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SEXUAL HEALTH

Co-creating inclusive sexual health services for middle-aged and older adults, including disabled people, in England: an innovative participatory approach within the field of sexual health

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ABSTRACT

Background. Middle-aged and older adults, including disabled people, are rarely engaged in helping to develop sexual health services to meet their needs. We used co-creation as a promising participatory strategy to develop ideas to inform more inclusive sexual health services for middle-aged and older adults in England. **Methods.** During April and May 2023, we recruited participants to take part in our co-creation workshops and interviews. The research team partnered with active community leaders with lived experience to co-design and co-organise sessions. Discussion topics were developed iteratively, centred on participant input, to ensure the sessions were accessible and appropriate for the focus population. Implementation of the co-creation workshops and one-to-one interviews was evaluated by gathering community facilitators' reflections on how they felt about their experience as facilitators and the success of the workshops. **Reflections.** Overall, co-creation activities are well-accepted and highly valuable means to engage middle-aged and older adults. We are identifying three strengths and four challenges worth noting. As for strengths, they entail: (1) shared informed decision-making; (2) co-leadership for conducting the research activities; and (3) importance of co-facilitation; and for challenges: (1) ensuring the venue/information is accessible to all; (2) recruitment of middle-aged and older adults for a stigmatised research topic; (3) need more time for co-creation sessions to make sure equal opportunity to contribute; and (4) integrating co-creation into existing community activities. **Conclusion.** Co-creation is crucial for inclusive health services, but underexplored in sexual health research involving middle-aged, older and disabled individuals. This study emphasises shared ownership, which enables the offering of practical guidance for researchers and healthcare professionals.

Keywords: co-creation, disability, inclusive research, interview, middle-aged and older adults, participatory research, sexual health, social innovation.

Background

Sexual health is fundamental to overall health and well-being, not merely the absence of disease, dysfunction or infirmity, and it must be respected, protected and fulfilled regardless of age, ethnicity or sexual orientation.[1] However, middle-aged and older adults, including disabled people, are often neglected in sexual health research. Although these population groups are more likely than younger individuals to experience complex sexual health issues and disability,[2] research practices in this area often centre on young adults without disabilities.[3–5] Although middle-aged and older adults, and disabled people face compounded barriers to healthcare access,[6–8] their use of sexual health services remains understudied as a result of misperceptions of sexual inactivity, stigma, or inaccessibility of sexual health settings either in GP surgeries or sexual health clinics.[9]

In the UK, individuals who grew up in the 1960s and 1970s – now aged in their 50s and older – had limited access to comprehensive sexual health education, and grew up when

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public awareness of sexually transmitted infections (STIs) and open conversations about sexuality, were less common.[10] This social context may have further contributed to the persistence and amplification of unmet sexual health needs among older populations.[10] To generate solutions to address these inequalities in health service provision, it is critical that the communities themselves are involved in service design and delivery. The inclusion of middle-aged and older adults, and disabled people in research has also been shown to have psychological and social benefits for the middle-aged and older adults themselves,[11] and has the potential to be highly effective at improving their 'buy-in' to varied initiatives within health systems.[12]

Despite this, existing research engagement fails to include them in the research process, particularly in the planning and coordination as co-leaders.[13,14] Innovative and inclusive ways of engaging middle-aged and older adults in sexual health research are needed, such as co-creation, which promotes bidirectional collaboration between researchers and participants throughout all research stages to create user-centred knowledge and resources.[15] Although co-creation has been used extensively in sexual health research, particularly in the area of STIs,[16] its application among marginalised communities, such as middle-aged and older adults or people with disabilities, remains limited, with no clear guidance on how to implement it in this context. In line with this, the Sexual Health in Older Adults Research (SHOAR) at the London School of Hygiene and Tropical Medicine (LSHTM) was launched in 2020 by using co-creation methods to improve sexual health services among middle-aged and older adults, including disabled people, in the UK. The SHOAR project aims to develop policy recommendations to improve sexual health services in the UK by identifying high-quality messages that encourage uptake of inclusive services among older adults, including disabled individuals, through co-creation activities.

