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Coproducing justice in public involvement: impact-led iterative development of a dance based community engagement project building relationships in marginalised communities

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Abstract

Background Public involvement must include people from diverse backgrounds, or it risks exacerbating health inequalities in prioritising the needs of the majority culture. Public involvement as a process tends to exclude people by being tailored to fit the norms of the dominant culture; therefore simply removing barriers to participation is unlikely to be effective as is the case in other areas of science engagement. Rather it is necessary to go beyond redistributive justice (fair distribution of resources, opportunities, and benefits within health research) towards relational justice (developing respectful, reciprocal relationships and fair treatment within the research process and seeking to develop models of involvement that are meaningful and appealing to all groups).

Methods An action research approach was applied to the iterative development of an arts based participatory community engagement project to engage South Asians in Leicester, particularly women from inter-sectionally deprived neighbourhoods. Seven action research cycles were completed between 2017 and 2024, of which the first five are reported here. Data collection and analysis are summarised in Supplementary Table 01 and a project summary can be seen in Supplementary Fig. 01.

Results The impacts of the project were considerably broader than simply developing engagement with, and access to under-represented communities. The project was empowering for participating women and supported the development of social capital. It is emphasised that this is an impact associated with participatory community engagement that moves in the direction of coproduction.

Discussion Community engagement using an arts-based approach was effective at engaging under-represented communities in health science involvement. It also offered the potential to build social capital that impacted health inequalities in tangible ways aligned with macro-level policy. Community engagement can also therefore be viewed as an efficient use of investment in offering significant added value.

Keywords Community engagement, Social capital, Public involvement, Underserved communities, Ethnic minority, Dance, Action research, Impact assessment

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Plain English Summary

Health researchers often work with publics to make sure they develop research that is important, and is designed to make taking part in research as easy as possible. However, most of the people who work with health researchers in this way are from white ethnic backgrounds, over the age 55 and from middle to high income groups. This often means that research could be designed in ways that don't necessarily meet the needs of other groups, and those groups end up being less researched. It is therefore important that health researchers try to include lots of different people in public involvement. Efforts to understand what stops people from under-represented groups taking part hasn't led to improvements. Researchers in Leicester developed a community arts project using a model called action research. This just means that researchers planned a version of the project, tried it out, measured success, and then thought about how to make it better. Importantly, we tried to incorporate any existing theories or ideas as they became relevant. We tried this model over seven cycles of action research. We found that Asian style dance was effective at engaging South Asian women who worked with the researcher and took part in public involvement. We also found that using this type of community engagement, instead of something like a committee, helped us build good relationships with participating women, and empowered them to build social capital (social resources like friendships, networks, and even investment) within their wider communities. This is particularly important, because it shows that using community engagement to support public involvement has benefits for communities as well as for researchers.

Background

This project explores the iterative development of a participatory community engagement project in the diverse and deprived city of Leicester, intended to support public involvement in research. The model was developed using action research [1] which enabled the project team to incorporate structured reflection and relevant literature and theory as the model developed.

Participatory community engagement has positive impacts in terms of health behaviours, health outcomes, feelings of self-efficacy, and the perception of social support, and specifically in excluded communities [2]. It therefore has potential to underpin effective public involvement by building a community of interest whilst also generating benefits for the community. In this paper we explore the impacts that resulted from a participatory community engagement project seeking to increase the diversity of people in public involvement by building networks and relationships.

While the sciences often receive more substantial funding than the arts, the arts tend to demonstrate higher levels of public engagement. From the perspective of a science seeking to build public trust, foster engagement, and inspire health behaviour change, partnering with the arts is not only pragmatic but also holds significant potential for impact [3]. This also presents an opportunity for the arts to access resources not limited to funds, but also including rigorous evaluation and scientific information [4].

The UK government defines health inequalities as *avoidable* differences in health outcomes between groups of people because of the conditions in which they are born, grow, live, work and age [5]. Patterns of

health inequality are driven by the clustering of these factors i.e. through a pattern of social exclusion [2]. Whilst health inequality is defined as relating to modifiable factors [5] this pattern of clustering effectively makes non-modifiable factors such as age, class and ethnicity indirect determinants functioning through social determinants [2].

As with most factors relating to social exclusion, factors cluster and operate to aggravate the effects of proximal factors, causing spirals of social exclusion and associated health inequality. Furthermore, social exclusion impacts health literacy, ability to adopt health behaviours, resilience, self-esteem, access to social networks and perception of self-efficacy [5].

It is a goal of the World Health Organisation (WHO) to reduce diabetes by a third by 2030 [6]. This demands engagement of individuals and communities in implementing change [3]. Public health interventions based on health behaviour models have been at best moderately successful and more successful in populations from higher social economic groups, thus contributing to widening health inequality [7, 8]. This has led to a growing classist and, by association, often racist narrative of blame towards those less able to change their circumstances [7]. Existing awareness raising interventions tend to seek to enable, exhort or persuade the individual to choose a healthy lifestyle [7] assuming motivation, drive, rationality, freedom to act and the individual use of cost-benefit based decision making whilst ignoring, to a greater or lesser extent, social representations, culture, social context, political context, historical context, poverty, and social exclusion [7, 8]. That is to say that models of health behaviour tend to neglect health inequalities.

