethnicity](https://www.oxford.gov.uk/info/20131/population/462/ethnicity) and is based on information in the 2011 UK Census
Co-designing the event

We worked with M&A Social Enterprise to understand what issues are most important to communities. We also worked with a Patient and Public Involvement Contributor from the Asian community and OHFT staff members with connections in the community.

Through this engagement we identified:

- Individuals feel less able to access support and information services for mental health concerns due to stigma, but it is an area of interest and need.
- Important topics include anxiety, mental health and young people, isolation and depression in older age, pressures faced by woman.
- There is a lack of awareness of opportunities to get involved in research and a level of mistrust associated with medical research.
- Events need to focus on issues that matter to communities and deliver on community priorities.
- Successful relationships build over time and need to deliver benefit more widely than just focusing on research.

We built on learning from previous events delivered by M&A Social Enterprise to develop engaging content and an accessible format. We designed the event to ‘open a door’ for people to talk about mental health, raise interest in brain health and mental health, and promote positive messages about getting involved in research.

We agreed to focus on International Women’s Day, Sunday 8 March 2020, to bring people together from across the community. We involved research groups and other mental health services based on the interests and needs identified through our engagement work. We included Bollywood singing and food.

We briefed staff attending the event on the stigma associated with mental health and research, and to make sure information stalls included fun and interactive activities.
Co-delivering the event

The event title was ‘Women Celebrating Women’ and themes used to promote it were ‘strength in diversity’ and ‘let’s talk about mental health’.

Information about the event was shared by M&A Social Enterprise and the Asian Cultural Centre through Facebook and Twitter, posters and flyers distributed in the community, and through their networks of contacts. Oxford Health NHS Foundation Trust and the NIHR Clinical Research Network also shared information on social media.

55 women attended the event, representing a wide range of ages and backgrounds.

Six information stalls attended the event, based on the topics of interest identified though the community engagement work. Three research groups from the University of Oxford Departments of Psychiatry and Experimental Psychology shared research engagement activities:

- OxDARE - Oxford Ageing and Dementia Research Network: Brain Health Quiz, highlighting preventative and risk factors for dementia.
- Child & Adolescent Psychiatry: Build a Brain Game, demonstrating the role experiences have on brain development in childhood.
- O-CAP - Oxford Cognitive Approaches to Psychosis: Anxiety and Virtual Reality Headset where users can safely experience everyday situations such as getting on a bus that people with anxiety can find distressing.

The Oxford Health NHS Foundation Trust Research & Development team attended with information about taking part in research studies, and an Oxford Health Governor attended with information about becoming a member of the Trust. Other information stalls included the Clinical Research Network Thames Valley and South Midlands and Restore – an Oxfordshire-based mental health charity.

The event opened with a story telling workshop where event participants were invited to share their experience of mental health. Issues discussed included anxiety, depression, low self-esteem and bullying. The role of faith, social media and the internet were also felt to be important, alongside the challenges of talking about these issues within the community.

Following the workshop, participants visited the information stalls, and enjoyed food and Bollywood singing.
Project learning and next steps

Feedback from community participants was gathered informally by M&A Social Enterprise and included:

• It was a relaxed and comfortable environment to talk about mental health.
• People enjoyed the workshop element and would have liked more time allowed for this.
• The research information stalls were not intrusive, and the information provided was insightful and thought provoking.
• It was a safe environment to try new things, for example the virtual reality headset.
• Singing and food was enjoyed by all.

Feedback from the researchers and information stalls was collected by Oxford Health NHS. All reported that the event had been valuable to attend and that there had been a good amount of engagement with community participants. Several made contacts to develop future activities.

The feedback indicates that, in line with the aims of the project, the event raised awareness of mental health and dementia research with the community participants, and increased understanding of experiences of mental health and dementia.

In reviewing the event we agreed these things worked well:

• Designing the event in partnership to ensure it was engaging and valuable.
• Making sure the topics aligned with interests and priorities of the community.
• Having interactive research activities to help promote positive messages about research.
• The community leading the promotion of the event to better reach seldom heard groups.
• Holding the event at a community venue which was familiar and accessible.

For future events we would make changes to:

• Allow more time for the workshop.
• Use a microphone so that everyone could hear feedback.
• Consider how we can address language barriers.
• Co-design feedback and sign up forms.

Oxford Health NHS and M&A Social Enterprise will continue to work together to deliver more community events and activities, and to build stronger engagement in mental health and dementia research.

“Comfortable environment to talk about mental health”

“Insightful and thought provoking”