This methodology outlines how the SHOAR project successfully used co-creation with middle-aged and older adults, including disabled individuals, to conduct inclusive research and inform policy by amplifying the voices of historically marginalised groups. This study used 45 years as the cut-off age, as psychological and physiological changes that impact on sexual health, such as erectile dysfunction or menopause, increasing the risk of sexually transmitted infections, commonly emerge in this age group.[17,18] The paper could be relevant to sexual health research that is interested in generating more innovative approaches to engage middle-aged and older adults not only in England, but worldwide.

Methods

We engaged middle-aged and older adults living in England via co-creation activities, including workshop-based sessions and one-to-one co-creation interviews, to gather input on improving sexual health services for adults aged ≥45 years. These activities were grounded in the WHO definition of sexual health[1] and participatory action research theory,[19] consisting of three iterative phases involving community partners. The three phases were: (1) Preliminary Phase – focused on setup activities and preparation; (2) Implementation Phase – conducting the co-creation activities; and (3) Follow-Up Phase – aimed at evaluation, dissemination of results and eliciting reflection for future improvement. Table 1 describes the overview of the co-creation process we took, and the roles of researchers and community partners.

Phase 1: Preliminary phase – setting up activities and preparations

Establish partnerships

The research team partnered with Independent Living Alternatives (ILA), a social enterprise for disabled people, as key community leaders from the start of the study. The two community leaders were key contributors to the co-creation throughout the whole process, and they were joint decision-makers and facilitators for key activities. Additionally, a Community Advisory Board (CAB) comprised of middle-aged and older adults with and without disabilities was convened following the recruitment of community leaders to support the planning and designing of all project stages to ensure shared leadership. Alongside their inclusion, a steering committee group of key stakeholders (middle-aged and older adults, healthcare professionals, disability experts and advocates, and experts in gerontology) was formed to provide additional feedback on discussion topics, and promotion of co-creation activities through in-person meetings and feedback.

Co-planning and co-design of activities

Within the research team, two members (EK and HC) coordinated all activities and took responsibility for engaging in conversations with community partners. The session plans, designs and discussion topics for group workshops were developed iteratively, incorporating feedback from the CAB and steering committee group. Discussions were conducted either online or in person, and participants had the option of one-on-one or group conversations based on their preferences. For a detailed guide to the workshop utilised in the session, refer to a paper from the SHOAR project.[20]

We also co-developed a topic guide for one-on-one co-creation interviews based on previous research findings on sexual health services with this age group (Supplementary material file S1).[18] Agreed discussion topics included: experiences with sexual health services, suggested improvements to sexual health service provision, sources and content of sexual health information for middle-aged and older adults and disabled individuals, and definitions of sexual health for this age group.

Table 1. Three phases of the co-creation process and roles of researchers and community members.

Co-creation phases		Roles of researchers	Roles of community members
Phase 1: Preliminary Phase (approx. 3 months)	Establish partnerships	• Co-creation leads initiate community groups, project timeline, organise meetings.	• Key community leaders, community-based advisory board (CAB), steering committee identified.
	Co-planning and co-design of activities	• Workshop design plan finalised following community feedback.	• Community members provide guidance on accessible and appropriate engagement practices, session plans.
	Recruitment and promotion	• Co-creation leads run and manage social media platforms. • Creation of promotional materials led by team's graphic designer.	• Key community leaders, CAB engage personal and professional contacts. • Leaders provide feedback and guidance on promotional materials.
Phase 2: Implementation Phase (approx. 2 months)	Co-facilitation of activities	• Research team co-facilitates workshops and interviews. • Co-creation leads manage in-person and virtual logistics.	• Community members co-facilitate workshops and interviews.
	Data collection	• Research team manage data collection.	• Community members share personal experiences and motivations for participating.
Phase 3: Follow-Up Phase (approx. 2 months)	Evaluation	• Co-creation leads develop evaluation and feedback questionnaire.	• Community facilitators provided feedback and reflections on research process to date.
	Dissemination of results	• Co-creation leads collate results, and perform initial result and thematic analyses. • Coordinate results presentation, creation of dissemination materials.	• Steering committee and key community leaders support data analysis, ensure equity in selection of results for presentation, disseminate results among contacts.

approx: approximate.

