Project title: Developing and evaluating innovative tailored peer-led Obesity UK support groups to provide support for, and improve research coproduction with, least heard and underserved communities.

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Plain Language Summary

Aim

To develop and evaluate tailored peer support groups for South Asian Muslim women and people who identify as LGBTQIA+.

Background

Obesity UK currently runs twice-weekly peer-led support groups, which provide much needed support for its members. However, these groups are not well attended by South Asian Muslim women or members of the LGBTQIA+ communities.

Methods

We invited community members to take part in workshops and surveys to understand what they wanted from a peer support group. We used the findings to develop and test new peer support groups with community facilitators. We then interviewed participants and facilitators to find out if they worked or not.

Key findings

It was important to pay the facilitators of the South Asian support groups and to manage people's expectations about what peer support is and is not. South Asian women who took part in the support groups particularly valued being given the opportunity to be listened to.

Online workshops did not engage the LGBTQIA+ community with lived experience, but an online survey did. The community wanted hybrid peer support sessions.

The use of language (moving away from obesity) and a safe space were important to both communities.

Dissemination, outputs and impact

We produced training toolkits which included tailored guides for each community (including translation to Urdu) alongside case studies, evaluation reports, visual summaries and training films.

Patient and public involvement

Community members developed and led every stage of this project.

Conclusions and future plans

Safe inclusive peer support was important to both communities, however future sustainability is reliant on facilitator and venue funding for the South Asian women's group, and improved community engagement for the LGBTQIA+ group. More codeveloped research is needed to fully meet the needs of both communities, which will be the focus of a community-led large follow-on study.

Summary of Research Findings

Background

Obesity is a serious chronic disease affecting around a third of all UK adults (1) and can lead to the development of multiple serious, life-limiting conditions (2), that can significantly impact people, families, health care systems, society, and the wider economy. Tackling obesity is therefore a government priority (3) and part of the NHS Long term plan (4). This plan recognised that people are already starting to self-manage their condition supported by peer support in the community and online (4). Structured peer-led support groups play an important role in empowering patients and supporting long-term self-care and weight management (5).

Obesity UK is the UK's leading patient advocacy charity for obesity and runs regular well attended peer-led support groups. These support groups are run by volunteer facilitators who bring in speakers on topics of interest to members to help empower members with current evidence and providing a unique opportunity to engage members in research coproduction. There are, however, many communities who are underrepresented in the current groups, including South Asian Muslim women and women and non-binary people identifying as LGBTQIA+, the communities we chose to focus on. South Asian communities are more likely to develop serious co-morbidities such as type 2 diabetes at a lower BMI (6), and women identifying as lesbian, or bisexual are more likely to develop obesity (7).

Despite the elevated risk, there remains a lack of good quality research in these communities (8, 9) and a lack of appropriate tailored support, as further identified by the Leeds City Council Member champion for LGBT+ (sic) and ethnically diverse communities, and by a rapid scoping review of the UK literature conducted by the research team, which identified only a few evaluations of peer support groups incorporating weight management (10, 11) and nutrition and physical activity support (10-16) for South Asian women, and nothing for the LGBTQIA+ community (see Appendix 1: rapid scoping review to underpin the pilot). Much of the evidence identified focused on evaluations of mental health peer support group programmes for both South Asian women (17-19) and the LGBTQIA+ community (20-24). The review also highlighted key challenges and ingredients for success when working with these two communities. Challenges included threats to sustainability (funding, resources, unequal access to training and support for facilitators, group members lacking confidence to become facilitators) and safety issues (boundaries and confidentiality). Additionally, for South Asian women, sociocultural barriers (such as time/family constraints, difficulty being able to prioritise own health needs and language barriers) and for LGBTQIA+ communities, challenges with group members and facilitators being vulnerable to experiencing burnout and emotional challenges. For success, groups need to ensure trusted, familiar, accessible settings, a safe and culturally tailored space (ground rules, experience in common, member choice and control), culturally appropriate recruitment methods, inclusive communication, effective facilitator training and support and group sustainability and longevity of funding.

