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COMMENT

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# Cancer early detection research priorities in some underrepresented communities: a commentary of the learnings from a community priority setting project

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## Abstract

**Background and approach** Priority setting partnerships for health and social care, which aim to unite patient, professional and other stakeholder priorities for research don't always accurately reflect the views of underrepresented communities. Few have utilised community engagement methods. We expanded on an existing James Lind Alliance Priority Setting Partnership that asked patient, public and professional stakeholders what their top 10 research priorities were in cancer early detection. We worked with community partners to design and deliver an accessible and equitable community-based priority setting project that sought to understand the cancer early detection research priorities amongst underrepresented communities in Greater Manchester. This article reflects on and shares recommendations for future PSPs where community-led participatory methodologies are being considered. Participatory research priority setting activities were undertaken in four community sessions. Community-led activities with four partner community organisations were delivered across separate community ranking workshops involving 39 community members (92% Black, Asian and other ethnicities) and one action-planning workshop with 20 stakeholders, which brought community members, researchers, and community engagement practitioners together. Engagement methods were co-designed with community partners following recommendations from a power-sharing toolkit.

**Impact and learnings** This community PSP project developed a revised top 10 priority list for cancer early detection research along with new research ideas. An inclusive research action plan was co-developed to address key themes from across the workshops. The project empowered community members who had never been involved in health research before to contribute to research developments, to learn about health research, and become engaged within local community centres. Future projects considering the use of community engagement and co-production methods should ensure activities are co-developed with the relevant community-partner stakeholders and that there is enough opportunity to develop reciprocal relationships between researchers, organisations and members of the community.

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**Conclusions** Community engagement approaches to priority setting are valuable methods for engaging with underrepresented communities. Reciprocity and community-benefit should be at the forefront of these projects. We suggest a method for how future partnerships might choose to co-deliver community engaged priority setting.

### Plain English summary

Priority setting partnership (PSP) projects in health and social care research aim to bridge the gap between what members of the public feel is important compared with healthcare professionals, researchers and other stakeholder organisations. In 2019, a cancer early detection research PSP project was published in *Lancet Public Health*, which included a ranked top 10 list of research priorities for cancer early detection. This commentary article describes a follow-up community PSP that builds on the original PSP and aims to deliver an inclusive community-driven approach for priority setting in some underrepresented communities in Greater Manchester, England. This project was delivered in a collaboration with Vocal – an organisation which brings together people and health research for everyone's benefit – and researchers from the National Institute for Health and Care Research (NIHR) Manchester Biomedical Research Centre (BRC) Cancer Prevention and Early Detection Theme. Working with local community partners, we engaged with underrepresented communities who were not previously involved in the 2019 PSP and asked them to rank and prioritise what was important to them in cancer early detection. We used a community-engagement approach, co-producing and co-delivering workshops in local community settings. In this commentary, we reflect on our experiences of developing and delivering this alternative approach to research priority setting, which followed principles of power sharing, reciprocity, co-production, participatory methods and community-engagement. We share our lessons learned from the project and suggest ways in which future projects may wish to adopt this approach.

**Keywords** Public involvement, Co-production, Community engagement, Cancer early detection, Research priority setting, Inclusive research, Health inequalities

## Background

Across the globe, cancer is amongst the leading causes of death [1]. A diagnosis of cancer at the earliest possible stage leads to an improved chance of survival when compared to cancers detected at advanced stages [2, 3]. In the United Kingdom (UK), Cancer Research UK, NHS England and the National Cancer Plan [4] have announced their strategic ambition to detect three of four cancers at stage I by 2035 [5]. Efforts to improve the early detection of cancer are focused primarily on cancer screening tests and early detection tools, as well as encouraging help-seeking behaviours with early signs and symptoms of cancer [6].

Cancer early detection (CED) research is focused on developing innovative cancer detection tools as well as improving access to screening and cancer care to achieve national targets [4]. However, in order for these new early detection interventions and screening strategies to be successful, they must be meaningful and applicable to all populations and communities impacted by cancer [7]. UK research demonstrates the evidence of existing inequalities across cancer types including delayed diagnosis, later stage presentations and poorer health outcomes for Black and Asian groups and for people from socioeconomically deprived communities [8, 9]. It is important that new innovations in cancer do not exacerbate existing health inequalities and as such, inclusive research practices are necessary to understand and break down barriers to equitable cancer care [10]. It is well known that

participation in CED is disproportionate to the need across sociodemographic, religious and ethnically diverse communities [11–13]. In a bid to address some of these disparities in health research, community approaches to research and engagement are recommended to overcome barriers to participation in cancer research [11].

### Priority setting in health research

According to published priority setting research, there is inconsistency between the priorities of researchers and those of healthcare professionals, the public, patients, and carers [14]. In an attempt to address this, research priority setting partnerships (PSPs) aim to unite priorities for health and social care research [15]. The National Institute for Health and Care Research (NIHR) funded, non-profit organisation and the James Lind Alliance (JLA) specialises in the methodological orientation, design, and development of PSPs across the full spectrum of health and social care topics [16]. Published PSPs supported by JLA methodologists have included children's cancer research priorities [17], priorities for breast cancer surgery [18] and kidney cancer [19] amongst others. Priority setting activities (PSA) aim to connect researchers, healthcare professionals and the public.

