


BMJ Open Child and family experiences of a whole-systems approach to physical activity in a multiethnic UK city: a citizen science evaluation protocol

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ABSTRACT

Introduction Whole-systems approaches are being adopted to tackle physical inactivity. The mechanisms contributing to changes resulting from whole-systems approaches are not fully understood. The voices of children and families that these approaches are designed for need to be heard to understand what is working, for whom, where and in what context. This paper describes the protocol for the children and families' citizen science evaluation of the Join Us: Move, Play (JU:MP) programme, a whole-systems approach to increasing physical activity in children and young people aged 5–14 years in Bradford, UK.

Methods and analysis The evaluation aims to understand the lived experiences of children and families' relationship with physical activity and participation in the JU:MP programme. The study takes a collaborative and contributory citizen science approach, including focus groups, parent–child dyad interviews and participatory research. Feedback and data will guide changes within this study and the JU:MP programme. We also aim to examine participant experience of citizen science and the suitability of a citizen science approach to evaluate a whole-systems approach. Data will be analysed using framework approach alongside iterative analysis with and by citizen scientists in the collaborative citizen science study.

Ethics and dissemination Ethical approval has been granted by the University of Bradford: study one (E891—focus groups as part of the control trial, E982—parent–child dyad interviews) and study two (E992). Results will be published in peer-reviewed journals and summaries will be provided to the participants, through schools or directly. The citizen scientists will provide input to create further dissemination opportunities.

INTRODUCTION

Physical activity levels and impacts

Across Europe, less than one-third of people aged 2–18 years old achieve the recommended 60 min of moderate-to-vigorous physical activity per day.¹ Such high levels of physical inactivity are fuelling a worldwide public health problem and negatively impacting

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The study design allows children and families to be at the centre of our understanding of what encourages and discourages them to be active.
- ⇒ By conducting citizen science as part of a reactive process evaluation, improvements to the research and the implementation can be made in real time, centred around those who matter most.
- ⇒ The data collection methods are designed to facilitate a positive participant experience.
- ⇒ The study has a small sample size, which will likely make it more difficult to capture a diverse range of experiences.

children's physical fitness, cardiometabolic health, bone health, cognitive outcomes, mental health and adiposity.^{2–3} Physical activity levels reduced further during the COVID-19 pandemic,⁴ with recent evidence suggesting the reductions have remained post-lockdown.⁵ Children from socially disadvantaged areas and ethnic minorities—who were already the least active—were most negatively impacted by the COVID-19 pandemic, further exacerbating health inequality.^{6–9} Additionally, across all age groups, girls are less active than boys, creating gendered health inequity.¹

Progressing to whole-systems approaches to physical activity

To date, most interventions have focused on individual behaviour change, resulting in minimal effects on physical activity behaviours.^{10–11} To address this issue, the WHO Global Action on Physical Activity report proposes a systems-based approach, involving cross-government, multisectoral partnerships and community engagement.¹² To enact effective systems-based approaches, it is recommended that programmes work closely with local people to develop solutions

tailored to intended recipients' context and experience.^{13–15} Recently, Sport England (the arms-length body of government responsible for growing and developing grassroots sport and getting more people active across England) has invested £100 million across 12 Local Delivery Pilots.¹² The purpose of each pilot is to design and implement a whole-systems physical activity approach, providing a unique opportunity for evaluation.

Evaluations of whole-systems physical activity interventions

There is a growing body of evidence surrounding whole-systems evaluations^{14 16 17} that suggests mechanisms underpinning complex and whole-systems interventions are likely more varied and dynamic than singular or less complex interventions.¹⁸ As physical activity interventions become more complex, it is increasingly important to explore what works, where, for whom and in what contexts.¹⁹ This is essential to understand the transferability, replicability and upscaling of interventions and to inform policy change.²⁰ Additionally, timely and integrated evaluation can inform dynamic systems change through continuous improvement of the intervention design and implementation.¹⁴

Literature reviews of evaluations of system approaches to health recommend several approaches and methods: the embedded researcher approach, qualitative inquiry (process evaluation) through a systems thinking lens, systems mapping, network mapping, ripple effect mapping and dynamic systems modelling.^{14 17 21–23} Such methods are applied in evaluations of whole-systems approaches.^{14 17 19 24} However, to our knowledge, there are no existing guidelines, protocols or evaluation studies reporting on evaluating whole-systems approaches focused on children and families. Given the increasing adoption of whole-systems approaches to physical activity and/or other health behaviours, there is a need to build further evidence around appropriate, effective and innovative methods for evaluating systems-based interventions,^{21 22} including those involving children and families.