Methods

1. Community Co-Design Process

South Asian Muslim Women: In March 2023, four co-design workshops were promoted via social media, existing networks, and community links by co-investigator HI, to recruit South Asian women. In total 44 South Asian Muslim women attended the workshops. Three workshops were held in Bradford at a community centre, Mosque, and sports centre, while one was online via Microsoft Teams. Facilitated by HI and conducted in English and Urdu,

the workshops discussed Obesity UK support groups, barriers to attending obesity peer support groups, and what a good group would look like.

LGBTQIA+ Community: Workshops for women identifying as LGBTQIA+ and people with marginalised genders were advertised via social media. Five online workshops (n=39 participants) were conducted September 2023, facilitated by researcher TB and PPI-co-investigators KD and HB. Due to imposter participants these workshops were abandoned in favour of an online coproduction survey which ran from March to April 2024. The survey (completed by 44 community members) was advertised via more targeted social media LGBTQIA+ networks, and explored language, structure, delivery, membership, promotion, and access requirements for peer support.

2. Peer support group development South Asian Muslim Women's Group

Based on the workshop insights, a twice-weekly in-person peer support group was launched in two Bradford Mosques in September 2023. Advertising targeted South Asian Muslim women through English and Urdu posters at Mosques, community centres, grocery stores, and leaflets. The group was also promoted via social media and community networks. Three South Asian Muslim women, trained by Obesity UK, facilitated the group. Due to initial low attendance, the group relocated to a community centre, merging with an existing coffee morning. This group met for 10 weeks.

LGBTQIA+ Group

Based on survey findings, the team collaborated with Yorkshire MESMAC to establish a monthly hybrid LGBTQIA+ peer support group), advertised through Eventbrite and social media, held at Yorkshire MESMAC and Zoom, and facilitated by LGBTQIA+ co-investigators and MESMAC staff (started June 2024).

3. Peer support group evaluation South Asian Muslim Women's Group

A focus group was conducted with women who attended the group. Online interviews were conducted with group facilitators, organisation manager, and the guest speaker was asked to provide feedback through an online form. Data collection tools were co-produced, and participants were given information sheets, privacy notices, and consent forms. The interview and focus group data was transcribed and anonymised and coded using thematic analysis.

LGBTQIA+ Group

As this group is still in progress (until November 2024), preliminary feedback was collated via testimonials from the two facilitators and MESMAC staff involved in running the groups.

4. Production of facilitator training guides

Informed by the findings from the scoping review, community workshops and evaluation, a set of training guides for facilitators were co-developed with Obesity UK and community members to produce: one general guide, and one for each community.

Ethical considerations

Ethical approval for the evaluation was granted by LBU (reference: 118637).

Findings

SOUTH ASIAN MUSLIM WOMEN

1) Co-design workshops

44 South Asian Muslim women attended the workshops (Community centre: 8 women aged>60, all non-English speaking; Mosque: 16 women, mixed ages, English and non-English speaking; Sports centre: 12 women, mixed ages, all English speaking; online via Teams: 8 women, mixed ages, all English and many engaged in community work with South Asian women). Workshop participants highlighted the need for facilitator and venue payments, and venues that are familiar to women. Women specifically identified local Mosques, community centres or schools, with good transport links to be ideal settings to hold the support groups. Workshop participants provided a wealth of ideas on the structure and content of the support groups and suggested that support group attendees would be willing to voluntarily contribute around £1 each time they attended the sessions to help cover running costs.

2) Peer support groups

Attendance at the first setting was poor, however after changing the venue and combining with an existing coffee morning, attendance increased with an average of 7 women attending the weekly sessions. Learning from the evaluation of these sessions revealed the following themes:

Suitability of the venue - It is important to balance the need for a familiar community place with the importance of creating an inviting environment – areas for improvement suggested by the facilitators included creating more open spaces, adding pot plants and natural light. The benefits of being attached to a pre-existing group (coffee morning), included convenience and reduced travel time. Participants also found it easier to attend consecutive sessions when they are already familiar with the group structure and attendees and have an established routine of regular attendance. However, there was some confusion as to when the coffee morning ended, and the peer support group started that required clarification.