Different methodological approaches to PSPs have been used previously, including surveys, in-person workshops, systematic reviews, Delphi questionnaires and consensus ranking [20]. The outcome of these activities provides guidance for funders to direct prospective

health research funding initiatives towards projects that are most important to the end users of that research [14]. This is particularly important in current cancer research strategy and delivery, as research funders are now involving patients in their funding processes and planned activities more than ever before [16].

### Reason for a community-led participatory priority setting project

In 2019, UK-based researchers led a PSP to produce a top 10 list of research priorities for CED research. The research aimed to understand CED research priorities from non-research stakeholders, including members of the public, patients, and carers [21]. This PSP work modified the nominal group method for research priority setting, which used online voting and survey methods (2 online surveys in total, comprising 554 respondents to survey 1 and 241 respondents to survey 2) followed by an in-person workshop (with 16 patient representatives and 12 health-care professionals) that sought to reach a

consensus on the priorities [21]. The output of this work produced a list of top 10 research questions for researchers and funders to prioritise for future CED research (attached in Table 1). Full detail of this PSP can be found in the Lancet Public Health publication [21].

Upon the completion of the 2019 PSP, outputs derived from the work were reviewed by a research advisory group of community leaders with experience of racial inequalities (the Black, Asian, Research Advisory Group [BRAG]), facilitated by Vocal and strategic partner of the NIHR Manchester BRC. Community advisory boards in health research facilitate research and community partnerships with the central aim of increasing representation and a diversity of voices within clinical research [22, 23]. BRAG presented three key recommendations to develop a more equitable PSP, presented in Table 2.

Recommendations from these discussions with BRAG included expansion of the existing work of the 2019 PSP, exploring CED research priorities amongst communities that the existing PSP had not engaged with. These

**Table 1** The 2019 Top 10 Cancer early detection research priorities (taken from Badrick et al., 2019) and aggregated rankings from community-led PSP project

|                      | 2019 Top 10 CED research priorities                                                                                                                                                           | Top 10 community-led PSP CED research priorities                                                                                                                                                                                   |
|----------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Research priority 1  | What simple, non-invasive, painless, cost-effective, and convenient tests can be used to detect cancer early?                                                                                 | Can a blood test be used to detect some or all cancers early, and how can it be included into routine care?<br>↑ moved up 1 rank from 2019 PSP                                                                                     |
| Research priority 2  | Can a blood test be used to detect some or all cancers early, and how can it be included into routine care?                                                                                   | What simple, non-invasive, painless, cost-effective and convenient tests can be used to detect cancer early?<br>↓ moved down 1 rank from 2019 PSP                                                                                  |
| Research priority 3  | Would increasing access to tests to diagnose cancer within General Practices improve the number of cancers detected early, and is it cost effective?                                          | Would increasing access to tests to diagnose cancer within General Practices improve the number of cancers detected early, and is it cost effective?                                                                               |
| Research priority 4  | What cultural, religious, gender (including transgender), and behavioural issues (including stigma associated with illness) prevent a person from reporting early symptoms of cancer?         | What cultural, religious, gender (including transgender), and behavioural issues (including stigma associated with illness) prevent a person from reporting early symptoms of cancer?                                              |
| Research priority 5  | How can genetic testing be effectively used to identify individuals at risk of developing cancer?                                                                                             | What is the best way to coordinate information between different health-care sectors and professionals to improve early detection of cancer?<br>↑ moved up 4 ranks from 2019 PSP                                                   |
| Research priority 6  | Can we use a cancer-relevant diagnostic tool (e.g., reminders in medical records) to help recognise patients presenting on multiple occasions with similar symptoms?                          | Can effective screening tests be developed for cancers we do not currently screen for (e.g. lymphoma, ovarian, pancreatic and prostate cancer)?<br>↑ moved up 1 rank from 2019 PSP                                                 |
| Research priority 7  | Can effective screening tests be developed for cancers we do not currently screen for (e.g., lymphoma, ovarian, pancreatic, and prostate cancer)?                                             | How can genetic testing be effectively used to identify individuals at risk of developing cancer?<br>↓ moved down 2 ranks from 2019 PSP                                                                                            |
| Research priority 8  | Can we use data from patients who have already been diagnosed with cancer to look for early warning signs that might have been missed or not investigated appropriately at first appointment? | Can we use a cancer-relevant diagnostics tool (e.g. reminders in medical records) to help recognise patients presenting on multiple occasions with similar symptoms?<br>↓ moved down 2 ranks from 2019 PSP                         |
| Research priority 9  | What is the best way to coordinate information between different health-care sectors and professionals to improve early detection of cancer?                                                  | Can we use data from patients who have already been diagnosed with cancer to look for early warning signs that might have been missed or not investigated appropriately at first appointment?<br>↓ moved down 1 rank from 2019 PSP |
| Research priority 10 | Can we predict how a tumour develops more accurately, and would this approach help to reduce unnecessary investigations and treatment (i.e., overdiagnosis)?                                  | Can we predict how a tumour develops more accurately, and would this approach help to reduce unnecessary investigations and treatment (i.e. overdiagnosis)?                                                                        |