Recruitment and promotion

Promotional materials, consisting of a combination of text and graphics aimed at explaining the study and encouraging engagement, were developed through an iterative process in collaboration with the CAB, steering committee group and professional illustrators (Supplementary material file S2). Community leaders provided recommendations on promotional material and language to ensure the appropriateness and acceptability of all promotional materials to the target population.

Promotion of the co-creation workshops took place from 1 April to 27 May 2023, through a hybrid approach, such as social media (Twitter, Instagram, Facebook, LinkedIn), organisational newsletters (Independent Living Alternatives), Inclusion London, Shaping our Lives, Eventbrite and professional networks, such as staff and community listservs, to ensure outreach to diverse populations. Interested participants were asked to complete an online registration form for the co-creation workshops.

Key community leaders and the CAB leveraged their positions embedded within the community to encourage participation, improving the perceived validity of and increasing public trust in the research study. Co-creation workshops and interviews were open to all ages, but focused on middle-aged and older adults, and disabled people.

Phase 2: Implementation phase – conducting the co-creation activities

Co-facilitation of activities

Each co-creation session was facilitated by two or three members of the research team, in collaboration with four community facilitators. The community facilitators were identified with support from community leaders to build trust and encourage participation. Among them, two were community leaders who also acted as facilitators and self-identified as disabled adults. A third facilitator, who also self-identified as disabled, was initially a participant and later joined the facilitation team. The fourth facilitator was a healthcare professional who had been introduced via a sexual health organisation, and who conducted research on sexual health among older people.

Community facilitators were required to meet the following criteria: have experience with small group facilitation; be aged ≥45 years old, or be an older adult researcher or other key group; be willing to write up a brief description of the event; help people submit ideas; and deal with logistics. Facilitators were supported by a facilitation guide (Supplementary material file S3), which provided guidance on group work, inclusivity and presentation of topics. However, these requirements were flexible, allowing for reasonable adjustments to ensure inclusivity. For example, facilitators with disabilities could request additional support, such as an assistant, to help with tasks like writing. Each facilitator received £120 GBP after the discussion as remuneration, and all participants signed an informed consent form. £50 GBP was provided to each participant as remuneration for their time and expertise.

In all sessions, discussions tended not to be dominated by any particular voice, and facilitators did their best to manage social dynamics to provide everyone with equal opportunity to participate. Additionally, to minimise the risk of biasing

discussions, facilitators generally prompted discussions with open questions or scenarios, taking notes on responses.

Co-creation workshops. A total of seven co-creation workshops were organised between April 12 and May 27 2023, and lasted between 90 min and 2 h (Table 2). Six of the workshops were held in person – three organised by the research team, one by community leaders, one by a community member and one by a healthcare provider. Of these, three co-creation workshops focused on the disabled population group. Additionally, one virtual workshop was hosted on Zoom and organised by community leaders. In-person workshops took place in university conference rooms, community centres and in a community leader's private venue. Logistics were managed by HC to ensure all participants' accessibility needs (e.g. large text materials, lift access, wheelchair-accessible toilets, hoist) were met. During the online co-creation workshop, Zoom accessibility functions, including closed captioning, were available for participant use. All co-creation workshops were limited to a maximum of five participants per facilitator to ensure the group size was manageable and all voices could be heard.

During the co-creation workshops, facilitators synchronously performed administrative tasks and led sections of the discussion. Administrative tasks included note-taking, time-keeping and moderating discussions. Sessions were not audio recorded to ensure participants' anonymity and encourage open discussions of a sensitive topic.

