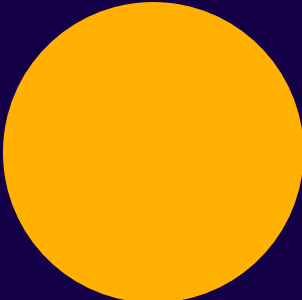
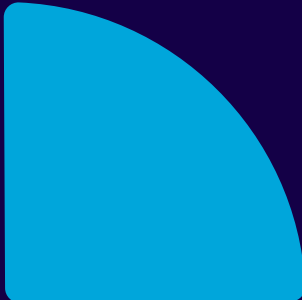
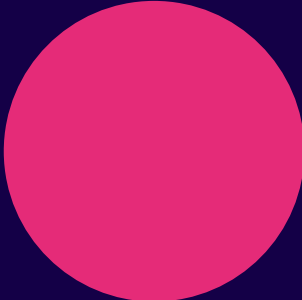
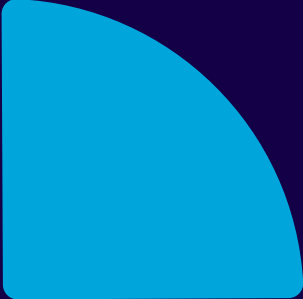
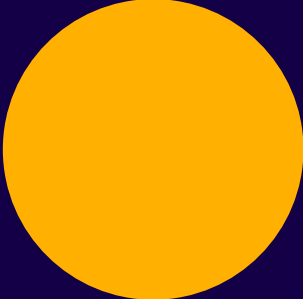