**Table 2** Recommendations from BRAG to develop the existing cancer early detection PSP

| BRAG recommendation                                                                                                                                                                                                                      | Suggested community-engagement approach to address recommendations                                                                                                                                                                  |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| A community first approach is necessary to further develop this work by adopting a tailored engagement plan for the communities who were not part of the previous involvement and engagement conversations.                              | More time developing relationships with local community partners and co-designing an engagement plan would enable recruitment to workshops that included historically excluded voices.                                              |
| Greater ethnicity representation of participants was necessary in order to represent the diverse Northwest UK population. Participants in the 2019 PSP were 87% and 98% White in survey one and two respectively (Badrick et al., 2019). | Bringing the priority setting activities into the community, delivering activities in community-spaces and ensuring appropriate translation and interpretation services was suggested as a way of supporting activities.            |
| Efforts to increase accessibility to the survey design in order for participants to voice their CED research priorities was necessary, taking into account health literacy barriers to participation.                                    | A co-design modified community-led approach to the priority setting activities can create space for discussion. Interactive in-person activities enable community members to rank their cancer early detection research priorities. |

recommendations formed the rationale for the community-engagement project presented and reflected on within this article.

**Inclusivity in community engagement**

Community engagement is critical to meaningful involvement and co-design with those that the research serves to benefit [24]. Capturing the lived experiences of people, especially healthcare service users, leverages change by enabling healthcare organisations to look beyond traditional ways of understanding and changing healthcare services [25]. In health and social care research, community engagement is a vital component of the research cycle, enabling partnership working and shared understanding between researchers and communities [23]. The value of community engagement has gained significant traction in recent years, with research institutions and funders expecting research teams to engage with communities throughout the research process [26, 27]. Patient engagement models have increasingly become included within funding models and research design [28].

Members across local communities have historically had little voice in the agendas and prioritisation of health research that is being delivered to benefit them with research agendas often defined by funders [26, 29]. There are risks associated with poorly executed community engagement, for example not including a representative group of individuals to steer the direction of the research relevant to the population group [30]. Drawing upon the

recommendations put forward in Table 2, we co-developed a community-engagement approach to PSP that involved creation of intentional spaces for communities who had not been involved in the 2019 PSP.

**Aims and objectives of the community priority setting project**

The project presented in this commentary aimed to work in partnership with 4 existing community organisations to design and deliver a community priority setting project that built on previous prioritisation activities. The main aim was to rank the cancer early detection research priorities amongst underrepresented communities in Greater Manchester, England, specifically working with community organisations that support minority cultural, ethnic and socioeconomic communities.

Across a series of community ranking workshops, we aimed to ask people - who were not previously engaged with the 2019 PSP- their order of ranking of the top 10 CED research priorities (in Badrick et al., 2019). We also aimed to identify additional priorities missing from the top 10 list. A community-engagement approach intended to facilitate further time to build relationships, establish trust with community partners and members, and create spaces for people to rank the top 10 priorities for CED research. Following the completion of ranking workshops, we aimed to deliver a stakeholder action planning workshop that brought together public contributors of the project, community partners, community engagement specialists and cancer researchers to inform how we would embed the learning from this work into our cancer research infrastructures.

This commentary shares our learnings and practice on delivering a community-engagement research priority setting project.

**Methodological approach to participatory priority setting project**

**Community engagement**

Alternative to the first 2019 PSP which used the nominal JLA technique [21], our project adopted a community engagement approach to generating priorities. Community engagement allows for exploration of people’s experiences or perceptions of a particular health issue [31]. Qualitative methods used in engagement are argued to reduce the risk of under-representation of communities and can support meaningful interactions between community members and researchers [30].

Through discussion and dialogue with public contributors in this community priority setting project, we listened to people’s health values during discussions based on the top 10 CED research questions (Table 1). This approach relied predominantly on open discussion through interactive workshops. This enabled us to engage

meaningfully with local communities for the expanded priority setting project. This approach required creation of intentional and collaborative spaces within local communities which facilitated more in-depth conversations around the top 10 research priorities. This approach aligned with recommendations from BRAG which centred on spending more time with local communities in order to understand their CED research priorities.

### **Building on pre-existing relationships**

The project was delivered across a relatively short 6-month period (April to November 2022). A series of community-led workshops were co-designed and co-delivered with four local community organisations (Healthy Me Healthy Communities, Himmat, African-Caribbean Care Group (ACCG) and Wai Yin Society) who we had existing relationships with from previous CED and prevention projects, as well as through engagement and involvement initiatives led by Vocal. These four organisations supported community members from diverse ethnic backgrounds including Black British, African, Caribbean, South Asian and East Asian, and community members experiencing social and economic deprivation.