Using citizen science to evaluate whole-systems approaches to physical activity

The United Nations asserts that children have the right to contribute to decisions that impact them personally and affect the services they use.²⁵ Therefore, it is essential that children and their families are integral stakeholders within the evaluation of whole-systems physical activity approaches. Moreover, including local people promotes a more comprehensive and contextual understanding of what works and for whom.¹⁴ At present, previous evaluations of whole-systems physical activity approaches have not placed children and families at the centre. One way to address this is through involving the public through a citizen science research approach, which could improve research quality and lead to system changes.²⁶ By placing children and families at the heart of research,^{27 28} their needs can be better understood, and programmes adapted accordingly. A growing cross-disciplinary body

of evidence demonstrates the benefits of taking different citizen science approaches with young people.^{29–35} Citizen science has been used successfully to understand young people's physical activity experiences.³⁶ However, the potential to understand whole-systems physical activity approaches using citizen science has not been realised.²²

A key principle of citizen science is that citizen scientists should benefit from participating.³⁷ Research indicates that positive experiences for young people can be achieved by considering power dynamics, relationships and personal growth within citizen science.^{29 32 38–40} Furthermore, it is recommended that citizen science projects evaluate participant experience to understand the value of young people's contribution and to improve outcomes.^{41 42} The purpose of this paper is to describe a citizen science evaluation approach of the Join Us: Move, Play (JU:MP) whole-systems physical activity intervention with children and families. A secondary purpose is to outline the evaluation of participant experience within the citizen science process.

METHODS AND ANALYSIS

Aims and objectives

This paper describes a protocol for a citizen science research study, aiming to understand the mechanisms through which a whole-systems approach to physical activity (JU:MP) influences behaviour change among families and to evaluate participant experience within this citizen science project. The specific objectives are:

1. To understand perspectives and lived experiences around the physical activity of children and families in JU:MP delivery areas.
2. To assess the feasibility, fidelity and acceptability of JU:MP among children and parents/carers.
3. To examine the mechanisms of change that underpin the physical activity behaviour of children and families, when, how and why this happens within JU:MP.
4. To contribute to dynamic systems change through informing programme refinement based on ongoing findings from objectives 1–3.
5. To formatively understand children and families' experience as participants within a contributory and collaborative citizen science approach, to inform continuous study delivery improvements.

Study context

During the pandemic, 73% of Bradford children (9–13 years) were not meeting physical activity guidelines.⁴ On average, children of South Asian heritage and females were less active than their white British peers and males, respectively.⁴ Within the Bradford district, the number of children overweight or obese is higher than the national average (37.9% vs 34.2%), with higher levels in the most deprived areas.⁴³ Specifically, within the JU:MP area, average income is significantly below the UK average.⁴⁴ Bradford is the youngest city within the UK, with 24% of residents under the age of 16 years.⁴³

Join Us: Move, Play

JU:MP is a whole-systems physical activity programme, being delivered in the north area of the city of Bradford, UK. Evidence-led co-production and formative evaluation inform ongoing intervention refinement. JU:MP consists of 15 work streams informed by the International Society for Physical Activity and Health's eight investments that integrate physical activity across various sectors, for example, active travel, schools and community.⁴⁵ These work streams are aimed at creating societal (eg, local authority policy), personal (eg, how families travel to school), organisational (eg, changes to the culture and environment of schools and Islamic Religious Settings^{46 47}) and environmental (eg, green space and parks) change. Neighbourhood action groups (across eight areas) consisting of local cross-sector stakeholders develop, tailor and enact the JU:MP programme at a hyperlocal level. Children and families could interact with or be influenced by any of the 15 work streams. JU:MP is being delivered in two phases across different neighbourhoods. Within three pioneer neighbourhoods (pathfinder phase: 2019–2023), the intervention is now embedded. Five accelerator-phase neighbourhoods began the JU:MP programme in 2021 with programme delivery continuing until 2024 (figure 1). Further information can be found in Hall *et al.*¹⁹

The overarching JU:MP evaluation

The JU:MP evaluation employs a mixed-methods approach, which sits within the complementary philosophies of realist and 'systems thinking' methodology.⁴⁸ The concurrent mixed-methods approach contains two main elements: an effectiveness and a process evaluation (figure 1). The effectiveness evaluation includes: (1) a controlled trial focused on primary-age children, examining effectiveness at the neighbourhood level, and (2) a pre/post-evaluation of children within the Born in Bradford cohort study at age 7–11 years,⁴⁹ and again at age 13–15 years, examining effectiveness at the population (North Bradford) level. The primary outcome is children's moderate-vigorous intensity physical activity.⁵⁰

The process evaluation includes an examination of the mechanisms and contextual factors influencing the implementation and impact of JU:MP and includes a focus on policy and strategy, overarching work streams, the JU:MP neighbourhood approach, and children and families. A mixed-methods data collection approach includes semi-structured interviews, observations, documentary analysis, surveys and participatory evaluation methods (eg, reflections and ripple effect mapping). For further information on the overarching process evaluation, see Hall *et al.*¹⁹ This paper describes two citizen science evaluation studies that are part of the overarching process evaluation: (1) an interview and focus group study with primary-age children and their families; and (2) a year-long collaborative study with secondary-age children and their families.