One-on-one co-creation interviews[20,21]. Between 9 May 2023 and 5 June 2023, as a supplement to the co-creation workshop, we conducted five co-creation interviews virtually via Zoom, each lasting between 45 min and 1 h, including the breaks. During the interviews, facilitators followed an interview guide, presenting participants with a hypothetical scenario to discuss and support ideation around their experiences with sexual health services, as well as their suggestions for improving these services.[18] Decisions around who would conduct the interviews were made in line with the participant's individual comfort level and requests.

Table 2. Co-creation workshop characteristics.

Session	Location	Disability focus	Facilitators
1	LSHTM[A], London	No	Research team
2	LSHTM[A], London	No	Research team
3	Facilitators' community space, London	Yes	Research team, community leaders (ILA[B])
4	Virtual	Yes	Research team, community leaders (ILA[B])
5	LSHTM[A], London	No	Research team
6	Community centre, Brighton	No	Research team, community facilitator (healthcare provider)
7	Community centre, London	Yes	Research team, community facilitator (stroke survivor support group leader)

[A]LSHTM: London School of Hygiene and Tropical Medicine.
[B]ILA: Independent Living Alternatives.

Data collation

Data collected during the co-creation workshops and interviews consisted of facilitator observations, participant reflections and suggestions on how to improve sexual health services for middle-aged and older adults in the form of written and typed notes. For one-on-one sessions, audio and video were recorded from the interviews after obtaining participant consent. Facilitators' notes from all co-creation workshops were collated and organised by co-creation leads, and stored in an encrypted LSHTM OneDrive folder. Any identifying information in the notes and transcripts was deleted.

Phase 3: Follow-up phase – evaluation, dissemination of results and eliciting reflections

Evaluation

Facilitator observations and reflections provided general feedback on how they felt about their experience as facilitators and the success of the workshops. Community leaders who acted as facilitators were asked to complete a short evaluation survey and open-ended questions on the following topics: overall satisfaction with co-creation workshop facilitation, preparedness and support, workshop objectives and expectations, materials and resources, participants, communication, and challenges (Supplementary material file S4). Data were recorded by co-creation leads and stored in an encrypted OneDrive folder.

Dissemination of results

When disseminating preliminary findings, the previously established promotional networks were utilised alongside communication directly with all participants who consented to continued engagement. Dissemination materials (e.g. infographics, presentation slides, posters) were co-developed with the two community leaders to ensure accessibility and acceptability.

Ethics approval

The project received ethical approval from the LSHTM Ethics Committee (Reference: 28458).

Reflections

This study aims to elicit strategies on how to improve sexual health services for middle-aged and older adults, including

disabled people, in England. Our research extends the literature by providing practical examples of a co-creation process and meaningful community engagement with middle-aged and older and/or disabled populations. Overall, co-creation activities are well-accepted and highly valuable means to engage disabled people, and middle-aged and older adults. We reflected on the SHOAR project's co-creation activities, based on the evaluation survey we conducted, identifying three strengths and four challenges worth noting. As for strengths, they entail: (1) shared informed decision-making; (2) co-leadership for conducting the research activities; and (3) importance of co-facilitation; and for challenges: (1) ensuring the venue is accessible to all; (2) recruitment of middle-aged and older adults for a stigmatised research topic; (3) need more time to make sure equal opportunity to contribute; and (4) integrating co-creation into existing community activities.

Strengths

Shared informed decision-making

By providing detailed information about the activity's structure and process, we demonstrate the ability to successfully organise co-creation activities alongside middle-aged and older people, including disabled people, in England. The flexibility of workshop structure and content allowed facilitators to make informed decisions to tailor sessions to individual participants, further supporting a high level of engagement. Community leaders' co-leadership and community-centred involvement across co-creation activities provided empowerment and shared decision-making opportunities, which is often not part of traditional research methods.[22]

Co-leadership for conducting the research activities

This methodology is distinct from previous research on 'co-creation', and it provides examples of surface-level engagement, which simply asks communities for feedback on information and ideas generated by the research team.[23] Our co-creation efforts involved and empowered community leaders with lived experience, and partners at all stages, ensuring they shared ownership over the study from start to finish. As such, our findings also have practical implications for healthcare providers and public health professionals by providing guidance on community engagement.