Type 2 Diabetes is a significant concern, presenting significant financial burden on the UK National Health Service (NHS) [9]. Reduction is an internationally agreed target for both economic and social reasons [6]. Approximately 4% of the British population, and about a third of the population in Leicester are Asian [10]. The rate of diabetes in the British Asian population is about 20% higher than in the White British population and manifests between 10 and 15 years earlier; this means Asian people with diabetes have more complications caused by the long-term damaging effects of living with insulin resistance [10, 11]. By the age of 80, half the Black and Asian ethnic minority population in the UK will have Type 2 Diabetes compared to a quarter of the White British population [12] and Type 2 Diabetes is 14 times more prevalent in Asian children than in White British children in the UK [11]. Engagement efforts targeting Asian communities are therefore appropriate from the public health perspective.

This project was considered a priority for the NIHR Leicester Biomedical Research Centre and Leicester Diabetes Centre per NIHR policy on involving diverse publics in research [13] and more broadly the role of higher education institutions in enhancing public awareness and understanding of science, and tackling inequalities [14, 15]. Health science communication reflects the patterns of exclusion observed in wider science communication activity and observed in patterns of health inequalities. The most privileged in society are most likely to be able to access science. Low levels of engagement with science by minoritised communities has tended to imply that this is related to deficiencies in the communities; in lay language, to experience the problem is to become the problem [16]. Social justice concerns the just distribution of wealth, opportunity and justice within society and until recently has primarily focussed, at least in terms of implementation, on redistribution i.e. making existing health and science resources available to publics who are not accessing them through initiatives like free tickets to science museums made available to minoritised and under-represented communities [16]. Increasingly, researchers are becoming aware that redistributive justice is insufficient, and are focussing on relational justice, where we cooperate to create accessible health and science. This may offer a potential locus of work to expand diversity in public involvement and engagement [16]. It is unlikely that the existing policy approaches that focus on removing barriers to existing models of public involvement (e.g., Reward and Recognition, payment of expenses, working with translators) will be sufficient. Rather we need to collaborate with communities to create models of public engagement and involvement that are accessible and meaningful to communities.

Dance was considered to be an effective art form for multiple reasons. Cultural attitudes can create low levels of physical activity amongst Asian women [17–19]. Barriers to both community engagement and physical activity in Asian communities are similar to those in White European communities, but they interact with cultural, religious and socio-economic factors and normative considerations pertaining to gender and generation [20–22]. Asian populations in Leicester show an awareness of the importance of physical activity for health [22] but mainly in the context of weight loss as opposed disease management [23], and the relevant lifestyle advice is not widely implemented in day-to-day living [20]. This suggested to the researchers that there is an opportunity for local provision of fun, community focussed physical activity. Indian dance presents itself as an optimal choice; it is fun, non-westernised, and an acceptable pursuit for women. Jain and Brown [24] described community dance as situated within community, and as embodying traditional practice, transmission of tradition, connectedness and social acceptance. Vahabi [25] found that Asian women liked the idea of dance because it was less onerous than going to the gym or walking, and because time spent in the activity passed quickly and easily. It was described as a social activity, that is fun, enjoyable, easy, affordable, acceptable, makes one feel good, and most Asian women know the steps. Dance in a culturally popular style (Bollywood specifically) was preferred. It was felt this would not only provide an opportunity for physical activity but also a sanctuary from the demands of everyday life [25].

Methods

This project adopted an interpretivist position in which we sought to derive our understanding from the complexity of the social world in action and recognised that our action within the social world would restructure it [26]. Particularly, this project involved working with people and communities experiencing inter-sectional exclusion in relation to sex, ethnicity, religion and, in some cases, socio-economic status. It was vital that we recognised the inherent vulnerability with which we were working and approached it sensitively and with humility. The lead researcher is starkly aware and reflexive of her relative privilege as a white working class woman. The research was therefore embedded in the feminist approach [26], and was concerned with the relative power, responsibility and authority within the project and how this related to the implementation of effective engagement, participatory community engagement and public involvement.

Project background and setting

The NIHR Leicester Biomedical Research Centre (BRC) and the Leicester Diabetes Centre undertake significant

research into Type 2 Diabetes, which particularly affects some communities more than others in a stark illustration of health inequalities. As such it is vitally important that the public involvement functions of these research centres represents those populations affected by Type 2 Diabetes. The project is therefore grounded in the NIHR policy objectives for public involvement [27]. The project was initially modest in its aspirations, seeking to build community contacts. As the project developed, not only did the project team aspirations expand, but there were changes in both focus and practice. The focus shifted from diabetes as the priority of the research centres involved, to health more widely, reflecting responsiveness to the wants and needs of the communities involved. This also entailed a shift towards increasing coproduction in turn related to the empowerment of participating women.

Aim, design and setting

Project Aim: The overarching aim of the Dance and Health project was to explore the potential of a model of participatory community engagement to deliver accessible public involvement and engagement opportunities in South Asian communities within Leicester. The project was launched in Belgrave neighbourhood, moved to Oadby Wigston, then established in Belgrave, Oadby Wigston and Spinney Hill. The project is still being delivered at the time of publication.