Patient and public involvement

Public involvement through the citizen science methodology is integral to this study, as described in the Methods section of this protocol. Wider public involvement with youth research ambassadors from Born in Bradford⁵⁰ shaped the overarching study design, including, for example, incentives, methods and realistic time commitments.

Citizen science approach

Two interlinked longitudinal citizen science studies will help understand child and family experiences of the JU:MP programme. These will be complemented by an evaluation of the citizen scientists' experiences.

Citizen science is a transdisciplinary participatory method.⁵¹ While there is no agreed definition,^{52–54} for this paper, we define citizen science as the involvement of members of the public who work with professional scientists to advance research.⁵⁵ Citizen science projects can be viewed on a continuum. On one end, citizens are 'passive contributors' to activities⁵⁶; on the other, citizen scientists are fully immersed in a local community, and the research is a joint enterprise to help identify and solve societal issues.⁵⁶ Using Shirk *et al.*'s⁵⁷ typology, study one adopts a contributory model approach, where projects are designed by researchers and members of the public primarily contribute data. Study two adopts a collaborative model approach, where researcher staff create the project and 'members of the public contribute data and help to refine project design, analyse data, and/or disseminate findings'.⁵⁷

Guidance exists on conducting high-quality citizen science research,³⁷ including young people in research⁵⁸ and co-production in a Bradford context.⁵⁹ The following seven principles, adapted from the above documents, will guide the current citizen science approach:

1. Child-friendly involvement, including clear communication and feedback.
2. Power should be shared with the children where possible.
3. Voluntary participation should be offered at different stages of the research.
4. Researchers should respect the participants' knowledge; one way of showing this respect is by going to the communities.
5. Research should be inclusive and relevant to the children's lives.
6. Participation should include a reciprocal relationship where training supports participants.
7. Researchers should ensure that participants are safe and sensitive to risk. Research leads should consider ethical and legal issues.

A longitudinal research design will provide an understanding of families' direct experience with JU:MP and how this evolves.^{60 61} The longitudinal nature will facilitate the development of a meaningful relationship between the child, families and the researchers,^{28 29}