Mismatch of expectations - Initially, women anticipated facilitators would guide discussions with weekly topic guides and expected health advice. The women felt that some of the topics discussed were repetitive, and wanted more structured content, including activities like chair exercises, and more guest speakers.

Personal benefits - Participants valued the opportunity to be listened to. They enjoyed learning about foods, peer support, learning what other people eat, listening to each other, and helping each other.

Importance of shared ethnicity/religion- The importance of having facilitators and guest speakers from the same ethnic and religious background was strongly advocated for, in order to share cultural experiences and understanding.

Need for facilitator training and mentoring- Facilitators recognised that the needs and preferences of their group were specific to their community. Facilitators require mentoring, safeguarding knowledge, and training to effectively navigate the peer support sessions, including being able to manage sensitive conversations.

Group name ‘Obesity UK’ - Participants felt that the term "obesity" carries negative connotations and is too medicalised. There were suggestions to call it a wellness group, as ‘health and wellbeing’ encompasses a broader range of issues associated with obesity, such as mental health, exercise, and diet.

LGBTQIA+ COMMUNITY

1) Workshops

We had an excellent rapid response to promotion of the initial online coproduction. This resulted in the facilitation of 5 workshops with an average of 8 people signed up to participate. However, it became clear to Hannah and Kat, our PPI Co-Investigators who identify as members of the LGBTQIA+ community, after facilitating the second workshop, that there may have been some participants who did not identify as women or non-binary people from the LGBTQIA+ community (e.g. gave he/him pronouns, were unaware of what sharing pronouns meant or did not discuss their lived experience of being LGBTQIA+) and were possibly not living with obesity (see Appendix 13.

Reflections from the workshops). Nearly all participants took part without cameras on, were unwilling to put their pronouns in the chat and were unwilling to unmute apart from to state their preference for vouchers. This was very disappointing and upsetting for Hannah and Kat. Not all of those who had their camera off were imposter participants though and provided some important insights around the social anxiety and use of the chat preferences of some members of the community. To improve the remaining 3 workshops and to protect our team, we developed a code of conduct, setting out our expectations for the workshops to create a safe space for everyone. We emailed all participants signed up for subsequent workshops asking them to confirm that they identified as an LGBTQIA+ woman or non-binary person living with obesity in the UK; were willing to share pronouns and have their cameras on unless unsafe to do so; and were willing to unmute and actively engage in discussion or in the chat if they were feeling anxious.

Despite these additional steps, the same challenges continued, and by the fifth workshop we held a brief 5-minute individual pre-screening interview where we asked participants to confirm each element of the code of conduct (described above). This was challenging, for example, some participants were unwilling to put on their camera even briefly to identify themselves and did not seem to be familiar with the concepts of ‘obesity’ and ‘pronouns’. Whilst it was challenging to tease out findings between genuine and imposter participants, it was clear that having a non- verbal space was important, as LGBTQIA+ people discussed high levels of anxiety and neurodivergence which meant they often preferred contributing via the written chat function. It was also divided as to what people wanted from the peer support group. Some wanted help to manage weight loss and engage in physical activity, whilst others wanted nothing to do with the concept of weight loss and discussed body positivity and how to live happily in a larger body size. There was however consistency around the need to focus on self-confidence and peer support for dealing with stigma.

We believe that the challenges of imposter participants were exacerbated by use of wide social media recruitment strategy, and in future would focus on the use of only trusted LGBTQIA+ networks.

2) Survey

The survey was open to anyone from the LGBTQIA+ community and 44 people completed the survey, which was open for six weeks between March and April 2024, with an average completion time of 14 minutes. Participants did not receive payment for completing the survey. The 44 survey participants were socio-demographically diverse members of the LGBTQIA+ community who wanted to achieve body confidence and acceptance; support and community; health and wellbeing; advocacy and systemic change; inclusivity and accessibility; empowerment and confidence building. Which they felt should be achieved through a safe and inclusive space; safeguarding policy; security against outing individuals;

code of conduct; inclusive language; cultural sensitivity; promotion of diversity; and clear rules of engagement.