Belgrave: population of 20,565 people, of which the majority (85.4%) identify as having Asian ethnicity and Hindu religion (71.8%) although there is also a notable Muslim population (12.5%). Belgrave is in the top 30% of most deprived neighbourhoods in the UK [28].

Spinney Hill: population of 13,039. The majority identify as having Asian ethnicity (86.1%) and the main religion in the ward is Islam (71.7%) with Hindu second (15.5%). Spinney Hill is also in the top 30% of most deprived neighbourhoods in the UK [28].

Oadby and Wigston: population of 57,747, of which the majority are white (63.4%). There is a large Asian population (27.9%) and the main religions are Christianity (36.6), Islam (11.9%) and Hinduism (10.5%). Within Oadby and Wigston, only 16.3% of the population is in a ward that is in the top 40% of most deprived neighbourhoods in the UK, i.e. Oadby and Wigston is less deprived than Spinney Hill or Belgrave [28].

Characteristics of participants

Individual participants changed over the years of the project but were predominantly South Asian women over the age of 55, most of whom were Hindu. Participant characteristics were collected as part of the registration process.

Description of processes

Action research offers a practice based and reflective approach to implementing changes in practice that is situated in the work environment and with the practitioner [29]. It is derived predominantly from the field of education, and offers a flexible approach comprising of iterative cycles of action and enquiry [30]. As such, action research is formative as well as iterative, offering a mode of critical enquiry suited to public engagement and community engagement and enabling the development of an effective model of engagement through cycles of reflection, evaluation and modification. There are numerous models of action research which essentially comprise a cycle of planning, acting, observing and reflecting. In this research Sagor's model [1] as summarised in Fig. 1, was adopted and iteratively applied.

Clarifying vision and targets: Sagor [1] describes the initial task in this phase of action research as choosing a focus and refining it. Sagor's [1] model of action research presented the opportunity to reassess this focus at each stage of the project so the researchers were able to respond to the action research cycle, the dynamic policy environments and logistical realities across the project partnership.

During the clarifying visions and targets phase of each cycle relevant literature based on the evolving focus of the project was considered. A review of the literature and relevant theory considered throughout the iterative development of the project is given in the Background section.

Next in the clarifying visions and targets phase researchers considered what success looked like in that cycle, and determined criteria for assessing impact [1].

Articulating a theory of action: In this phase of each action research cycle plans are developed to tackle the challenges identified in the clarifying visions and targets phase [1]. This involved considering the intervention

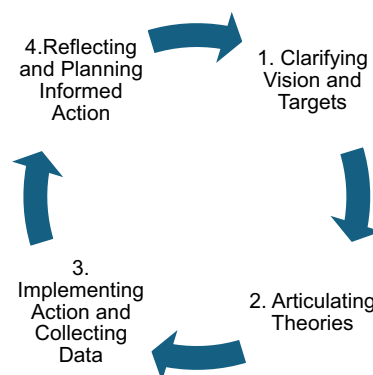


Fig. 1 Sagor's [1] model of action research

context, existing good practice or research, and ongoing learning and observations [1]. At this stage policy and logistics were considered e.g., meeting funder criteria.

Implementing action and collecting data: This stage entailed implementation of the theory of action, and collection of data according to the plans developed in the preceding stage [1].

Reflecting on data and planning informed action: Observed impacts were analysed in the context of how the theory of action was implemented in the real world, recognising that the plan may not always have been followed. Using a process of embedded critical reflection across the whole project team, underpinned by ongoing consideration of the theory and literature, as well as the macro-policy environment and logistical realities across the project partnership, researchers reflected on what was learned [1]. This involved ongoing communication and meetings with project partners that included space and time for reflection and discussion. The process enabled the researchers to determine lessons learned in the project phase that were used to inform the visions and targets for the subsequent action research cycle.

Description of processes of analysis

Analysis was embedded in each action research cycle, and the approaches used are summarised in Supplementary Table 01. We sought to ensure the analysis was credible and trustworthy, whilst acknowledging the subjective and descriptive nature of the findings [31]. This aligned with Sagor's [1] model of action research, as each cycle presented an opportunity to establish credibility and trustworthiness by referring back to existing theory and research, and incorporating new theory and research as it became relevant. This also underpinned the use of qualitative content analysis for focus groups with participants in the final cycle of action research described separately in Pritchard, Darko and Stevenson [4].

The project model also presented opportunity to embed researcher reflexivity and self-reflection in a comprehensive manner, to support our capacity to generate trustworthy and credible analysis. Finlay [32] identifies five facets of reflexivity and self-reflection and we consider how four of these are embedded into the project.

1. Introspection—the ongoing process of action research embedded introspection into the project, for example, the project team would reflect on their experiences and share their reflections in the meetings (see point 2).
2. Inter-subjective reflection—regular meetings with project team members were embedded to support both relational and operational aspects of the project. These helped develop our understanding of the pro-

ject impact across perspectives, utilising the different cultural competences of the project team members. This was fundamental to the process of developing the model of engagement and provided a source of data for the action research cycle without excessively burdening project participants.