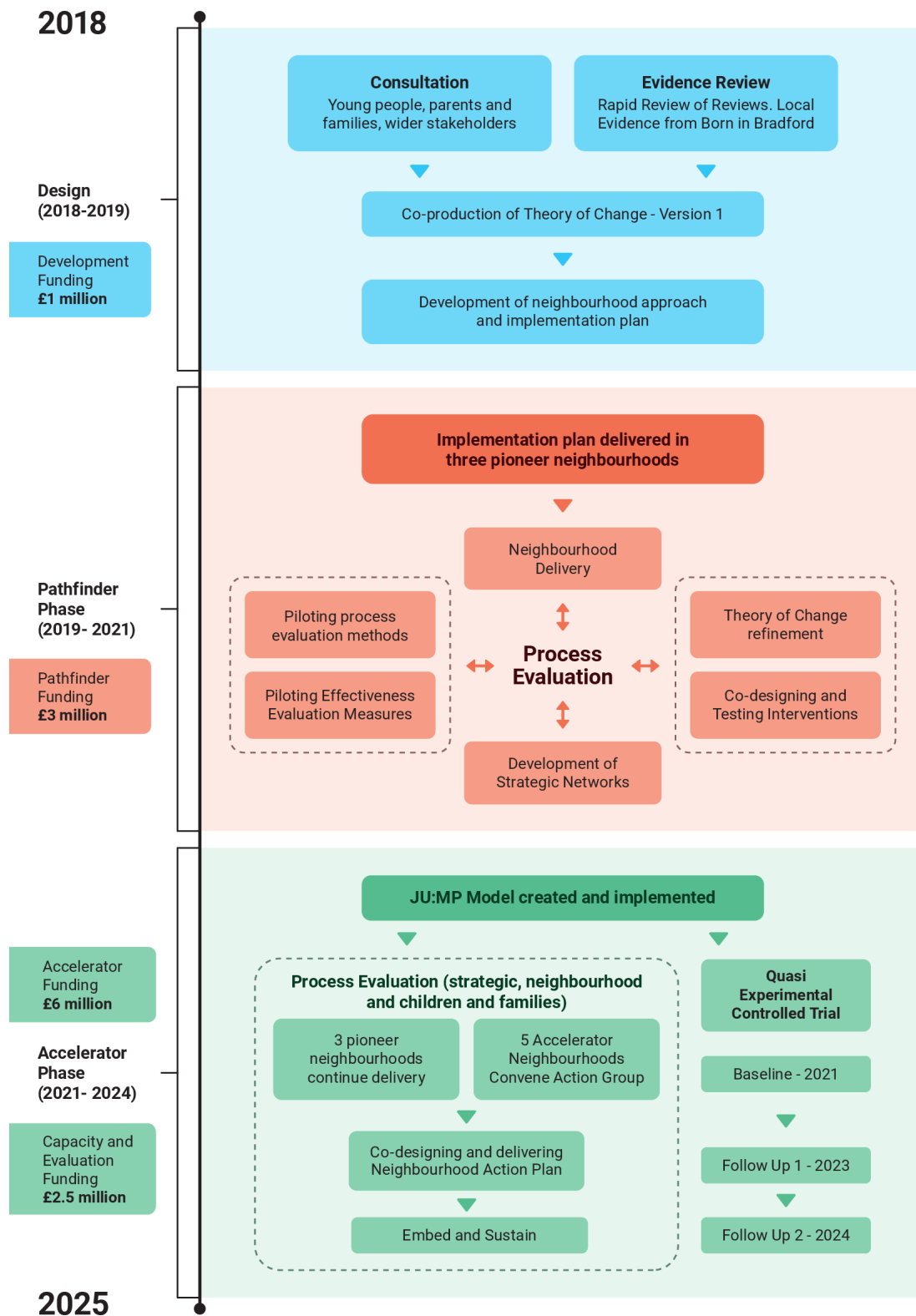


Figure 1 JU:MP overall timeline. JU:MP, Join Us: Move, Play.

provide time to explore change mechanisms and take seasonal variations in children's physical activity levels and sedentary time into account.⁶²

Study design

Herein, we describe the design of the two studies that make up the citizen science evaluation, including

contributory citizen science (study one) and collaborative citizen science (study two) (see figure 2).

The two studies have been designed in a way that the level of citizen science participation required is age appropriate.⁶³⁻⁶⁵ The contributory citizen science study will accommodate the views of younger children and

