[Evidence to decision framework](file:///C%3A/Users/aox/AppData/Local/Microsoft/Windows/Temporary%20Internet%20Files/Content.Outlook/A5320PQD/EtR%20Explanations%202012%2009%2005%20ado.docx) - health system and public health

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| How important are the partners themselves and the partnership, its management and conduct to routine collaboration between researchers and voluntary sector community organisations and individuals from diverse ethnic communities? |
| ***Problem:*** Collaboration between researchers and diverse ethnic communities is often short-lived***Factors influencing success:*** *the partners and the partnership****Main outcomes:*** continued collaboration***Setting:*** UK***Perspective:*** Population | [***Background***](#_top)***:*** A key purpose of health research is to improve the health of people in society. However, health research often ignores or forgets diverse ethnic communities and these groups become under-served by research and service delivery that follows from that research1-4. Engaging people from diverse ethnic communities or organisations in the research process helps ensure the needs, interests and unique perspectives of diverse ethnic communities are included in health research and subsequent health-service delivery. Various factors, however, often prevent meaningful collaborations between researchers and people from diverse ethnic communities. Identifying and overcoming these factors is an important research and social equity priority. |

|  | [research EVIDENCE](#Evidence) | [ADDITIONAL CONSIDERATIONS](#Information) |
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| PROBLEM | **The Better Collaboration Better Health rapid review**The BCBH rapid review of 18 included studies reporting on 17 partnerships. Most collaborations occurred in the United States (n=13); 2 in Canada, 1 in Australia, and 1 in the United Kingdom. The studies represented the views and engagement between researchers and people identifying as Black, Hispanic, First Nations, Inuit, Aboriginal and Torres Strait Islander, and Chinese American ethnicities. The ethnicity of the researchers was mostly not reported.The review identified **the partners themselves** and **the partnership, its management and conduct** as key to a successful long-standing community-based research partnerships based on a study by Brush et al1. Our review work allowed other domains to be captured but these two – the partners and the partnership – remained as the two most important headings.Key takeaway messages for ***the partners themselves***: 1. **Characteristics of partners**

Various interrelated partner characteristics are described as being important to successful collaborations between researchers and people from community-based and diverse ethnic groups. In particular, successful collaborations are facilitated when everyone, academics and community members alike, are inclusive and diverse and bring their skills and experience to the proposed research. Additional elements of positive long-term collaborations include empowering and engaging partners at all levels (particularly community-members) and sustaining established relationships.1. **Relationship among and between partners**

Positive relationships between partners are facilitated when everyone acknowledges each other's experiences and power imbalances, adopts an open and transparent approach, recognises each other's priorities and pressures, and embraces cultural differences. Trust is perceived as a key element on which to build and develop successful collaboration.Key takeaway messages for **the partnership, its management and conduct:**1. **Partnership characteristics**

Strong communication and high flexibility in partnership roles and the way research is conducted appear to be important indicators of long-term collaborations. Both these elements appear rooted in the aim of fostering respectful and inclusive collaborative research, which is responsive to community needs.1. **Partnership processes**

Structures appropriate to the needs of the partnership and clear guidelines and procedures to which all partners must adhere are elements of successful long-term partnerships. Regular evaluations of the partnership processes may be regarded as a way to enhance and strengthen the partnership and identify what works well and what does not.1. **Partnership resources**

The success and sustainability of long-term partnerships are linked to the way resources are fairly managed and shared throughout the partnership.1. **Partnership capacity**