3. Mutual collaboration—project participants were supported to increasingly contribute to the development of the model of engagement and our understanding of its impact.
4. Social critique—efforts were made to overcome power imbalances for the purposes of facilitating open and honest communication between project participants and the researcher. The use of culturally popular dance forms supported this by presenting the researcher as vulnerable and through the experiences of laughing and learning together.
5. Discursive deconstruction—this approach to reflexivity was not embedded within this project.

The long form of GRIPP2 (Additional file 1) was used to report our involvement activities, providing more details on the contextual development of the project between 2017 and 2020 and a critical reflection of the project.

Ethics

Ethical review of the project was undertaken by the Social Research Ethics Group at the Deanery of Biomedical Sciences at the University of Edinburgh.

The action research cycles

Action research cycles were implemented for four stages of iterative development. Furthermore, one incidental phase of the project arose, in which observations were still made but which was not a formal action research cycle.

To aid the reader in understanding the research processes, a summary of the project timelines is given in Supplementary Fig. 01, and the types of data considered at each stage of the project, and methods used to analyse the data are described in Supplementary Table 01.

Cycle 1: Feasibility Assessment

Research Question Cycle 1: Which of the proposed models of engagement recruit the target audience of South Asian women effectively?

A pilot project was planned and delivered in 2017. Groundwork involved the lead researcher (who was employed as the Public Involvement Manager in Leicester Diabetes Centre and the NIHR Leicester BRC) establishing a collaborative project team:

1. Leicester Diabetes Centre (LDC)

2. NIHR Leicester Biomedical Research Centre (BRC)
3. University of Leicester (UoL)
4. University Hospitals of Leicester NHS Trust (UHL)
5. Proximal research and NIHR infrastructure including the NIHR Clinical Research Network for the East Midlands (CRN), the Centre for Ethnic Health and the Applied Research Collaboration (ARC) for the East Midlands
6. The Aakash Odedra Dance Company
7. Shiamak Midlands

The project was funded by the NIHR East Midlands CRN and compared feasibility of six models of art-science engagement hosted at the Desi Masti Dance School in Belgrave Road:

1. Engage adults in the family by offering free dance classes to younger children (5–11). Whilst children attend free classes, clinical researchers and health workers from the research centres can engage waiting adults in discussion, information sharing, and tailored advice based on personal diabetes risk scores and body composition readings.
2. Engage adults in the family by offering free dance classes to older young people (12–16) employing the same methods as above.
3. Engage adults directly with free adult dance classes in the evening, followed by a 30 min discussion session based on materials from the LDC diabetes education programme DESMOND [33]. Unlike sessions 1 and 2 the clinical researchers from the research centres and the PhD researcher leading the project would participate in these to explore if dance helped build relationships and dismantle power dynamics.
4. Engage the whole family by offering free health themed academic enrichment sessions to younger children aged 5–11, focussing on maths, English and science.
5. Engage the whole family by offering free health themed academic enrichment sessions to young people aged 11–16, focussing on maths, English and science.
6. Engage the whole family in dancing together, with free classes for all ages on the Saturday morning of the same week in late August.

The sessions were advertised in a widely distributed leaflet, by email to the contacts of the BRC and the LDC, and on social media channels of all partners, and with most notable success that of the Desi Masti dance school.

Cycle 2: Bollyfit Sessions

Research Questions Cycle 2: Is the Dance and Diabetes model still effective at engaging South Asian women if delivered once a week, over 10 weeks? Is dancing together an effective way to build relationships between the academic project partners and people from the community?

The previous action research cycle demonstrated it was possible to directly engage the South Asian adult population through provision of a culturally appealing, targeted arts-based activity at an accessible time and location, in line with the findings of O'Mara-Eves et al [2]. Therefore a similar model of engagement was adopted in the second action research cycle in partnership with the same community organisations. It was a logistical priority for the dance school and tutors that the project was more aligned with their usual mode of delivery, so the model was adjusted to deliver sessions once per week over a 10 week period.

At this time, the INVOLVE Guidelines for Co-Production [34] became available in draft which introduced a macro-level influence on the vision of the Dance and Diabetes Project. In order to guard, at least in part, against any tendency for coproduction to be exploitative, there was a focus in the INVOLVE guidelines on mutuality, managing power dynamics and building effective relationships. The project at this stage therefore sought to focus on relationship building.

Importantly, given the persistent challenge of finding financial resources for engagement activity [35], in 2018 funding became available through the Wellcome Trust Institutional Strategic Support Fund award to the University of Leicester, and was accessed to build on the findings of the 2017 feasibility project.

The project was delivered over 10 weeks, offering participants one free dance class per week in the evening. Those living with or at risk of Type 2 Diabetes were prioritised. This was not a particularly stringent requirement as most people of Asian descent over the age of 50 are high risk for diabetes unless they have an unusually low BMI. Leveraging the community presence and contacts of the Desi Masti Dance School, 18 participants mainly from Belgrave but also Oadby Wigston were recruited. This reflected the strong local presence of the dance school within its proximal community and also its outreach activity.

Five of the 30 available places were offered to LDC and BRC health research personnel and subsequently to wider university and hospital personnel. Only three health research workers were recruited. Notably, personnel were required to participate on their own time, which likely disincentivised their participation. Two representatives from a community Diabetes UK Support Group were recruited.