The child and family process evaluation

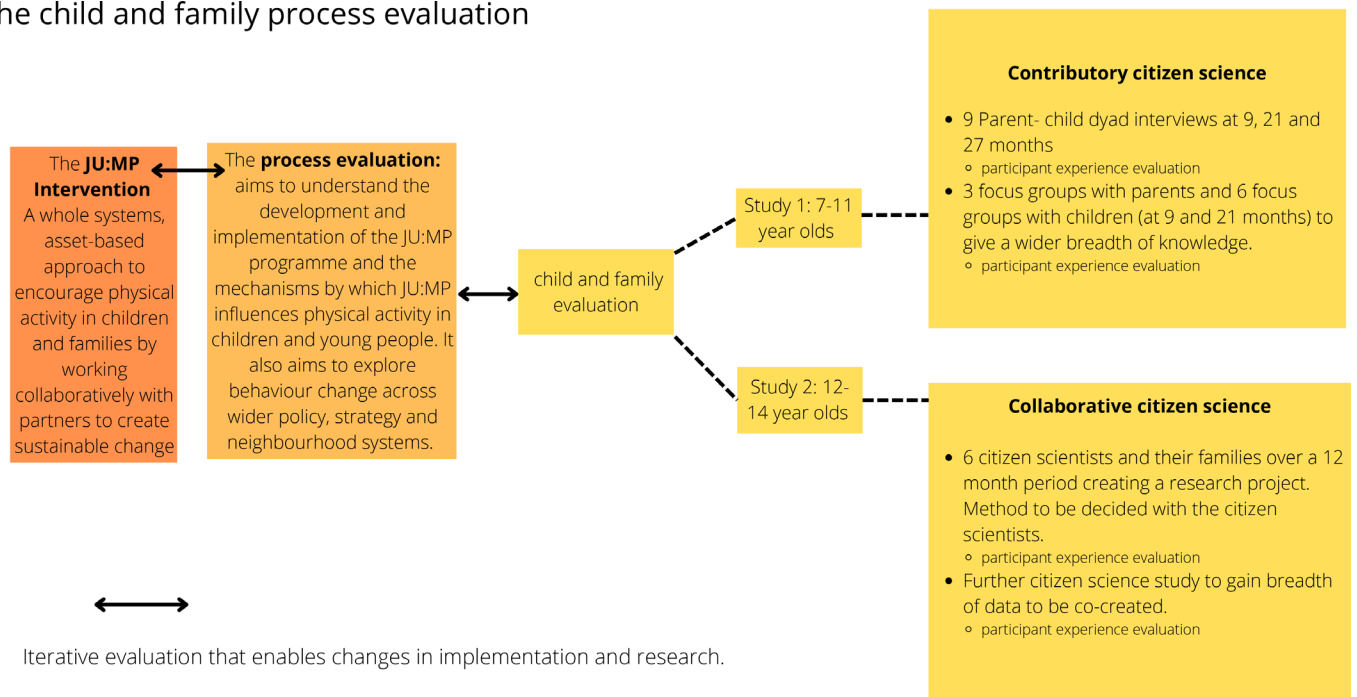


Figure 2 Citizen science evaluation study design, including contributory citizen science (study one) and collaborative citizen science (study two). JU:MP, Join Us: Move, Play.

their families through focus groups and interviews.⁶⁴ For the collaborative citizen science study (ages 12–14 years), participants choose the study method, which may involve independent data collection in different neighbourhood locations and/or independent use of technology. These methods may not be suitable for primary-age children due to parental concerns of personal access to smartphones.^{66 67} Ongoing findings from both studies will be added to the agenda for the six weekly research and implementation meetings, where they will be discussed, and actionable outcomes created to inform the JU:MP programme development and delivery. Actions are added to future meeting agendas and progress is recorded.

Ethics approval was granted by the Chair of Humanities, Social and Health Sciences Research Ethics Panel at the University of Bradford for both studies (June 2022). For study two, given the collaborative citizen science approach, ethics approval covers participant onboarding, the study in principle and the first workshop. Ethical amendments will be submitted at (at least) two further points: (1) once the data collection method has been decided on and (2) once the data analysis approach has been finalised (further details in the Data analysis section).

Equity of access has been considered in both studies. In addition to the information mentioned in the study design, any reasonable accommodation will be made to include eligible children who wish to take part. This will include following schools' instructions on how to accommodate learning differences, as well as ensuring physical accessibility for children with disabilities. If language is a barrier to participation, suitable accommodations will be

made, for example, the provision of study information in the relevant language or a translator. If further specific barriers to accessing the research arise, current best practice will be followed to ensure inclusion.

Study one: contributory citizen science with primary-age children and their families

Study one uses two data collection methods: focus groups (separate child and parent focus groups) and parent-child dyad interviews. Focus groups allow for a diverse range of responses and provide children with less intimidating environments than interviews.⁶⁴ The parent-child interviews—which pair a child with their primary caregiver—allow for more detailed and longitudinal exploration of people's experiences and engagement with JU:MP, and physical activity behaviour change mechanisms. Parent-child dyad interviews will aid understanding of how parents shape children's behaviour as well as allowing parents to expand on the child's verbal expression.^{68 69} The study draws on a range of concepts relevant to intervention evaluation that the focus group and interview topic guides were informed by⁴⁸ (see table 1).

Study one: sampling, recruitment and incentives

Focus group and interview participants will be recruited from the three neighbourhoods included in the JU:MP control trial (see The overarching JU:MP evaluation section) to permit integration of findings across evaluation components. Each family will receive a £20 voucher per interview as a token of appreciation for their time.

Focus group recruitment: parents and children will be recruited from the sample who provided consent

Table 1 Concepts and their application within the study

Concept	Definition	Application within the study
Feasibility ⁸⁸	Feasibility: how easy is it to participate in different elements of JU:MP?	<ul style="list-style-type: none"> ▶ What has made it easy/hard to engage with JU:MP ▶ What would make it easier to engage with JU:MP
Participant fidelity ^{89–91}	The extent to which participants understand the concepts and purpose of the intervention and are exposed to and engage with the intervention.	<ul style="list-style-type: none"> ▶ Exposure participants have to different elements of JU:MP ▶ Receipt of knowledge of physical activity and its benefits; and knowledge and understanding of the JU:MP intervention ▶ Responsiveness—the extent to which participants feel the various components of JU:MP are useful ▶ Engagement—the components they report seeing/hearing about and/or engaging with/or taking part in
Acceptability ⁹²	Anticipated or experienced cognitive and emotional responses to the intervention.	<ul style="list-style-type: none"> ▶ Affective attitude (anticipated or experienced thoughts and feelings about JU:MP) ▶ Burden (the anticipated or experienced amount of effort required to engage with JU:MP) ▶ Ethicality (the extent to which JU:MP fits within their value system) ▶ Self-efficacy (participant's confidence that they can perform the behaviour required to participate in JU:MP) ▶ Opportunity costs (anticipated or experienced benefits or values that are given up to engage with JU:MP)
Mechanisms of change ⁹³	How does the intervention produce change within the delivery context?	<ul style="list-style-type: none"> ▶ What elements of JU:MP works, for whom, and in what context ▶ Wider intended or unintended impacts of JU:MP