Survey participants wanted the sessions to be for anyone in the community who self-identifies as living in a larger body and requested hybrid meetings run monthly in the evenings with a chat and transcription function for those joining online. Survey participants wanted a balance of structured sessions and content developed from within the group, with a desire not to have weight-focussed sessions. Popular suggestions for sessions included: daily challenges and practical solutions - what's it like living in a larger body, how to cope, navigating everyday life; mental health and coping strategies; weight stigma and barriers in society/healthcare; gender identity and body image; 'fat' liberation and body positivity.

In terms of language preference, survey respondents preferred positive and affirming terminology such as 'fat', 'plus sized', or 'larger body', and objected to the terms: 'obesity' or 'at risk of living in a larger body'. These survey findings were used to develop the pilot peer support groups in collaboration with MESMAC.

3) LGBTQIA+ pilot peer support groups

Five sessions have been run so far (June – October) with limited attendance so far: June: 3 attendees, 2 in person, 1 online; July: 0 attendees; August: although 12 were registered nobody attended (when we contacted them to ask why, they all stated that this was due to personal reasons and not due to anything that we had or hadn't done); September (now delivered online only due to lack of in person attendees): 2 online attendees who shared helpful reflections on the branding change to emotional eating, stating they wouldn't have attended the group under the previous branding; October; 0 online attendees, 1 turned up in person but the group had moved to online only so could not participate. Key findings from these pilot sessions include:

- Sessions were predominantly attended by men who identified as cisgender and gay, who naturally focused on issues faced by gay men in the community.
- A significant portion of the discussions revolved around language use, highlighting the importance of careful and inclusive communication. At the start of each subsequent session, we shared reflections from the previous session, particularly focusing on the use of language and potential triggers, to establish awareness and sensitivity for the follow-on discussions.
- To try and overcome barriers with terminology like 'larger body', we rebranded prior to the August session to focus on emotional eating as this was a term more members identified with.

Conclusions

Whilst we had initially planned for the peer support groups to be run on a self-sustaining voluntary model, as the Obesity UK general peer support groups are run, this was changed in response to the South Asian Muslim women coproduction work, which highlighted a need for facilitator payments, with participant voluntary donations to cover costs. However, unfortunately the voluntary contributions collected during the pilot sessions, didn't come near to covering the facilitator and venue costs which has implications for the sustainability of similar peer support groups within this community. Future groups therefore need to explore community funding opportunities, or the viability of volunteer facilitators and guest speakers/activities, to ensure the sustainability of groups within this community. More

research needs to be undertaken with South Asian Muslim female researchers, to fully understand the wider support needs of South Asian Muslim women living with obesity.

The presence of imposter participants posed significant challenges to the integrity of our coproduction work with the LGBTQIA+ community. It was perceived that a significant proportion of workshop participants did not identify as an LGBTQIA+ woman or as non-binary, possibly motivated by the prospect of monetary (gift voucher) compensation, which impacted on the PPIE coinvestigators running the session, and the value of the contributions made. However, we responded agilely by reverting to an online coproduction survey which provided some extremely valuable community insights.

The workshops, survey and group session highlighted barriers relating to the use of language, with an overarching rejection of terms related to body size and obesity. Future research is needed on the use of language in this space; and how to build trust and engagement with LGBTQIA+ people, to maximise the benefit of peer support within this community.

Learning from this project has been critical in informing the development of tailored training guides, implementation, and evaluative case studies, to inform the development of future tailored peer support groups across wider communities currently underserved by existing Obesity UK support groups. The resources developed will also help to share learning to improve the facilitation and inclusivity of existing Obesity UK support groups.

Research coproduction with the two communities and Obesity UK has also led to the co-design of a large programme for the codevelopment of a community led insight repository to inform the development of more equitable and inclusive obesity policy, practice and research. This is currently under development, as part of the Yorkshire Obesity Research Alliance: bringing lived experience together with the regional office of health improvement and disparities, integrated care boards, academics institutions and local third sector partners to co-create a truly community led application.