The success and sustainability of long-term partnerships are linked to activities aiming at building research capacity among partner members.**The Better Collaboration Better Health focus groups****Key takeaway messages for *the partners themselves***The BCBH interviews suggested that partners need to have a shared idea of what collaboration means, including the partnership being one of equals, all members playing to their strengths and researchers really listening to public members. The research team needs to recognise that lived experience shapes how a person views the world, and that should influence the research. There should be a shred understanding of an outcome everyone is working towards.**Illustrative quotes:***“it's all about equal partnership, really, isn't it? And everybody playing to their strengths and everybody understanding and recognizing what everybody else is bringing to the table and being open enough to listen. [..] This is the whole unconscious bias and everything, isn't it? That I think we all go in with our own perceptions and so constantly challenging yourself.”**(R06, programme grant holder, clinical trialist/methodologist)**“Collaborating with me just feels like what we're doing now, which is just local people with researchers just expressing our views and hopefully we get listened to.”**(MBME C7 DEC participant, no previous involvement in health research)* *“Erm... Collaboration just means working... Not on our own, but working with other people who are involved in, or wants to be involved in the same project as yourself. Erm, you know, whether near or far. It's a matter of just working together with other people to have an outcome.” (MBME C7 DEC participant, PPI member)***Key takeaway messages for** ***the partnership, its management and conduct***Interviewees valued collaboration and say benefits for both research and for public contributors. There was discussion around funding, and access to it and handling this was an important part of partnership management. How to make a partnership sustainable, and how to offer something to public contributors beyond the direct research collaboration was raised as a challenge by researchers. How to make connections was a challenge, especially for researchers at the start of their careers. Experienced researchers highlighted the difficulty of changing their own way of working/thinking given the demands of other research and clinical activities.Finally, lack of diverse ethnic community members in public advisory committees for research.**Illustrative quotes:***“It helps our community because it's been identified that there are health inequalities and the number one on the list is in the black community. And there's evidence now to prove that. And now because they're participating and engaging in research, .... It leads to government being able to, you know, put in more funds because the researchers can have the data that is needed. So it encourages government funding into ...certain areas so that's a benefit.” (CAHN DEC FG participant, PPI member)**“...whenever we do the budgeting so there is a lot of budget we have to uh separate for the PPI activity but like again uh and because you need the feedback for your research so you cannot avoid that cost because if you are doing the research on minorities, you have to pay them some cost and it is increasing your budget but still ...what you get in the results ... in return you get the results which you are looking for.. [..] ...we have to pay like so much ...cost for ...child care activity and which is the highest cost ...we are paying for the PPI activity ...their transportation cost and all this stuff so yes the cost is there uh but uh it gives the result as well” (EHFP03 Researcher FG participant)**“But I think from our, from my perspective, my personal perspective was when the intervention was over, that was over. And we hadn't built in a way of offering support to those people from the community to then take the next step to whatever they wanted to do because they became involved for a particular reason. [..] And I think sometimes there's not enough funding to be able to support people who getting from the local communities who get involved in research onto their, you know, their next steps. (SAfH Researcher FG, research fellow)**“...well the challenges is engaging, ...and also when you have ...research activities are something on top of clinical activities. I'm also a practicing GP, so I know the time the moment I step in the practice and the until the moment I step out (there )is always this anxiety that you have so many tasks coming to you and parallel thing you know you have to keep track of different (things) and you have ...on top of that research activity. “ (R02, programme grant holder, academic GP)**“I'm very, very much at the beginning, ...But I suppose my problem is, is that I haven't identified exactly what communities yet. So a lot of this is sort of thinking anecdotally ... at my the people who have participated so far and thinking, OK, is that reflecting the patients we're seeing coming through our critical care. So the first part will be the sort of interrogation, identifying who these communities are. But I'm starting to try and put the feelers out in in the area for the populations that we know make up the mix of Tower Hamlets and North East London and sort of understand even how I would go about engaging with those communities that sort of make up our ...community. And even that step is quite challenging.” . (SAfH Researcher FG, new to research)**“No, no, I was just going to say that it's, it's just pragmatic, isn't it because you get, the funder calls are very short, you're trying to put in things very quickly, and so ..you go with what you know and that that possibly means that you always get the same opinion because there might be one or two people who on your university's PPI group that fits specific like demographic criteria for whatever thing you're looking at.” (SAfH Researcher FG, researcher starting a PhD)* | Two groups of researchers and members of diverse ethnic communuties discussed the Better Collaboration Better Health findings on 7th Nov 2024. Their key insights are listed below. ‘GP1 signifies contributions from Group 1 and ‘GP2’ contributions from Group 2.* A challenge to greater collaboration is that, from the perspective of many in diverse ethnic communities, researchers don’t want to collaborate with them [GP1]. Doing research is a path for academic career development, and working with diverse ethnic communities may slow down or risk career progression. [GP1].
* Historically, the relationship between researchers and diverse ethnic communities has been that researchers have ideas and then they consult with communites about them: this needs to change. Diverse ethnic communites have ideas too, and are in a good position to know what the communities they represent might want to see covered by research. The assumption that only researchers have ideas needs to change [GP1]. Community oirganisations can be a bridge between diverse ethnic communites and researchers [GP2].
* There is some mistrust around how data will be used, in particular how others might use the data against diverse ethnic community groups [GP2].
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|  | [research EVIDENCE](#Evidence) | [ADDITIONAL CONSIDERATIONS](#Information) |
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|  BENEFITS & HARMS OF THE FACTORS | **The Better Collaboration Better Health rapid review**The information identified within the BCBH review **was unable to quantify the size of benefits (or downsides)** of including or not including individual components that were linked to successful collaborations. In other words, links with success were found, but not how large their contribution to success may be.Nine indicators of success were mentioned more than 10 times across the 18 studies. In order of times mentioned these were:1. The partnership has structures to support processes
2. Partners recognise pressures, priorities and worldviews
3. There is effective communication
4. Diverse and representative partners
5. Partners are aware of power imbalances
6. The partnership has capacity to increase research
7. Partnership resources are allocated fairly
8. The partnership has clear and explicit guidelines for operation
9. Actively engaged partners