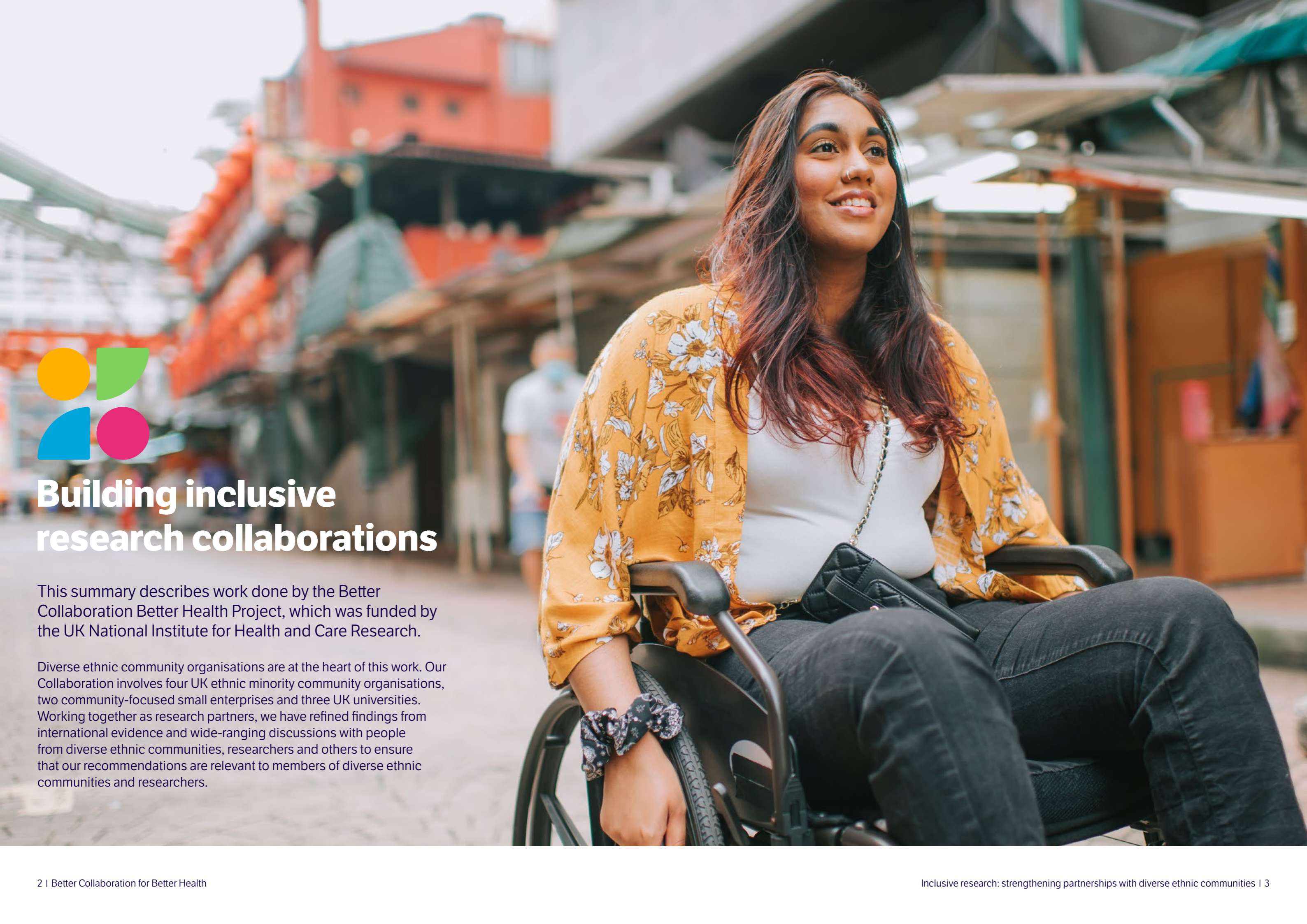
Better Collaboration for Better Health



Inclusive research: strengthening partnerships with diverse ethnic communities

A summary of the Better Collaboration for Better Health Project





Building inclusive research collaborations

This summary describes work done by the Better Collaboration Better Health Project, which was funded by the UK National Institute for Health and Care Research.

Diverse ethnic community organisations are at the heart of this work. Our Collaboration involves four UK ethnic minority community organisations, two community-focused small enterprises and three UK universities. Working together as research partners, we have refined findings from international evidence and wide-ranging discussions with people from diverse ethnic communities, researchers and others to ensure that our recommendations are relevant to members of diverse ethnic communities and researchers.

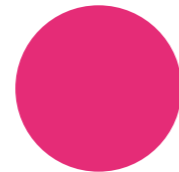
Supporting collaboration: key findings

Diverse ethnic communities and researchers want to work together.

However, there are real challenges to doing this, most notably linked to the availability and timing of funding. Reforming funding systems is the critical change needed to substantially increase collaboration between diverse ethnic communities and researchers.

In addition to funding changes, other recommendations included:

- Involving diverse ethnic communities from the very beginning of research.
- Ensuring that collaboration is an institutional responsibility, not left to individual researchers.
- Creating platforms for sharing research results and fostering partnerships.



Background

The purpose of health research is to improve the health of society. However, there is no shortage of evidence, underlined by, but pre-dating, the COVID pandemic that a great deal of health research ignores or forgets many in society. These groups become under-served by research and the delivery of health care that follows from that research. Diverse ethnic communities are among the groups under-served by research.

What we did

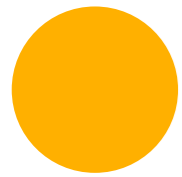
We did three things to explore how diverse ethnic communities and researchers can work together more effectively to design, run and report research that is rigorous and inclusive. Firstly, we looked at international research on successful, sustained collaboration between diverse ethnic communities and researchers. Secondly, we ran focus groups to hear directly from community members and researchers. Originally, we planned separate discussions, but our community partners suggested that bringing both groups together would be better.

Finally, all of this was discussed in two online meetings including members of our collaboration and people with no connection to the work. Draft recommendations were produced after the first meeting, and the final recommendations were agreed after the second meeting.



|| True collaboration means involvement from the very start.. too often we find that research bodies just helicopter into communities and expect instant engagement.. And it doesn't work like that because first you have to build up the trust of community members. ||

—CEO of charity organisation



What we found

Our review of international research found 18 studies, most of which were from North America. From these we found that strong partnerships include diverse, representative members who share power and build trust. Trust grows when partners acknowledge power imbalances, respect cultural differences, and communicate openly. Successful collaborations also require flexibility, clear guidelines, and regular evaluations to ensure effectiveness. Fair resource-sharing and building research skills within communities helps to sustain long-term partnerships.

We then spoke to people, 61 in total, who were a mixture of members of diverse ethnic communities and researchers. Participants highlighted many challenges to collaboration. Communities feel excluded, researchers lack cultural awareness, and engagement is often rushed. Research is inaccessible due to location, digital barriers, and unclear ways of participating. Crucially, funding issues limit involvement—travel costs, unclear payments, and lack of funding for translation and early engagement. Language barriers, distrust, and past negative experiences add to the challenges. Short funding timelines and rigid research structures make long-term collaboration difficult.

Members of our collaboration, as well as people with no connection to the work, met on 7th and 28th Nov 2024 to discuss these findings. By the end of the second meeting we had eight recommendations for which there was universal agreement.



Recommendations 1 to 3: funding and incentives for collaboration

The table below shows the eight recommendations, together with a justification for why the recommendation is important.

Recommendation 1: adjust research funding structures

Current funding systems are a major structural barrier to collaboration between researchers and diverse ethnic communities. Changes are needed to:

- Provide pre-award funding to support the co-design of research.
- Simplify direct and timely payments to both community organisations and individuals.
- Ensure sustained collaboration through funding mechanisms independent of individual projects.