Patient and Public Involvement:

Aim

This study was led by and co-produced with, PPI members who were central to identifying the need, developing the study design, running the groups, organising the research and disseminating and implementing the findings.

Methods

1. PROJECT DEVELOPMENT AND MANAGEMENT

The study team was led by Obesity UK, and consisted mainly of PPI members, with the academic team providing a support role. PPI members included the Principal Investigator Ken Clare from Obesity UK; five PPI co-investigators: Maryam, Aisha and Nazia representing the South Asian Muslim women's community, Hannah and Kat representing the LGBTQIA+ communities, who were supported by the following wider PPI team members: Abida our South Asian community lead from Bradford4Better; Yasmin, Sajida, Salma and Mehnaz who facilitated the South Asian pilot support groups; and Aly from Obesity UK and Tom from MESMAC who supported the LGBTQIA+ peer-led support groups. PPI-Co-I's and team members have been central to the project management: from steering weekly project

management meetings; and facilitating wider community engagement, which is core to this work.

2. COPRODUCTION & COMMUNITY ENGAGEMENT

Our PPI team facilitated multiple community coproduction workshops within their respective communities which were pivotal in codesigning the tailored peer support groups. LGBTQIA+ PPI members also developed and conducted the LGBTQIA+ coproduction online survey.

3. PILOTING PEER SUPPORT GROUPS

Our PPI team were central to the implementation or the pilot peer support groups, leading the groups facilitation, logistics and evaluation.

Study results

Our South Asian female co-Investigators and team members were fundamental to finding suitable community venues and recruiting women to the peer support groups. This was critical given the importance of established trusted relationships, and shared religious and cultural understanding within the community. Working through these close networks provided a huge advantage in terms of recruitment and implementation, but did present some challenges in ensuring instructions through the communication chain.

Likewise, our LGBTQIA+ co-investigators and wider team members were equally as critical to locating suitable safe spaces to engage the LGBTQIA+ community, where awareness of stigmatisation and marginalisation of this community was paramount in the agile coproduction and peer support group codevelopment progress. The greatest challenge faced with our LGBTQIA coproduction work was the imposter participants we experienced within the workshops which deeply affected our PPI-Co-investigators, it also very clearly reinforced the importance of safe spaces within this community. Piloting of the peer support groups for the LGBTQIA+ community has also provided a much greater insight into the challenge of engaging this community, and the critical importance of language. Despite ongoing adaptations to recruitment materials and methods we continue to experience low attendance in the pilot peer support sessions which has affected PPI-Co-Investigator morale.

Our community members also played a pivotal role in the interpretation of the evaluation findings, providing important cultural understanding and context to the case studies and project documentation.

Discussion and conclusions

Our community co-investigators and wider team members played a pivotal role in the interpretation of the coproduction and evaluation findings, providing critical cultural understanding and context to the case studies and project documentation. This study simply would not have been possible without our PPI team. They led the project conception, coproduction, implementation, evaluation and interpretation, with the academic team providing project support and methodology advice.

Reflective/critical perspective

The role of community and peer researchers has been established for some time but has failed to really infiltrate academic research and practice development, perhaps due to the confines of existing academic and funding infrastructure. However, we feel this project provides a best practice example of how community led coproduction and research, with the partnership and support from academia can start to address some of the fundamental challenges in undertaking more inclusive and equitable research that is ultimately required to

truly address the currently engrained disparities in health provision and outcomes. We hope the follow-on programme grant will make some significant headway in further developing this approach to in the field of obesity. In addition, while we feel that this is a highly necessary funding stream, and welcome its continuation, changes to the funding application process and management are needed to ensure that this call is truly accessible to third sector organisations of all sizes.

Data sharing statement - See link

[https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253] for the NIHR position of the sharing of research data. The NIHR strongly supports the sharing of data in the most appropriate way, to help deliver research that maximises benefits to patients and the wider public, the health and care system and which contributes to economic growth in the UK. All requests for data should be directed to the award holder and managed by the award holder.

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