It was important to us and our community partners that we created opportunities to build on existing relationships, and to build cancer research capacity in the local community. A previous community research project, named Represent [32], which was delivered by some members of this team (HTU, BS) produced a roadmap to improve participant representation in CED research, centred on building trust and inclusion [7, 32]. We intended to leverage the learnings from Represent to develop inclusive methods for priority setting activities in health and social care.

We arranged in-person workshop planning meetings in the organisation's preferred working environment and held a collective planning workshop between all partners. However, establishing these relationships takes time, and it was helpful to be able to build on existing relationships held by the team and Vocal. It is important that these relationships are not transactional but mutually beneficial to the communities that our research/engagement seeks to service.

### **Co-design of ranking workshops**

The community ranking workshops were co-designed with the four community partners. We drew upon the work of Bridget Pratt's 15 principles of power sharing in community priority setting partnerships which include principles of sharing, being heard, compensation and space [26, 33], which highlights the importance of equitable and inclusive practices in community engagement in research priority setting. Pratt's work sets out the

groundwork for inclusive research priority setting with marginalised groups to develop meaningful research questions and topics [34, 35].

We used a designated project co-design workshop which was held with the community partner stakeholders. Co-design is known as the process of 'designing with and not for people' and can have a positive impact on communities, researchers and organisations [36]. We felt that embedding co-design across this participatory PSP project was vital to ensure that our approach was accessible and equitable to the community members taking part in the project.

Following the project design workshop, subsequent follow-up individual meetings were arranged with the community stakeholders to steer a collaborative approach to designing the community workshops. Accessibility and inclusivity of the ranking activities were key to ensure that public contributors had the space to understand, discuss, and rank their ED research priorities. This included the use of translated materials and the commissioning of a community translator via Wai Yin Society.

Decisions were made with community partners including structure of workshops, ranking activity method (using laminated cards with CED research prioritised printing in large text, including language translations), co-facilitators and local venues where people would be comfortable and felt a sense of ownership over the space. To support the structure and accessibility of workshops, community partners recommended that they co-facilitated the workshops with the support of the project team (HTU, RH). All workshops were held in the community organisation venue, as these were familiar and comfortable spaces for those choosing to attend the workshops. The decision for community stakeholders to co-facilitate workshops ensured shared identity, trust, and experience in the room [33]. Community stakeholders brought a '*reliable narrator and experience*' [33] to the room from their direct experiences.

### **Delivery of community ranking workshops**

Community contributors were recruited directly by the partner community organisations. Materials outlining involvement in the project were designed by the project team and shared with community partners for dissemination. These were translated into the relevant language as requested by community partners (e.g. Cantonese or Urdu). We intended to recruit people from all genders and across a range of ages and ethnicities. Demographic information was collected using a questionnaire, an approach previously shown to be feasible by Vocal [37].

Each community ranking workshop was delivered on a weekday and during a morning or afternoon slot, depending on the partner community organisation and members' preferences. Workshops lasted approximately

three hours, followed by an informal communal lunch. All participants received an honorarium payment for attending the workshops and had any travel expenses reimbursed, in line with NIHR and Vocal guidance at the time [38]. The guidance and payment rates for both the NIHR and Vocal have since changed [39, 40]. Community partners were also paid for all their time spent facilitating the project (including meetings, leading recruitment, co-facilitation, debrief). The Community Facilitators are already skilled professionals, expert at facilitating sessions with their communities. In this project their role was mostly pastoral, and they attended the sessions to support those who were taking part.

Clinical academics also attended the workshop to assist in answering community members' questions about the various CED research topics. All clinical academic facilitators were briefed beforehand (via a dedicated meeting) about the project aims and their role during the workshop. The academics received guidance from community engagement specialists throughout the project (HTRU, BS), which forms part of Vocal practice. Some also had prior experience of community engagement from other projects.

The session began by providing community members with information about the importance of early detection of cancer, and a summary of what happened in the 2019 PSP. This was delivered to the whole group and was limited to no more than 15 min to enable more time for deep conversation.

Then, time was spent as a group breaking down the questions line-by-line and the definitions of terms such as "overdiagnosis" of cancer. Across the four workshops, we iteratively built upon the new terms to discuss as we proceeded. Then, community members worked in pairs to discuss each of the 10 priorities and unpack meaning, supported by the facilitators and clinical academics who attended workshops.

Then as a whole working group community members came together to build a consensus on their top 10 research priorities for detecting cancer early. To determine priorities, we asked "what is the most important to least important?". In keeping this open approach, community members prompted each other during this group discussion to consider feasibility and their likelihood of accessing that service or CED test. If there was disagreement, this was discussed as a group, and members voted the final rank decision together. In the final part of the workshop, we asked community members if they felt anything was missing from the existing top 10 priorities. Community members engaged in this activity using post-it notes and pens to write down their thoughts as the ranking activities commenced. We then intentionally held time at the end of the ranking exercise, to ask

members if they felt any questions were missed from the top 10 list.