The review concluded that the success 'of long-lasting collaborations is a multifaceted concept which includes a combination of ingredients. These ingredients cover various domains and sub-domains of the partnership. While it is difficult to provide a list of the most important indicators of success, some of the most salient indicators appear to be trust, mutual respect, consideration of cultural differences and power imbalances as well as taking partners' perspectives and needs into consideration when defining roles and processes. Underlying all of these elements and processes is the understanding that successful collaborations require time to build, operate and thrive, as well as resources to support people’s time and activities.’**The Better Collaboration Better Health focus groups**The interviews highlighted better research done by researchers and better understanding of research and health conditions by public contributors as key benefits of better collaboration between researchers and diverse ethnic communities. Collaboration was rewarding. There were many suggestions for how to improve collaboration between diverse ethnic communities and researchers– see table on next page. **Illustrative quotes:***“I have to say ...because I was present in two of the three focus group, we ran to develop the intervention and (it) was so rewarding to be in that you know we had White British, we had different ethnicity, we had a ..computer scientist and then we had ...unemployed people from different background. We had a very good representation of black people as well and (it) was very good to ...have everybody in the room to have the PPI (co-applicant) who was co facilitating and really putting everybody at ease ...You really enjoy it as a researcher to be in that environment when you see something, you know it's something special. ...you know to to be able to hear all these different point of view”. (R02, programme grant holder, academic GP)**“It helps our community because it's been identified that there are health inequalities and the number one on the list is in the black community. And there's evidence now to prove that. And now because they're participating and engaging in research, .... It leads to government being able to, you know, put in more funds because the researchers can have the data that is needed. So it encourages government funding into ...certain areas so that's a benefit.” (CAHN DEC FG participant, PPI member)***Suggestions for how to foster greater collaboration between diverse ethnic communities and researchers.**

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| **DEC participants including PPI leads working with researcher academics** | **Researcher participants** |
| ***Bridge between DEC and researchers******People**** PPI working groups within institute level
* Community champions
* Faith leaders, school governers, community organisers, community councilors
* Acting as a midpoint between researchers and DEC

***Place**** Target key locations of people/community you need for your research (cost-saving and time-saving)
	+ Bespoke spaces to avoid work seeming tokenistic
* Invite community organisations to you as part of engagement work (shows respect)
* Work with smaller organisations
* Think diverse places/settings e.g. go to community, invite into research environment

***Making research/research opportunities accessible to members of the public**** Raise curiosity (education) of people
* Be flexible e.g. have drop-in sessions, workshops for people to register interest, give advice/feedback
* Have people from the community to discuss the research

***Resources to support better collaboration**** Be flexible e.g. offer hybrid option
* Interpreters
* Open lines of communication
* Time and funds to build relationships

***Funding******For individuals**** Reimbursement provision for any engagement events
* Reimbursement for involvement work
* Incentives to support people with other commitments e.g. childcare

***For organisations**** Recompense the smaller organisations

***For researchers**** Access to more funding so they can do more research work with DEC

***Strategies for doing better collaboration**** PPI/DEC involvement in early stages, within study design, right till the end (ensure representation)
* Do research on a community/community organisation on how best to engage, to collaborate
	+ Understand need of people/community
* Manage expectations of community/people, have ‘honest’ conversations
* Connect, establish relationships with community gatekeepers – understand their stance on research in general and work up
* Research needs to resonate with community gatekeepers so they think it’s worthwhile/trustworthy to engage/inform their community
* Give feedback to communities
* Use culturally sensitive approaches/be respectful of culture e.g. when going to mosque
* Show that the time offered by people is valued, value the experience shared by people; be open to feedback and opinions
* Celebrate with the community outside of the research