Justification	<ul style="list-style-type: none"> • Trust-building is essential for collaboration but takes time and effort, which require funding to sustain relationships and fund agenda-setting and co-design work. • Early-stage co-design work is underfunded, leaving institutions and community organisations without resources to engage effectively. • Current payment models, such as payment in arrears, do not work for community organisations that lack the financial capacity to cover costs upfront.
Possible Alternative Funding Models:	<ol style="list-style-type: none"> 1. Block grants for institutions and community organisations to support pre-award co-design. 2. Pre-award funding for promising ideas at the expression of interest stage. 3. Seed funding and proof-of-concept schemes with minimal application and bureaucratic processes. 4. Participatory budgeting or community commissioning to empower community organisations. 5. Universities reallocating resources for pre-award collaboration, potentially with funder support.

Recommendation 2: mandate collaboration through funding

Funding requirements should mandate collaboration with diverse ethnic communities, supported by clear evidence of involvement in proposals.

Justification	<ul style="list-style-type: none"> • Researchers are motivated by funding conditions; requiring collaboration would make it a standard part of research design. • Financial support must accompany these mandates to ensure feasibility. • Researchers need guidance and resources to help them engage effectively.
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Recommendation 3: understand community motivations

Researchers must work closely with communities to **understand what motivates** participation beyond financial incentives.

Justification	<ul style="list-style-type: none"> • Trust and sustained collaboration require understanding community priorities, such as addressing relevant research questions and delivering results that matter to them. • Non-financial support, such as training or access to institutional resources, can strengthen relationships. • Sharing results with communities fosters trust and demonstrates the value of collaboration.
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Recommendations 4 and 5: responsibility for collaboration

Recommendation 4: institutionalise collaboration

Collaboration with diverse ethnic communities should be an institutional responsibility not only reliant on individual researchers.

Justification	<ul style="list-style-type: none"> • Current collaborations often depend on the enthusiasm of individual researchers, making them vulnerable to turnover and burnout. • Institutions should allocate resources for sustained relationships with communities, rather than relying on project-based funding or one-off opportunities. • Recognising collaboration as a key part of academic career progression would incentivise researchers to engage meaningfully.
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Recommendation 5: improve researcher training

Training is needed to build researchers' confidence and skills in working with diverse ethnic communities.

Justification	<ul style="list-style-type: none"> • Researchers often lack the skills and resources to engage communities effectively. • Training should cover intersectionality, anti-racism, and the systemic barriers faced by ethnic minorities in research. • Community organisations should be involved in training delivery, potentially alongside researchers or research facilitation staff, and compensated for their contributions.
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Recommendations 6 and 7: developing research projects

Recommendation 6: engage communities early

Diverse ethnic communities should be involved in research design from the very beginning and throughout the entire research and dissemination process.

Justification	<ul style="list-style-type: none"> • Current practices often involve communities late in the process, limiting their ability to influence research design. • Early involvement ensures that diverse perspectives are considered and that the research addresses relevant issues. • Sharing results directly with communities enhances trust and demonstrates the impact of their involvement.
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Recommendation 7: enable community leadership

Community organisations should have the opportunity to lead or co-lead research projects.

Justification	<ul style="list-style-type: none"> • Community organisations often have higher levels of trust and better insights into community needs than researchers. • Current funding mechanisms favour researchers as leaders, which can marginalise community voices. • Allowing community organisations to lead projects could enhance participation and relevance.
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Recommendation 8: bringing researchers and diverse ethnic communities together

Recommendation 8: create a collaboration platform

A platform should be developed to connect researchers and diverse ethnic communities and facilitate the sharing of research results.

Justification

- Both researchers and community organisations often struggle to identify who to approach for collaboration.
- A platform would simplify connections, showcase available expertise, and promote community organisation involvement in analysis and dissemination.
- Sharing results through the platform would highlight the impact of collaboration and acknowledge community contributions.

Our collaboration



Relationships have to be built – we need to invest in that both monetarily and through our time.

— Public and Patient Involvement Lead



Conclusions

Diverse ethnic communities and researchers want to work together, but there are real challenges to doing this at present, most notably linked to the availability and timing of funding.

Without tackling funding issues (Recommendation 1), progress towards more effective and sustained collaboration between diverse ethnic communities and researchers will be limited.



Would you like more detailed information?

You can send us an email and we will be happy to answer any of your questions: info@trialforge.org

Similarly, you can also visit our website at trialforge.org/trial-diversity/bcbh/

Better Collaboration
for **Better Health**