Materials used included large, laminated cards that detailed each cancer early detection research question, and these were placed on tables and were available in the dominant language spoken by the community members. We used a professional translation service to translate these materials, which were then checked by community partners ahead of the session. One workshop was held concurrently in Cantonese and English and facilitated by project team and Wai Yin team members whose first language was Cantonese whilst the project team facilitated conversations in English for those who did not speak Cantonese or who preferred to speak English. For the session with South Asian women, facilitated by Himmat, we did not require an Urdu translator as all women preferred to speak in English and have access to the written materials in English and Urdu. To support the flow of conversation during this workshop, we did not ask for English interpretation throughout. The project team (HTU and RH) debriefed with the co-facilitator at sub-sections across the workshop to gather the key messages from the conversation.

We did not record or transcribe word-for-word the content spoken by the participants of the workshops. This is because community engagement does not tend to adopt this approach, although research also shows there is little agreement in how to measure outcomes of community engagement [41]. The level of 'data' collection is also dependent on the level of involvement, effort and desired reach of engagement methods [42]. PPIE/community engagement is not qualitative research, and we would not routinely transcribe events. This project was a collaborative endeavour, with community participants as equal members of the team. The lead facilitators (HTU and RH) took notes during the group discussions to capture key conversations. Then, collated notes and post-it notes/paper completed by participants were combined onto a single excel document. Participants were encouraged to use post-it notes if this supported them to unpack what each question meant to them and their importance. In-between the workshops, HTU and RH populated the excel document with these notes and inductively categorised these using summative codes to support our understanding. For example, a post-it note labelled "the patient is also important in this" attached to the question "What is the best way to coordinate information between different health-care sectors and professionals to improve early detection of cancer?" was coded by RH and HTU as "patient role in cancer early detection". The purpose of this was not to conduct a formal qualitative analysis but to understand community priorities and to synthesise our discussions. Combining this information enabled high-level priorities to be generated across discussions

and from across the four community workshops. We found this approach useful in tying together the prominent conversations and topics raised across these workshops, these priorities then formed the processes used to inform the action plan that followed this work (see Sect. "Community-driven conversations can inform inclusive research action planning for research infrastructures").

Following discussion and consensus building from across the four workshops, the project team aggregated the rankings from across the workshops to form a final revised Top 10 research priorities for detecting cancer early, from a community perspective (Table 1, second column).

### Stakeholder action planning workshop

A final action planning workshop was held in November 2022 which brought together community partners, community members, cancer research clinical and non-clinical researchers, and public engagement specialists. During this workshop, we presented the outputs from across the community ranking workshops and devised an "Inclusive Research Action Plan".

## Outputs, impact and learnings from the community priority setting project

### Participants

Thirty-six community members and 5 clinical academic researchers took part in four community ranking workshops. In total, thirty attendees including community partners, community members, cancer research clinical and non-clinical researchers, and public engagement specialists attended the action planning workshop. All community members were residents in Greater Manchester. Most community members were from Black, Asian and other ethnicities (92%) and 87% identified as female. Community members were members of the public, carers, and healthcare professionals.

Working with community organisations that support minority cultural, ethnic and socioeconomic communities enabled the project to engage with groups who are often underrepresented in priority setting projects [33]. This was a key objective of the project and the rationale for delivering a community-engagement approach. However, fewer men were recruited and participated across the community ranking workshops than we would have hoped. This could have reflected the workshop approach which was delivered and facilitated by all females and offering a 'coffee and chat' which may have appealed more to women than men. Moreover, the workshops were conducted during the day and on weekdays. Whilst the partner community organisations were not gender-specific, this may have also impacted our recruitment of men to the workshops.

### Cancer early detection research priority rankings and discussions

Largely similar aggregated rankings were shown from the community priority setting workshops, when compared to the 2019 PSP rankings. Community members made decisions about the research priorities in terms of their lived experiences of accessing healthcare and cancer services. The top three ranked research questions chosen in this project aimed at increasing access to simple and non-invasive testing - similar to the ranking outputs from the 2019 PSP (in Table 1).

Overall, there were two research questions ranked differently between the two PSP projects. The first came from the priority question about use of genetic testing - "*How can genetic testing be effectively used to identify individuals at risk of developing cancer?*" - which shifted down to the 7th priority (5th in the 2019 PSP). Many community members perceived a low likelihood of being able to access genetic testing services for cancer; and many felt they would not be able to access these services at all. Discussions were also held on the ethical implications around use of genetic information.

The second main question with a different ranking was "*What is the best way to coordinate information between different health-care sectors and professionals to improve early detection of cancer?*", which was ranked higher (5th by this project) than the 2019 PSP (ranked 9th). Lack of trust in the healthcare system was a prominent discussion point that influenced this ranking, along with prior experiences of delayed health referrals.