***Language**** Use language that people can understand
* Ensure meaningful dialogue e.g. lazy Q&A
* ‘Research’ label can be off-putting for many communities

***Training (for engagement work, involvement work)**** Cultural competency training/training in inclusive research for researchers
* Viewing peers do involvement activities
* Offer training to community champions
* Researchers to have better understanding of functions of ‘engagement’, ‘involvement’ instead of lumping them together
* Relationships need to be maintained throughout the research cycle (with time and funds in place)

***Accessibility/wider considerations*** * Diversity more in ethics/governance committees
* Wider advertising of research and its benefits in general/Normalise research in society via diverse places e.g. schools
* Platform for people access filtered information – will help to build trust
* Focus research on societal problems and marginalised groups
* Have diverse research teams
 | ***Bridge between DEC and researchers******People**** Patient/Public Advisory Groups/PPI Co-Applicant
* An advocate to act as a bridge between DEC and researchers
* Someone to lead patient and public engagement
* Community champions/people with connections / People who can facilitate building of relationships over long term e.g. community leaders

***Place**** Build on things already in place e.g. community centre, place of worship and then spread awareness about research
* Hold engagement events (while awaiting Hub)

***Resources to support better collaboration**** Time and expertise to build relationships
* Need for flexibility among researchers
* Materials needed to be thought up front

***Funding**** Funding limitations ‘self-made’ - cost the PPI/DEC involvement appropriately (depends on how important PPIE is viewed)
	+ Clear budgeting and appropriate budgeting
* Dedicated allocated funding to be available for early career researchers to carry out engagement work
* Division of budget between community organisation and university/grants held at community level can have benefits in the long run

***Making research/research opportunities accessible to members of the public**** Sharing of information/knowledge/opportunities e.g. through varying participation initiatives
* Dissemination of findings beyond academia (newspapers/magazines /to organisations)
	+ Also contributes to the destigmatisation of conditions/participation in health research

***Language**** Use language that people can understand

***Strategies for doing better collaboration**** Researchers need to make themselves more accessible to DEC
* Early involvement of PPI to get things right at the beginning (ensure representation)
* Efficient and prompt communication between research team and participant (i.e early stages of recruitment, early engagement)
* Plan properly, set agendas
* Better understanding of what both groups want and then prioritise
	+ PPI involvement different when studying different conditions (i.e Dermatology vs Maternal Health)
* Address barriers e.g. language
* Recognise the work of the community – feedback to community, provide certificates, acknowledge in scientific publication
* Use of PPI tools/framework e.g. PIRIT tool (Public Involvement in Research Impact Toolkit)

***Use of engagement framework**** Understanding the Six (Gender, Generation, Geography, Genes, God and Gap in Knowledge)

***Quick win (when less time)**** Access an existing PPI pool and seek advice
* Access established networks, experience of peers

***Training and shared knowledge/learning among researchers**** Researchers should collaborate their efforts to facilitate more collaboration between DEC and researchers
* Piggyback on contacts made with local communities generated by another research team (particularly supporting early to mid career researchers)
	+ Provides reassurance, community organisations are ‘trusted’
	+ Creation of a network/hub to avoid recreating same wheel e.g. network led by community organisations badged by NIHR
* Build a community of practice e.g. diversity in PPI groups, build links with community at the outset
* Carry out more inclusive research

***‘Hub/Network’ of resources between researchers (i.e. clinicians to signpost patients, researchers to link with community organisations/DEC, participants for support groups)**** benefit of hubs/networks (however tight deadlines)- supporting early to mid career researchers