Shiamak tutors delivered ‘Bollyfit’ classes adapted to a mature demographic. These are high energy, ‘aerobic’ style classes consisting of Bollywood style moves. Subsequent to classes there was a 15-min space to socialise and chat. The choice of Bollyfit sessions instead of Bollywood dance classes was not anticipated by the researcher. Discussion with the dance company and dance school representatives identified that they thought this would be a more welcome model of delivery as a higher intensity workout would be desirable in terms of health outcomes.

Cycle 3: Bollywood Sessions in Oadby Wigston

Research Questions Cycle 3: Did Bollywood style dance more effectively facilitate engagement and relationship building through dancing and learning together? Did participants engage with, value and enjoy a more structured style of engagement comprising a 30 min health and science discussion following each dance class?

Based on reflection on the previous action research cycle it was decided that the model of delivery, one session per week for 10–12 weeks (a term) would be maintained. However, the style of dance was changed to Bollywood with participants learning a routine together, and a more structured engagement session was delivered after each dance class. Therefore, the Dance and Diabetes model developed into a 60 min dance class and a 30 min diabetes and research discussion. Funding was secured by the community dance partners through the National Lottery.

New project partners Moving Together delivered all promotion, recruitment and administration for the project. The project moved out of the busy dance school to one of the Aakash Odedra Dance outreach locations, a large church and community centre hall in the Oadby Wigston neighbourhood. Although Oadby Wigston is less deprived than Belgrave, it does include pockets of significant deprivation. Sessions were also moved into a religious building which we recognised might be a barrier to some wishing to attend. As participants exited the session they evaluated the dance and discussion sessions separately using traffic light emoji stickers.

Incidental: Garba Sessions

Research Questions Cycle 4: This phase arose independent of the action research process and therefore there was no formal research question addressed.

Sessions in Oadby Wigston ceased once the National Lottery funding ended. Participating women themselves relaunched the sessions with a Garba instructor at the same church hall, pooling personal funds in order to pay the associated expenses themselves. The lead researcher was invited to join them and host discussions. The opportunity presented by the self-organisation of the

participating women was discussed with project partners and it was agreed that the researcher alone would continue to engage in these sessions whilst community dance project partners focussed on funding applications.

Classes took place at the same time and place and comprised 30 min of circuits, followed by 30 min of Garba dance and 30 min of health science discussion hosted by the researcher. Garba is a type of circle dance, associated with a range of cultural celebrations, often danced with sticks. By taking on the delivery and organisation of the sessions, the participants marked a shift in power dynamic and took control of the project. They became the people inviting health and science personnel into their space and community on their terms and according to their interests, and without gatekeepers.

Towards the latter half of the summer, a request for information on menopause was made. Despite the majority of the women being post-menopausal, they were very keen to learn more in order to support their daughters and daughters in law. The researcher reached out to colleagues and an opportunity arose to align the project with a menopause awareness project running through the University of Leicester. This was discussed with the participating women, and they were enthusiastic to invite the speakers from the menopause project to four sessions.

Cycle 5: Dance and Health 2019

Research Questions Cycle 5: Is the Dance and Health model effective at engaging South Asian women from more socio-economically deprived neighbourhoods? Is the Dance and Health model effective at engaging Muslim women? Do observations of the project support the assertion that community engagement can build social capital in ways that could potentially help address health inequalities?

National Lottery funding was secured to support a one-term pilot in the winter term of 2019, expanding the project to two new neighbourhoods to explore the effectiveness of Dance and Health across different cultural and socio-economic groups. Subsequent to a successful pilot phase, it would also provide sufficient funds to support the project delivery in two new neighbourhoods, Belgrave and Spinney Hill, and continue in Oadby Wigston throughout 2020. Sustainable funding presented an opportunity to more fully explore the potential of the project to achieve greater equity in health science communication, and consider the wider social impacts we began to observe.

In November and December 2019, dance sessions were delivered by Shiamak instructors (notably, male) through the Aakash Odedra Dance Company, administered by

Moving Together in 3 venues per week followed by a 30 min health science discussion:

1. Spinney Hill Neighbourhood: St Peter's Church Hall, 5 sessions.
2. Wigston Neighbourhood: St Paul's Church Hall, 4 sessions.
3. Belgrave Neighbourhood: Desi Masti Dance School, 4 sessions.

The sessions in Spinney Hill and Belgrave used the content developed for the Oadby Wigston discussion sessions, specifically an introduction to Type 1 and Type 2 Diabetes, lifestyle factors underpinning diabetes (physical activity and diet), heart health and lung health, and mental wellbeing. In the Belgrave group, the organiser of the local diabetes peer support group took an active role, and as part of her employment with the Stroke Association ran a discussion session checking blood pressure. One participant delivered talks in the community on mental wellbeing as part of a voluntary role and led such a session in each of the neighbourhoods. Discussion session content in Oadby Wigston continued to expand beyond diabetes.

Current Project Status

Project delivery continued throughout COVID, albeit it in a significantly altered form with differing objectives. The project was restarted within communities in 2022, and is currently delivered in Braunstone, Belgrave, and Oadby Wigston. An aligned project offering different activities targeted to the Black African and Caribbean population in Leicester has been launched. Details of the 2022–23 summative evaluation can be found in Pritchard, Darko and Stevenson [4]. This project is now the purview of the new Public Involvement Team that replaced the researcher in the 2022–2027 BRC funding cycle. The new team continue to operate embedded reflection as part of their practice in this and other BRC projects to ensure the ongoing production of good practice insights.