When asked about their sense of preparation and support to lead the workshops, community facilitators noted that the presence of the research team and key community leaders in the sessions led them to feel adequately supported and prepared to lead. One noted that, she 'appreciated support from staff . . . [as] it's important that the [community] facilitator feels supported and has opportunity to have backup support [from research staff].' One community facilitator noted that 'disability organisations are regularly asked for research participants in a 'faceless' way' and felt that the 'research team's presence helped to address that perception among participants'. Another emphasised the importance of co-leadership between the research team and community members in noting that it helps participants 'to understand that this isn't 'public sector duty' research, but 'a real project that's going somewhere'.

Importance of co-facilitation

Overall, including middle-aged, older and disabled adults as facilitators for co-creation workshops was highly valued, with one community facilitator reflecting that 'participants noted they enjoyed it and felt they learned things . . . [and] the research has triggered a number of follow-on conversations.' In doing so, group discussions centre participants, create space for diverse ideas and provide an opportunity to share challenging experiences safely.

Challenges and solutions

Ensuring the venue/information is accessible to all

Meanwhile, facilitator reflections and feedback revealed that there was a very high level of satisfaction with the events overall. They noted that 'finding an accessible venue, [and] coordinating people [to attend]' were the most challenging elements of event organisation. We encountered venue accessibility challenges when arranging in-person workshops for disabled people to have physical accessibility (e.g. having adequate transport and parking facilities). Although our research study originally aimed to capture ideas across the UK, all in-person events were limited to London and Brighton. Conversely, virtual co-creation workshops and interviews provided an accessible way for participants who experienced challenges travelling for an in-person event. To make sure there were no technical barriers, we offered technical support sessions over the phone and email based on their preference.

Recruitment of middle-aged and older adults for a stigmatised research topic

The recruitment of middle-aged and older adults for research on a stigmatised topic proved challenging, particularly among individuals from communities where sexual health remains a taboo subject to talk about.[24] However, shared leadership with a community organisation and other key community leaders led to participation in breaking down their misconceptions about 'sexual health', which should not be discussed with others, thereby improving their willingness to engage in our research.

Need more time for co-creation sessions to ensure equal opportunity to contribute

When asked about co-creation workshop objectives and desired outcomes, feedback indicated that having a longer lead time to plan group sessions and materials for various audiences, particularly disabled individuals, would be helpful to further improve upon the co-creation workshop

implementation. One community facilitator noted that additional time 'would've provided more opportunities to get more feedback and run the sessions better'. Facilitators agreed that in all sessions, participants were thoroughly engaged in discussions, and felt all participants had equal opportunity to share their opinions and reflections when asked about their perceptions of participant engagement.

Integrating co-creation into existing community activities

Finally, the original co-creation plans involved engaging participants in pre-established activities middle-aged and older adults would frequently participate in, such as book clubs or support groups. However, the research team was only able to coordinate one group workshop during a regularly scheduled community support group. The remaining six workshops were organised independently by the co-creation leads and community leads as one-off events. Although facilitators worked to minimise any discomfort during organised co-creation workshops, it is possible that integration into regularly scheduled community groups may yield deeper discussions.

Conclusion

Co-creation is increasingly recognised as essential for developing inclusive health services. However, there is a notable gap in the literature regarding how to effectively organise co-creation within sexual health research, particularly for middle-aged and older adults, and/or disabled individuals, who often face barriers to participating in such activities. Engaging community leaders and partners with lived experience was central to this study, ensuring they shared ownership of the research process from start to finish. This approach not only strengthens the inclusivity of the findings, but also provides practical guidance for healthcare providers and public health professionals on effective community engagement strategies. Further exploration of this methodology across diverse population groups and settings is crucial to fully evaluate its efficacy and potential for broader application.

Supplementary material

Supplementary material is available online.

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Data availability. All data generated or analysed during this study are included in this published article (and its supplementary information files).

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