***Accessibility/wider considerations**** Raise (wider) awareness of research
* De-mystifying research/normalising participation in research e.g. via charity collaboration
* Dissemination of findings in terms anyone can understand
* Research topics needs to come from the community (currently from NIHR)
* Changes in university infrastructure to ensure timely payment
* Changes in research culture to consider diversity at all levels (and should not be down to lone researcher)
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There was no real downside or harm of increased collaboration mentioned, apart perhaps from time and cost. | Two groups of researchers and members of diverse ethnic communuties discussed the Better Collaboration Better Health findings on 7th Nov 2024. Their key insights are listed below. ‘GP1 signifies contributions from Group 1 and ‘GP2’ contributions from Group 2.* The value of participation/collaboration is not always clear, or made clear, to diverse ethnic community members [GP2]. This is not just, or even mainly about money, this is about making the shared goal clear to everyone, what the benefit to the community will be [GP2]. The end point needs to be important to everyone [GP2].
* Researchers often do not share the results of collaboration with the communities involved in that research, or acknowlegde the contribution made by communities. This needs to change [GP1].
* Communities need to know what the impact of collaboration has been, what happened, what has changed [GP2].
* Researchers often do not know why they want to talk to members of a particular community [GP2]. Researchers also need to make clear whether they are looking for an individual’s perspective, or a community perspective [GP2].
* Researchers could support diverse ethnic communities by sharing expertise they have beyond a particular research topic, for example by upskilling e.g. by developing skills in Excel, or other software. Or bringing general information and resources about a clinical area to support people with that condition. In other words, don’t just come with questions but give something back too [GP1 & GP2].
* Once collaboration is started, communication needs to be regular so that everyone knows what is happening. Expectations of what is possible in terms of e.g., change need to be clear to everyone from the start of the collaboration [GP1].

Two groups of researchers and members of diverse ethnic communuties discussed the Better Collaboration Better Health draft recommendations on 28th Nov 2024. Their key insights are listed below. ‘RGP1 signifies contributions from Group 1 and ‘RGP2’ contributions from Group 2.* The discussion about greater collaboration between researchers and diverse ethnic communities has been going on in the UK since at least 1994, without real change. Hopefuly this time things will be different [RGP2].
* Researchers should do more public engagement. It’s a way to start a conversation with different groups and it doesn’t need a lot a funding. It is part of making research more diverse [RGP1].
* The recommendation about a platform is exciting, but perhaps a longer-term aim [RGP2].
* Involvement of community organisations needs to include not only planning, but analysis, writing and publication. Involvement in these tasks is less frequent [RGP2].
* Recommendation #8 shouldl also include a push to involve community organisations in analysis, interpretation and publication RGP1+RGP2 summary discussion].
* Community organisations need to be involved in setting research agendas, not just to inform design [RGP2].
* There can sometimes be a tension between what drives researchers (e.g., getting a publication) and what community organisations have to do (e.g., run a food bank). The published output may not be as important, there is a day job to do [RGP2].
* It is important to make sure expectations are matched. Is a person bringing lived experience to a discussion, or there to represent a community? Some people may be more comfortable with one than the other, or it may be just oen of these that is needed. Everyone needs to be clear what expectations are [RGP1+RGP2 summary discussion].
* The recommendations are likely to carry more weight if NIHR [National Institute for Health and Care Research] is behind them rather than them coming entirely from community organisations and researchers [RGP1+RGP2 summary discussion].
* The recommendations ought to say something about what the recommendation means for different types of people (e.g., researchers, community organisations, funders) [RGP1+RGP2 summary discussion].
* The use of language in the recommendations would need to be looked at to ensure that as many groups as possible, especially funders, could take them on board. Funders would need clarity around what more could they do to support researchers and community organisations? Many funders may think that they have done this already. It might also be tricky to suggest recommendations that work across all funders, or even all parts of a single funder [RGP1+RGP2 summary discussion].
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| VALUES | **The Better Collaboration Better Health rapid review and focus groups**The BCBH rapid review and focus groups took the value of improved collaboration as a given. The research question was not whether it is valuable, but how to make long-term collaboration between researchers and diverse ethnic communities more likely.  | Two groups of researchers and members of diverse ethnic communuties discussed the Better Collaboration Better Health findings on 7th Nov 2024. Their key insights are listed below. ‘GP1 signifies contributions from Group 1 and ‘GP2’ contributions from Group 2.* There were no specific comments on values.