JU:MP, Join Us: Move, Play.

and assent to engage in the JU:MP control trial when in primary years 1–3 (aged 5–8 years). The sample for the focus groups will be recruited when the children are in years 2–4 (aged 6–9 years). Schools will be selected from different areas to ensure a geographical spread of participants. Parent focus groups will typically take place in different schools to child focus groups to enhance the diversity of responses. Children and parent participants will initially be randomly selected but revised based on advice from teaching staff (eg, if the family has since left school, or if the sample lacks diversity in socioeconomic backgrounds, ethnicity or physical activity behaviours). Different participants will be selected at different data collection time points to allow a range of families to share their experiences. Two weeks before the child focus group, parents will receive a letter or email from their child's school to notify them and provide an opportunity to withdraw consent. Verbal consent (parent group) and assent (child focus group) will be recorded at the start of each focus group.

Parent–dyad interviews: the eligibility criteria are as follows: (1) those who live in the JU:MP control trial neighbourhoods and (2) including a child in primary years 2, 3 or 4. Participants will be recruited through local community networks and social media. A random sample will be selected from those who express interest in participating and have suitable availability. Informed

verbal consent will be obtained from adult participants, and assent from child participants.

Study one: data collection methods

Interview data collection will take place approximately 9, 21 and 27 months after the JU:MP accelerator-phase programme launch (September/October 2022, September/October 2023 and March/April 2024). Focus group data will be collected at the first two time points. Multiple data collection time points enable findings to provide repeated feedback on programme delivery to enhance the likelihood of engagement with and impact of JU:MP. Participants' basic demographics (postcode district/name of neighbourhood; gender; age; ethnic group) will be collected during the interviews and focus groups to describe the sample characteristics relative to the population.

Focus groups: six focus groups with children and three focus groups with parents will be held in schools. Two researchers will be present at each focus group: one to facilitate the session and one to take reflexive field notes. The children's focus groups will incorporate the Write, Draw, Show & Tell⁷⁰ technique to explore children's understanding of physical activity. This participatory visual method allows children to express their views, thoughts and emotions non-verbally and/or verbally, facilitating inclusivity and engagement.⁷⁰ Images depicting various

components of JU:MP will also facilitate discussions (see [table 1](#) for an overview of focus group discussion topics).

Parent–child dyad interviews: nine parent–child dyads (three from each neighbourhood) will be interviewed at each time point. Photo elicitation methods will be used to stimulate discussion. Before each interview, families will be asked to take photos showing their physical activity as part of a normal week and images depicting various components of JU:MP will be shown in interviews. Both sets of images will be used to facilitate discussions around child and family physical activity behaviours. Interview questions will focus on the parent and child's understanding of physical activity, their (change in) physical activity behaviours, why they may or may not have engaged with the JU:MP programme and what impact this has had ([table 1](#)).

Study one: data analysis

Data analysis will be undertaken using a framework approach.⁷¹ Interviews and focus groups will be audio-recorded and transcribed verbatim. Once imported into NVivo (QSR International, Melbourne, Australia), data will be coded into a framework previously developed to analyse wider JU:MP process evaluation data. This will facilitate the integration of data and findings with the broader process evaluation. Further detail as to how the framework was developed and the rationale for this approach can be found in Hall *et al.*¹⁹ A recurrent cross-sectional analysis will be applied for the focus group data to explore differences across the three different focus group cohorts.⁵¹ For interview data, a trajectory analysis will be used to examine change over time within the parent–child dyads participating in the study.

Study two: collaborative citizen science with secondary school-aged children and families

Study two is a collaborative approach—with data collection developed in partnership with the citizen scientists. The longitudinal study will take place over a year (September 2022–September 2023) and focus on the citizen scientists and their families' experiences of physical activity and the JU:MP intervention.

Study two sampling, recruitment and incentives

We aim to recruit six female citizen scientists, aged 12–14 years, and their families. We are targeting females due to females being consistently less active than males¹ and our public involvement work indicating that families, particularly those from South Asian backgrounds, may be more accepting of a single-sex research project. The study will be advertised as female only; when the children and guardians give consent, this will be taken as gender self-identification as female. Participants will be selected to ensure a diverse sample according to family composition, ethnicity, geographical location and previous interaction with JU:MP. Three families will be selected from one pioneer neighbourhood (60% Pakistani ethnicity) and three from an accelerator neighbourhood (75% white

British ethnicity), enabling exploration of families' experiences at different stages of the JU:MP delivery process. The household earnings in both areas are below the national average,⁴⁴ and the researchers have taken steps to ensure socioeconomic status should not be a barrier to recruitment.