Findings for the action research cycles

Cycle 1: Feasibility Assessment

Sessions offering academic opportunities in math and English, and the Saturday afternoon family event did not recruit sufficient interest to support delivery. It was anecdotally reported by adults attending sessions that the Saturday session would not be likely to recruit as Saturday is the day on which families shop, often together.

Dance sessions for young children were of limited success. Children did attend for these sessions, but the close-knit and supportive nature of the community meant that

one parent would bring a large number of children along together. As a result, whilst we had acceptable levels of attendance of children to justify running a class, we only had 3 different adults waiting for them.

Dance sessions for teenage young people were also of limited success. The early sessions in the week did attract enough young people to justify running a class but attendance dropped off later in the week. Adults did not accompany teenage attendees. The densely populated city environment and location of the school on a main shopping street made it very safe for young people to travel without supervision in a group. Older teenagers assumed responsibility for younger ones. The intense nature of delivery (daily for 5 days) did not appeal to the teenagers. Attendance tailed off after day 2, and delivery ceased on day 3.

Dance sessions for adults were successful. Initial uptake was adequate, and after the first class, word of mouth led to rapid increase of attendance beyond capacity of the studio and leading to a need to turn people away if they had not booked. Based on the pilot it was decided to seek to engage directly with adult women from Asian backgrounds.

Cycle 2: Bollyfit Sessions

Successful recruitment of participants who attended consistently demonstrated that we could adopt a less intensive model of delivery and still achieve engagement, and that there were recruitment opportunities related to working with project partners present in the community [2, 36].

The delivery of an aerobics-style class was frustrating as preceding communication with the dance school had focused heavily on how the aim of the project was to build relationships between the research centres and local people through dance, particularly by working on and developing a new skill together. Furthermore, the researcher wanted to explore how inequalities in perceived power (derived from authority) could be reduced by engaging in an activity where the research centre staff were recast in the role of novices in the activity. The misunderstanding suggests that this had not been fully understood or taken on board by all partners. Bollyfit, being aerobic and fast-paced, eliminated opportunities to talk and laugh during sessions that had felt important and valuable in the feasibility sessions. As a social and cultural type of dancing, in that people move and laugh and learn together, Bollywood has potential to offer a range of social and emotional benefits. It was therefore decided that future activity would be delivered as a more traditional dance class and focused on learning a routine.

Timing of the sessions and the physical structure of the building was observed as inhibiting social interaction.

Dancing took place in the upstairs studio, which was immediately required after the class with the expectation that participants would gather in the reception area to socialise after class. However, given the need to promptly exit the dance studio, a sense of urgency to leave was created and socialisation was fairly minimal.

The researcher, participating personnel from the research centres and community members felt that the sessions would be more effective if there had been more structured engagement activity around health and science incorporated within the sessions. Conversation was somewhat inhibited by the structure of the dance school and number of classes running. Participants had to leave promptly as the next class came into the studio, and the space for waiting and changing was extremely limited.

Cycle 3: Bollywood Sessions in Oadby Wigston

Between 13 and 24 South Asian women attended the 12 sessions (average 16 per class). Attendance increased throughout the term to the point that there were issues with meeting demand particularly associated with participants bringing friends and family.

Two women emerged as leaders amongst participants, and helped to run the classes and discussions, for example, co-facilitating discussions, or liaising with the project team over issues with registration related to people wanting to bring visitors with them. The participant leaders established a WhatsApp group. The local GP attended as a participant and her role developed to include health promotion and contribution to the project by addressing clinical queries. She went on to lead her own sessions on some topics, associated with but not limited to diabetes in response to requests from participating women.

The feedback from the evaluation was encouraging but homogenous; the only time yellow or red stickers appeared was in relation to a session by the GP looking at blood pressure and the participants indicated that this was not a criticism of the session but an expression of discontent from participants whose blood pressure was higher than desirable!

It was a common observation from project partners that sessions were chaotic with women often arriving 45 min prior. Extensive socialisation was evident both before and within sessions. This was embraced as far as practicable.

Incidental: Garba Sessions

Whilst not a formal action research cycle, the assumption of organisational responsibility by participants in the project is itself an important finding that suggests that the engagement model was successful in empowering participants and demonstrated that the project reduced social isolation, a known cause of health inequalities [37]. This

supported existing claims that participatory community engagement has the potential to address health inequalities [2, 38]. However, this may have been a reflection of the higher social capital within the less deprived neighbourhood of Oadby Wigston [39, 40].

Cycle 5: Dance and Health 2019

Attendance averaged 25 (range 22–30) in Oadby Wigston, 15 (range 13–18) in Belgrave and only 7 (range 4–9) in Spinney Hill. The project did not attract participants effectively in Spinney Hill.

Progress towards empowerment was maintained in the established Oadby Wigston group and implemented more rapidly within the new sites e.g., participating women in the new sites influenced the topics of discussion and led discussion sessions themselves.

Discussion

In this reflection we consider the implications of the findings for public involvement and community engagement, the implications for theory of social capital, and the effect on practice/praxis.