We demonstrate that community-led engagement approaches to research priority setting can be used equitably to gain a consensus, and to a degree that traditional nominal PSP methods cannot. Intentional spaces should be provided that create time and space for community members to unpack and discuss research questions.

The clinical academics present at the workshops had varying expertise and backgrounds. Researcher bias may have influenced the discussions, particularly if additional information or disproportionate weight was given to community members. This could have shaped participants' decision-making, including the way they ranked priorities.

### More time was needed to expand on conversations that matter outside of the Top 10 Priority List

During workshops, we also asked participants from the outset of ranking if they felt that any research questions from the 2019 PSP were missing. Notably, we spent the final phase of the workshop focusing on this and therefore less time was given for community members to develop these - which likely impacted the outcome. However, in 2 of the 4 community workshops, following the consensus rankings of the top 10 research questions,

people also developed their own research questions that they felt were important but missing. The three community-priority questions, which notably were not ranked, that come out of these discussions included:

- What are the effective ways of increasing public awareness about the symptoms of cancer?
- How can community and engagement about cancer early detection with the public be improved?
- How can public awareness about cancer early detection be improved to help minimise stress and anxiety during a cancer diagnosis?

Due to the scope and focus of this community PSP on CED research, this meant that often the topics community members wanted to discuss, such as issues of access to care, were outside of scope and not discussed in depth. Despite access, trust and inclusion being a priority for community members, we often felt there was not enough time to discuss these.

In recognition of the limited time during community-ranking workshops to discuss and develop these research ideas, these were brought to a stakeholder action planning workshop for discussion with researchers, healthcare professionals and community members. The outcomes of this workshop recommended (as an action point) to dedicate future community engagement and research projects to further refine, develop and steer their own community-led research. More time is necessary to understand these issues across different underserved communities, as there may be further priorities that people wish to add. If future projects successfully develop these questions, this work will represent a full-circle of community-led research development, with community members at the heart, defining and developing their own research ideas for public benefit.

#### **Community-driven conversations can inform inclusive research action planning for research infrastructures**

The stakeholder action planning workshop was held to bring the learning and recommendations from this community PSP work forward into future related CED research projects across various research infrastructures at the local level. During the workshop, we developed our own “Inclusive Research Action Plan” which was to be embedded across the Cancer Prevention and Early Detection Research Theme (CPED) in the NIHR Manchester BRC, in collaboration with Vocal. The action plan comprised of three core actions to be carried forward as a result:

1. To strategically embed inclusive practice recommendations within the research and public involvement infrastructure in Greater Manchester.

2. To further develop community and researcher engagement across our CPED research and public involvement infrastructure in Greater Manchester.
3. To further investigate the questions developed as part of the community priority setting ranking workshops.

Embedding community stakeholder partners and the lived experience of local community members and partner organisations in inclusive research action plans ensures that the new strategic ambitions of the various research infrastructures (e.g., the NIHR Manchester BRC) align with community-needs. However, resource limitations may serve as a barrier to implementing these and in ensuring the longevity of new action plans. Often action plans are diverse and require multiple stakeholders to be accountable for different ambition targets. This is not to be underestimated if you are to ensure that equitable approaches to research are carried forward and embedded in everyday research practice.

#### **Projects must be driven by reciprocity and community benefit**

Traditionally, community engagement and patient and public involvement (PPI) has weighted greater importance on research benefit over community benefit [34, 43]. Demonstrated by the community impact of this project, we feel the need to change the narrative and culture of the reasons *why* we deliver these projects. We must prevent researchers parachuting into community spaces to benefit the research only. Whilst we are not moving away or ignoring the vital impact that community engagement and PPI have on the inclusivity, value, and morality of health and social care research [24, 25], it is important that projects consider how the consequences of these projects have direct impact on communities and individuals.

An example of the community benefit as a result of this project can be understood through the feedback provided by community members following workshops. Community members reported that they felt empowered following discussions to share all that they had learned about cancer early detection and the upcoming research amongst friends and relatives. We wanted to ensure that workshops were a space where community members felt empowered to learn about CED topics that were relevant to them. We did this by ensuring we had professional knowledge in the room (e.g. clinical academics) to answer questions, and by providing signposting and information resources to community members during and after the workshops.