Families will be approached through JU:MP Community Engagement Managers and other partners who work directly with the communities, to facilitate trust.^{30 72} Informed consent from the parents and assent/consent from the children will be obtained before data collection commences and at key data collection points as the project evolves.

The study two incentive package was developed in partnership with the youth research ambassadors from Born in Bradford prior to the commencement of the study. The incentives (to the total value of £400 per family) given throughout the study include family vouchers, child vouchers, money donated to the child's charity of choice and team-building activities.

Due to the small sample size if the citizen scientists withdraw from the study, we will continue to recruit up to halfway through the study. Amended information and consent forms will be used to recruit once the study has taken shape. If citizen scientists are unable to make a workshop, any progress made will be communicated to them by the facilitator at a time convenient to the citizen scientist. If the citizen scientists do not return data at agreed time point, prompts will be sent to encourage submission.

Study two: data collection methods

Over the longitudinal study, the citizen scientists will be expected to collect data every fortnight on personal and family experience of JU:MP and physical activity. Depending on the data collection method selected, the data could be entered securely online or physically brought to the workshop. The citizen scientists will attend training workshops on how to conduct ethical research, plan and carry out data collection and analysis. Families will be asked to contribute to the data collection and, if the citizen scientists see it as appropriate, comment on the data analysis.

There will be six group workshops in addition to regular contact between the researcher and citizen scientists across the year (see [table 2](#)). The first two workshops will be facilitated by a researcher, and subsequent workshops may be co-led with citizen scientists as the project develops. The first workshop will be held in a location mid-way between the recruitment localities. Citizen scientists will be asked if this is a suitable location for future workshops.

Workshops one and two will focus on training and project development. Key decisions will focus on: finalising the research question, selecting the data collection method(s), ethical issues, how the citizen scientists want to transfer data, data analysis and dissemination. The citizen scientist will have the opportunity to use

Table 2 Workshop plan

Month 2022–2023	Schedule
September	Workshop 1—full day Researcher led <ul style="list-style-type: none"> ▶ Research question agreed ▶ Data collection method selected ▶ Data analysis plans discussed ▶ Ethical code produced ▶ Timings of further meetings and data collection and the meeting location will be arranged <i>Participant evaluation</i> Ethical amendments submitted—once approved, new information will be sent to families to consent
October	Data collection begins (data collection every 2 weeks; approx time spent by families is 20 min every 2 weeks—to be confirmed with citizen scientist) Meeting/contact with the citizen scientist to decide on final data analysis plans Ethical amendments will be submitted now the data analysis method has been selected
November	Workshop 2—half day <ul style="list-style-type: none"> ▶ Researcher led ▶ Reflection on the process ▶ Data analysis training ▶ Data analysis with citizen scientists ▶ Families updated by citizen scientists <i>Participant evaluation</i> Activity arranged—citizen scientists' choice. Family voucher
December	
January	Longer researcher check in to ensure citizen scientists are supported
February	Workshop 3—half day <ul style="list-style-type: none"> ▶ This and further workshops could be co-led with the citizen scientists ▶ Data analysis ▶ Discuss further research with peers ▶ Discuss data analysis with families ▶ Family update by the citizen scientists <i>Participant evaluation</i> Family and child voucher
March	Optional workshop to discuss peer citizen science study
April	
May	Workshop 4 <ul style="list-style-type: none"> ▶ Team-building activity ▶ Data analysis ▶ Decide next steps for the research—data dissemination including non-traditional formats <i>Participant evaluation</i> Activity arranged—citizen scientists choice. Family voucher
June	
July	Workshop 5 <ul style="list-style-type: none"> ▶ Team-building activity ▶ Data analysis ▶ Decide next steps for the research—data dissemination including non-traditional formats Participant evaluation Family and child voucher

different methods, surveys, interviewing, photovoice and journaling within the workshop to inform their chosen data collection method. In later workshops, if appropriate, families will be brought into the workshops to see the data analysis. The workshops have

been designed to be both accessible and engaging for children.⁷³

Optional study

Citizen scientists will have the option to design and conduct a wider research study to understand physical activity experiences among their peers (of all/any gender). There is potential for the citizen scientists to gain breadth of data and unique insights, given evidence that young people can be more open and willing to share experiences with peer researchers than professionals.⁷⁴ This optional study will be introduced in workshop three, and if the citizen scientists want to take it forward, they will guide the study's scope, reach and audience. Through this, the citizen scientists will learn further skills on how to plan and deliver a research project from the start, including first-hand experience of the academic ethics process.