The process of engaging in action research, and relating this to the growing understanding of the underpinning theories of social capital and previous research into delivery of successful participatory community engagement and public involvement inevitably shifted practice in the direction of a more critical and reflective approach. This facilitated a shift from policy-driven and operationally-focussed approaches to critically-reflective and theoretically-informed approaches; what in action research terms is described as a shift from practice to praxis [41] linking theory, thinking and practice in a practical philosophy [42].

Throughout the project there was consistent support for the previous research of Sung et al [43] and O'Mara Eves et al [2]. The meta-analysis by O'Mara-Eves et al [2] drew conclusions that help guide good practice in participatory community engagement for which this project demonstrated support in three respects. 1. A culturally specific approach was effective. 2. It was essential to invest in building relationships. In respect of these two points, dance was an effective tool; it supported relationship building, provided cultural specificity and helped to create feelings of cohesion [44–46]. Furthermore, 3. Sufficient management capacity was necessary to support the delivery of high-quality effective and participatory community engagement.

The principles reflected in the decisions and actions that were undertaken in relation to the iterative development of the project through the process of the action research also reflected the domains identified by Sung et al [43] as determinants of effective community

engagement (flexibility, a sense of belonging, commitment, communication, being genuine, relevance, sustainability). Throughout the project sustainability was a challenge related to the short-term and minimal nature of community engagement and public involvement funding, and its disincentivised status within higher education structures [35]. Dance was culturally relevant to participants which helped support recruitment and it is likely that researcher participation in the dancing helped dismantle power dynamics and demonstrated the researcher was genuine both socially and professionally. Flexibility was important for maintaining relevance such as when the project adapted to deliver engagement on the topic of menopause, which empowered participants to take responsibility within the project.

In the fifth action research cycle, the project did not successfully attract participants in Spinney Hill. The reputation of Desi Masti project partners in Belgrave and Oadby Wigston neighbourhoods was an important factor facilitating recruitment in those neighbourhoods. Within Belgrave, the dance school studios presented a known and therefore welcoming, safe and culturally accessible location in line with the recommendations of O'Mara-Eves et al [2]. Whilst the dance school has no physical venue of its own in Oadby Wigston, the use of a modern, well-lit venue (albeit a church) with good parking created a safe and culturally accessible temporary space for the project. Recruitment during the initial stages of the project was facilitated by two modes of communication; working with a trusted gatekeeper and word of mouth. The dance school were able to leverage their network contacts to reach people in the community and invite them to engage. Furthermore, the trusted nature of the gatekeeper organisation granted some credibility and acceptability to the project. Word of mouth recruitment required that the initial experiences of early recruits were positive, however the venue in Spinney Hill was cold, poorly lit, poorly maintained and not very clean, and very much reflected the deprivation of the neighbourhood. The recommendation from O'Mara-Eves et al [2], that a venue that feels physically and culturally safe is required may have been failed in this respect.

In previous action research cycles we recognised that project partners help develop cultural competence as highlighted by O'Mara-Eves et al [2]. It is likely that a project partner with specific cultural competence pertaining to the Muslim community in Leicester would have helped. This further highlighted the need for granularity in approach to working with different communities, highlighting the inappropriateness of treating minoritised communities as homogenous.

Recruitment to Spinney Hill sessions may therefore have been affected by the intersection of greater levels of

deprivation, increased diversity and lower social capital. The nature of the sessions may also have been less culturally appealing to Muslim women. The cumulative effect of these factors is likely to have increased barriers to recruitment.

In the fifth cycle of the project it was also observed that lessons learned over the preceding two to three years were generalisable (to some extent) to different socio-economic groups given that the iteratively developed model that was effective in the less deprived district of Oadby Wigston, was also effective in the more deprived ward of Belgrave. The differing levels of social capital may make it more difficult to build effective participatory community engagement activity in deprived areas than in wealthy areas in terms of finding safe, welcoming environments. The project was fortunate in having a welcoming and acceptable venue in the more deprived Belgrave ward. However, the challenges encountered in Spinney Hill suggest that we are missing something in terms of creating effective participatory community engagement with Muslim women and that may be partially related to the inability to find an appropriate venue [2, 43], the absence of an appropriate project partner, or aspects of mode of delivery of the project such as having a male tutor [21, 36, 47].

Implications for theory

The work of Sung [43] and O'Mara-Eves [2] supports the notion that by leveraging networks and engaging communities, there is a tangible path towards addressing health inequalities. Roura [38] consolidates these viewpoints by asserting that community engagement can directly impact health disparities through the mechanisms of distributive and relational justice, thus linking increased social capital with tangible improvements in public health outcomes. This is consistent with the work of Emily Dawson [16] on delivering social justice in science engagement and education.

In considering how the project informs the theories of social capital and social justice, and implications for health inequalities it is important to consider that we can only relate *good quality* public involvement and community engagement, (as defined by O'Mara Eves et al [2] and Sung et al [43]) to development of empowerment and social capital.