We also learned that new members of the local community accessed new services as a result of taking part in the project. At all community ranking workshops,

community partner stakeholders were present to answer any questions about the organisation, including health and social care services that they provide (e.g. finding employment, accessing healthcare, family support, food and supplies). As well as community members accessing new services, people who took part in these workshops also became involved in other cancer-related research projects made accessible through Vocal's model of working both in research and in the community. An example of this can be seen in this feedback, which was shared during Vocal's evaluation of the project, from one community partner (SD) below:

*After a workshop, I had a conversation with a participant who had not been to the centre before and who was dealing with complex difficulties. As a result of this conversation, I referred them to several partner organisations for direct support and discussed other projects at the centre. The participant accessed financial and emotional support, went on to do several courses at the centre, and joined the foodbank. The participant went on to participate in a number of other health research projects, assisted in recruiting for them, and was trained to facilitate future workshops*

As well as supporting local residents, the project also promoted confidence of our community partners to co-facilitate research workshops. This felt especially important because some of our partners had not been involved in health research work before. Feedback from community partners included the importance of clear explanation of what is meant by PPI, to support explanation to local participants, as well as reducing the use of acronyms in meetings and workshops. Members of BRAG and community organisations who co-designed and facilitated the workshops are also listed co-authors on this manuscript. This has ensured the community-voice has been at the centre of our dissemination strategy and demonstrates a community co-researcher partnership [44]. Further feedback can be seen in the supplementary information (Supplementary File A).

Dissemination strategies should prioritise returning to the community to share findings in accessible, culturally relevant, and bilingual formats. Visual tools such as bi-lingual posters, infographics, or illustrated summaries could be employed to ensure participants understand the results, how their contributions have been used, and the outcomes achieved. For this project, we produced a one-page summary report of project outcomes, using plain language summaries and translation, and shared this with each of the community groups via online and face-to-face meetings. Community members also attended the action planning workshop.

Vocal acted upon the advice given by the community in both projects and developed an asset-based community priority setting approach in partnership with the James Lind Alliance Lab and Healthy Me, Healthy Communities that expanded the scope of a priority setting partnership to focus on local community health and wellbeing priorities instead of researcher or intuitional themes like early-cancer detection. The project solidified relationships between Vocal and Healthy Me Healthy Communities by creating the opportunity to run further in-depth PPI projects, such as Gorton Health Matters. Such projects empowered the local neighbourhood, involving local residents, community leaders, and health and community leaders – and providing a collaborative project to focus on the specific local priorities in the area.

Furthermore, the CPED theme researchers have continued their relationship with Healthy Me, Healthy Communities, Wai Yin and the ACCG. As of the date of this article, we are sad to report that Himmatt has closed and is no longer providing community services. Whilst returning to these organisations with a further PSA is likely not the appropriate response, it demonstrates the need for exploratory funding to build genuine, long-term relationships and cross agency partnership working.

#### **Methodological implications for future priority setting health partnerships**

This community PSP project demonstrates the value of using co-design and community engagement methods in research priority setting and for improving patient and public involvement and engagement methodologies [30]. Across this paper, we illustrate an inclusive methodology for research priority setting in historically excluded communities, as supported by other researchers in this area [43]. Key to the success of this community PSP project was the time spent building relationships in-person (i.e. via group and 1:1 community stakeholder planning meetings) which enabled a shared partnership and understanding across the project. We recommend community-embedded projects utilise a co-design approach when designing community-delivered workshops for research priority setting. We present the key principles of this project design workshop in Table 3, which may be translated to future community engagement projects. These principles reinforce existing community engagement principles of power sharing, reciprocity, co-production and participatory methods [25, 45]. Table 3 includes examples of how our project demonstrated these principles. We recommend future similar projects to ensure enough time is prioritised ahead of workshops to support community stakeholders to feel appropriately supported to co-facilitate priority setting workshops. Community engagement and co-production methods should ensure that enough time and space is given to the engagement

**Table 3** Principles recommended to be included in community-engagement project co-design workshops

| Recommendations for inclusion in project co-design workshops   | Talking points                                                                                                                                                                                                                                                                                                                | Illustrative example from this project                                                                                                                                                                                                                                                                               |
|----------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Participatory methods                                          | <i>How do we ensure our workshops feel collaborative and inclusive for all citizens that choose to attend?</i><br><i>How do we ensure our workshops are relevant and engaging to citizens?</i><br><i>How do we ensure all citizens feel involved and empowered to participate and contribute to sharing their priorities?</i> | We worked directly with community partners to decide activities such as using laminated cards and ensuring room space was adequate to move around the space. We translated our materials. We delivered workshops in the first-spoken language of citizens to ensure language did not break the flow of conversation. |
| Power sharing                                                  | <i>Who will lead engagement with community members? Did the previous model (if previously worked with organisation) work last time? What can we do to make sure the facilitation runs smoothly?</i>                                                                                                                           | We spend the time during the design phase to meet regularly with community partners to decide these and adapted our approach depending on feedback.                                                                                                                                                                  |
| Co-design: Developing community agreements                     | <i>How do we agree to work, behave and act together throughout this project, during workshops?</i>                                                                                                                                                                                                                            | We developed our own community agreements with community partners and introduced these at the start of each workshop. We asked citizens if there was anything they wanted to add to these before we started workshops.                                                                                               |
| Reciprocity: Community contribution, accountability and legacy | <i>How do we bring opportunities within this project? i.e. sharing information about studies that are recruiting, signposting to services</i><br><i>How can we ensure reciprocity? How can we build knowledge? How can add value to new or existing networks?</i>                                                             | We made sure there was time during each workshop for community partners to share information about their local services as well as for our team to share information about cancer. When that was not possible, we took away citizen questions and sought a response and shared this back with the community.         |
| Co-design                                                      | <i>How do we want to structure the ranking workshops? What might people find hard to unpack or challenge? What activities might allow someone to do that?</i>                                                                                                                                                                 | All community priority setting workshops were co-developed from the outset with our community partners.                                                                                                                                                                                                              |

methods adopted, so that the process is a true reflection of co-creation and the model of “Nothing about us without us” [46], authentically co-developed with communities.