Study two: data analysis

Citizen scientists will be introduced to different analytical approaches appropriate to the data collection method(s) selected, and will be supported to decide on an analysis method based on the options presented and their own ideas, and to undertake analysis of the data. Given the onerous nature of traditional data analysis approaches, such as thematic analysis,^{75 76} citizen scientist and their families' analysis is likely to take an adapted approach, such as producing stories or case studies from the data. We anticipate that citizen scientists will be involved in analysing data collected in the period in-between workshops, from workshop three onwards, taking a cross-sectional approach.

Alongside the collaboratively chosen cross-sectional data analysis, data will also be analysed using a trajectory approach; this approach has been decided in advance by the researchers to take full advantage of the longitudinal data. It is adapted from the idea of rivers of multilingual reading.⁷⁷ The citizen scientists will choose which data are to be included and how. At each workshop, selected data will be placed along the 'river' and the families will note links or changes over time. This process of displaying the snapshots from each wave together will allow for identifying critical moments.⁷⁸

Overarching participant experience evaluation

The research team will evaluate the process and impact of the citizen science approaches on participant experience across both studies.⁷⁹ The guidelines adopted in this research intended to promote a positive participant experience, outlined in the Patient and public involvement section,^{37 58 59} and inform the evaluation. Three data collection methods will be used: a body sort exercise, an individual reflection card and researcher observations. Any adaptations to the citizen science process suggested by participants and/or researchers, and agreed upon by the participants, will be implemented on an ongoing basis.

The body sort exercise^{73 77 80} will take the form of a workshop activity with the citizen scientists. Cards will prompt key participant experience elements (eg, power relations, inclusivity) in an age-appropriate format. Participants will be able to add further cards detailing other aspects of their experience. Participants will place cards representing their experience on the body outline, and engage in discussion around this. Within study one (the Study design section), the body sort exercise will occur at the end of three of the six children's focus groups, and parent-child dyad participants will be asked to attend a focus group to discuss their interview experience, at each time point. Within study two (see the Study one: contributory citizen science with primary-age children and their families section), participant experience will be evaluated at the end of each workshop and will encompass citizen scientists' experience since the last workshop. Citizen scientists will also have the option to complete an individual anonymised reflection card in case they do not want to voice their opinion in front of the group. A secondary researcher will collect participant experience data to mitigate social desirability bias.⁸¹

Researcher observations, which allow an independent record of events and behaviours to be captured in real time,¹⁹ will be conducted to inform evaluation of participant experience. Researchers will observe focus groups (study one) and workshops (study two). Observations will not occur within the parent-child dyad interviews (study one) to avoid creating a power imbalance between the researchers and the participants. The lead researcher will complete a reflexive research journal, focused on participant experience and improving our research to create a better participant experience.⁸²

ETHICS AND DISSEMINATION

The current study adopts and advocates for a bespoke ethical approach for collaborative citizen science projects. Training for the participants, alongside a flexible, responsive approach to changes made as the project develops, ensures the projects meet high ethical standards,⁸² for example, if tablets are to be used in study two, data collection training will be provided on data management for the citizen scientists. Ownership of the research is an important ethical concept.³⁰ Where information is to be disseminated, work will be credited to the citizen scientists while ensuring the participants' and their family's views on anonymity are respected. The collaborative citizen scientists are of an age where evidence suggests they can carry out a research project and express their expert knowledge.^{29 82-84} However, as researchers under the age of 16 years, their consent alone is not legally adequate, and parent or guardian consent must be provided prior to research participation. Given the status granted to the citizen scientists, it seems incongruous not to allow them to provide their consent to take part in the project.⁸⁰ As a result, to meet institutional ethical standards, both the children (citizen scientists) and their families will be required to give informed consent before any child's participation in the research. If any safeguarding concerns are raised as part

of the research project, the university's safeguarding procedures will be followed.

A key element of citizen science is acknowledging the voluntary contributions to research by citizen scientists, with debates on how this should be achieved.^{37 85} Within both studies, incentives are used to compensate participants for their time. In line with European Citizen Science Association's characteristics of citizen science, incentives differ according to the project context and type.⁸⁶ One of the key characteristics of citizen science is that it is a voluntary undertaking, and therefore there is a fine line between incentives and payment, which has been carefully considered.⁸⁶ There is an emerging call for diversity in citizen science projects, with socioeconomic status being a known barrier to participation.⁸⁷ To reduce the participants' economic situation as a participation barrier, travel will be kept to a minimum, with research being conducted locally and any necessary travel costs reimbursed. Within study two, if technology is a barrier to a family participating, JU:MP will provide reasonable equipment (eg, a tablet) and reimburse reasonable data transfer costs if needed. The progress and findings of the study will be communicated to the citizen scientists and families in various ways, for example, animated videos, and citizen scientists in study two will contribute to wider dissemination of study findings. Results will be published in peer-reviewed journals and summaries will be provided to the participants, through schools or directly.

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