Few studies have examined the effect of participatory community engagement in health sciences on social and human capital but their findings suggest that community engagement is a way to develop resources within communities [2, 48]. Research in other fields, such as climate science and agricultural development also supports the potential application of the approach [48]. Arts based (health science) engagement in particular

offers a powerful tool for community engagement with the potential to impact health inequalities through the process of building social capital [49]. Arts projects can build social cohesion, which is related to better health. Arts projects therefore yield both personal and community benefits [50]. With health behaviour embedded in cultural and community norms, collective creativity presents an opportunity to build social cohesion with a focus on increasing healthy choices and encouraging health behaviours [50].

Public involvement in health research emphasises the inclusion of diverse patient experiences. This approach aligns with Pierre Bourdieu's concept of social capital, which he describes as the actual and potential resources linked to the possession of a durable network of more or less institutionalised relationships [51]. In the context of public involvement and community engagement, social capital can be fostered through both bonding and bridging mechanisms. Bonding refers to the strengthening of relationships within a homogenous group, enhancing mutual support and shared understandings. Bridging, on the other hand, extends beyond similar groups to connect disparate groups, facilitating broader perspectives and resource sharing [52]. Within the Dance and Health (initially Dance and Diabetes) Project both bonding and bridging were critical. An approach incorporating both enabled underserved groups to gain visibility and voice, thereby enhancing their social capital. Through strategic public involvement and participatory community engagement, health research can not only address but also harness the strengths of diverse communities, leading to more equitable health outcomes and a more inclusive research process. The findings of the Dance and Health Project suggest that this requires high quality engagement and involvement with a full consideration of how that engagement is made relevant and meaningful to the target community and therefore aspires to relational social justice [16].

Building on the foundational understanding of social capital in public and patient involvement, the Dance and Health (Diabetes) Project suggests that participatory community engagement and public involvement not only foster relationships and networks but also facilitates empowerment and social mobilisation towards greater distributive and relational justice. The enhancement of social capital through bonding and bridging aligns with the findings of Ocloo et al [53] and Cacari-Stone et al [37], which suggest that empowered communities can more actively influence social structures to promote equity.

In order to ensure there was potential for the project to build social capital either directly or through the reduction of social isolation [54] it was reiterated

that the dance classes needed to be about learning and moving together. This created an environment of social dancing with potential benefits including social interaction and emotional rewards [55], social engagement [56] and even an opportunity for participants to negotiate their understanding and experience of ageing [57]. These benefits are of course in addition to physical benefits [56, 58, 59]. Our utilisation of dance ultimately offered far more than simply the power to obtain an audience [60], but also reduced social isolation [55, 56].

Previous research suggests that community engagement (including public involvement) has positive impacts on health behaviours, health outcomes, feelings of self-efficacy which are in turn related to successful adoption of positive health behaviours, and the perception of social support, and specifically in excluded communities [2].

Thus we can conclude that the project offers health benefits that help reduce health inequalities to participants at multiple levels. The project provided an opportunity for healthy physical activity directly to participants. The health engagement component offered information and the opportunity to reflect on health behaviours that participants felt motivated them to adopt healthier behaviours. Finally the project itself created social capital, it built relationships and friendships, and facilitated access to information in a health positive group culture. This is itself a resource that has potential to offer health benefits and reduce health inequalities [38].

The multi-agency approach supported the ability of the project to deliver quality participatory community engagement and public involvement. The project demonstrated the need to ensure that multi-agency working is deliberative and open to maximise benefits. Time and space to build relationships and for effective and consistent communication was necessary and this highlighted the need for sufficient management capacity.

Study limitations

The action research approach intrinsically supported the development of empathy and compassion [61] as the project evolved from self-reflective approaches that predominantly sat with the researcher, to participatory action research involving the project partners and subsequently the participating women [29], and finally to a more politically driven emancipatory approach [62] where we started to explore the implications of our findings on approaches to public involvement in the context of social justice. Action research is not intended to be generalisable, and may be open to bias from the researcher and her collaborators though all efforts to avoid this have been made.

Conclusions

The project has implications for policy and practice. It demonstrates that delivering against the NIHR strategic objective of greater inclusion in public involvement cannot be seen as a simple process of removing barriers, but demands a restructuring of the very concept of engagement and involvement to make it meaningful beyond the norms of the dominant culture. An unsurprising implication of this reflection, and the project's support for Sung et al. [43] criteria is that public involvement and participatory community engagement funding is insufficient and insecure. It does not currently offer sufficient investment in the management capacities nor the systemic restructuring of practice required to move towards relational justice.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s40900-025-00714-2>.

Additional file 1 (DOCX 32 KB)

Additional file 2 (DOCX 42 KB)

Additional file 3 (DOCX 20 KB)

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Author contributions

R.P. delivered the Dance and Health project between 2017 and 2022, produced research materials, obtained ethical approval, recruited participants, collected and analysed data. E.S. supported the ethical approval process and development of research materials, and comprehensively supported R.P. as her PhD Supervisor. The manuscript was drafted by R.P. with significant contributions from N.D. concerning social capital and E.S. concerning the overall approach and science communication. All authors reviewed the manuscript.

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Availability of data and materials

No datasets were generated or analysed during the current study.

Declarations

Ethical approval and consent to participate

Ethical review of the research component of the project was undertaken by the Social Research Ethics Group at the Deanery of Biomedical Sciences at the University of Edinburgh.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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