However, this community PSP project was delivered over a relatively short period of time (6 months) which hindered the ability for broader engagement with certain community groups. If more time and resources were available, we would have engaged with male-specific community organisations in order to include their perspectives. Other underrepresented communities included the LGBTQIA+ community and people with long-term health conditions, mental health, physical and learning disabilities. We would have also planned additional workshop time for community members to further discuss priorities that they felt were missing. Future priority setting projects should consider factoring in additional time and resources to enable space for community members to discuss issues that are community priorities and influencing factors in priority setting but are outside of the scope of project objectives. These ethical dilemmas are common, and it is encouraged that community engagement in biomedical research should not dominate discussions based on instrumental goals over community-need [43].

The inclusions of the expertise of clinical academics supported learning and understanding of cancer-related topics during the workshops. If future priority setting projects adopt a similar approach, we recommend

consistency in explanations of the topics included in the questions. This is especially important to include in briefing with professionals that support PSAs to mitigate biases in the community ranking process.

Future community engagement and involvement for cancer research priority setting is required that creates the space and environment for men to rank their CED research priorities. Feedback from team members and community members at ACCG suggested that cancer and particularly prostate cancer was a culturally sensitive topic for men. This is an attendance trend we saw reflected across workshops. Our community partners advised that engaging men in these sensitive discussions about health and/or cancer would require working with established male only groups and in trusted settings where men are already comfortable with one another to speak about these issues. It is also important to consider that in mixed gender groups, some men or women may feel less able to express their views.

Previous PSPs have typically used nominal voting and online surveys for ascertaining research priorities, which may be less suitable approaches for research with under-served groups. Using a creative and interactive approach to ranking and prioritising research questions in this project enabled community voices that have been previously underrepresented in priority setting research to explore the meaning of research questions, discuss and make decisions about their priorities [47]. Co-developing these community ranking workshops in collaboration

with community partner organisations was also a vital process and effective methods for ensuring that we designed the space and environment to be as supportive as possible for community members to make these decisions. Delivering PSAs in the first language spoken by community members improves the flow of sessions and is a more effective way of priority setting and delivering engagement, rather than delivering in English and using interpreters. For reciprocal impact of health and social care engagement activities projects must ensure that signposting and resources are available throughout and after community engagement workshops, to support current and new service users access information and services.

Future research should include community and voluntary organisations as co-researchers or co-applicants within the project design. Such inclusion would demonstrate a commitment to genuine partnership, increase the real-world impact of the research, and avoid perceptions of researchers “parachuting” into communities without sustained collaboration.

## Conclusions and closing remarks

Community engagement can be a useful tool for priority setting partnerships in underrepresented communities. Activities should be co-developed with the relevant community-partner stakeholders and there should be ample opportunity to develop reciprocal relationships between researchers, organisations and members of the community. Outcomes of community-led priority setting projects can result in new research questions and inclusive action plans for research infrastructures. Reciprocity and community-benefit should however be at the forefront of research and engagement with groups who are typically historically excluded from these opportunities. Projects should consider how health inequity is impacted at the local, regional and national level for the health and social care area of focus. Removing hierarchical power must be fostered in these research and engagement environments to ensure that community members are able to make decisions about research priorities and feel supported to develop their own ideas.

## Abbreviations

|      |                                                 |
|------|-------------------------------------------------|
| PSP  | Priority setting partnerships                   |
| JLA  | James lind alliance                             |
| CED  | Cancer early detection                          |
| BRAG | Black and Asian research advisory group         |
| PSA  | Priority setting activities                     |
| NIHR | National institute for health and care research |
| HMMC | Healthy me healthy communities                  |
| ACCG | African caribbean care group                    |

## Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s40900-026-00943-z>.

## Supplementary Material 1

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## Author contributions

Funding acquisition: ET, RH, HTU, BS, EC and BS. Project inception and oversight: EC, BS, ET, AR, following recommendations from BRAG members (CS, NA). Workshop design, delivery and output generation: HTU and RH, with support of SD. RH led manuscript writing. SD led the writing of recommendations for working with community partners. All authors, including BRAG members (CS, NA) provided feedback on the manuscript and approved the final version.

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## Data availability

Data supporting this study are included within the article and/or its supporting materials.

## Declarations

## Ethics approval and consent to participate

Ethical approval was not required for this study.

## Consent for publication

Consent for publication was not required for this public engagement project.

## Competing interests

The authors declare no competing interests.

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