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| COSTS | **The Better Collaboration Better Health rapid review**The review did not aim to identify concrete costs of improved collaboration. Collaboration clearly has a cost though and one of the key indicators of success for long-term collaborations was fair allocation of the available resources. **The Better Collaboration Better Health focus groups**The BCHB focus groups did not aim to identify concrete costs of improved collaboration. However, cost and financial issues came up in both the list of suggestions for how foster greater collaboration above, and in barriers listed below. The discussions highlighted costs, and meeting them, are an important factor influencing success or failure. **Illustrative quotes:***“You could say sort of being involved, like say your time, so that could be being paid for your time. That helps because I'd say a lot of time this day and age, it's a struggle to get by. So people being paid for their time because you may have to take time from work or something. So being paid for your time is also possibly a big one there as well.” (MBME C2, DEC Participant)**“Recompense the smaller organisations. Their funding can stop, they have to be self-reliant. Pensioners are self-sustaining: I think there're trust issues because I think research as it is, I forgot to mention this and this is really important. I think it has a reputation of. Taking and not giving.* *I know that there are VCs organizations working on on producing policies around community engagement and looking at recompensing the organizations, not just the people, particularly the ones you've described. You know, they're very poorly funded.” (R05, PPI and Engagement Lead)* | Two groups of researchers and members of diverse ethnic communuties discussed the Better Collaboration Better Health findings on 7th Nov 2024. Their key insights are listed below. ‘GP1 signifies contributions from Group 1 and ‘GP2’ contributions from Group 2.* The lack of funding to support sustained collaboration is a substantial, structural barrier to researchers and diverse ethnic communities working together [GP1 & GP2]. Funding is needed not just to initiate collaboration, but to sustain it [GP1].
* Researchers follow funding, which means it is a tool to change behaviour [GP1]. Mandating collaboration and co-creation, and providing the funds to achieve this, is a tool funders could use to increase collaboration and participation with diverse ethnic communities [GP1].
* Research funders and academic institutions need to provide mechanisms to pay community organisations directly, not just to individuals [GP1]. Payment needs to be up-front; payment in stages does not recognise how community organisations work; they are not in a financial position to do work and be paid later [GP1]. Diverse ethnic community organisation do not have the financial capacity to wait for payment [GP2].
* Funding for collaboration between researchers and diverse ethnic communities needs to come right at the start of a study (i.e., what is the research question?) not part-way through when many decisions have already been made[GP1 & GP2]. At presnt there is little funding available to support work between researchers and diverse ethnic communties before a project is funded, i.e., little funding for project planning [GP2].
* The funding culture in the UK is very short-term, meaning both researchers and diverse ethnic communties are constantly chasing money [GP2]. Sustaining relationships is hard in this environment [GP2]. The short-term, limited funding means diverse ethnic community groups are unable to collabrate and work with researchers to the depth of involvement required to really change research and research outcomes for the better [GP2].
* Increased collaboration would be easier if diverse ethnic community organisations had a defined and sustainably funded role to provide support to researchers in an ongoing way [GP2]. Community organisations could for example then partner with local universities [GP2].
* Community organisations can apply for funding too, for example through UK lottery funding [GP1]. This could open up other funding options, although the community organisation would then be the lead, with researchers as co-applicants (or co-lead), and not the other way around [GP1].
* At present responsibility for collaboration between researchers and diverse ethnic community organisations rests with individuals, usually a relatively early career researcher. This is hard to sustain; the relationship is with a person not an institution [GP1]. The role is not seen as academic, but more of a coordinator [GP1].
* The relationship between researchers and diverse ethnic communities needs to be at the instutitional level (e.g. the University), not the level of individual researchers. It needs to be something that the institution sees as important and supports as part of its role, and does not rely on a few interested and dedicated individuals to run a service that the institution should be supporting. Without this collaborative links are vulnerable and unlikely to be sustained [GP1].

Two groups of researchers and members of diverse ethnic communuties discussed the Better Collaboration Better Health draft recommendations on 28th Nov 2024. Their key insights are listed below. ‘RGP1 signifies contributions from Group 1 and ‘RGP2’ contributions from Group 2.* Lack of timely funding to support collaboration is a structural barrier to routine collaboration between researchers and diverse ethnic communities RGP1+RGP2 summary discussion].
* Availability of funding is the #1 priority [RGP1 + RGP2]. The other recommendations are all of equal importance [RGP2].
* Good to see strong recommendations regarding funding. None of this is posible without funding [RGP2].
* There needs to be a big cultural shift for funding of organisations to put money up front [RGP2].
* The recommendations suggest pre-award funding is needed. Would would this funding look like? What would the parameters around the funding be [RGP1]?
* Funders and others have increasing expectations for what is done before funding is awarded, and there is little time to meet these expectations [RGP1].
* The logistics of how to transfer money to community organisations is challenging. It was easier in the past– the community organisation would send an invoice and the university would pay, simple. University Finance rules now make it hard, with researchers looking for workarounds to enable engagement with community organisations [RGP1].
* Universities have got better at systems for paying individuals, but not for paying organisations. Payment in arrears for example does not work for community organisations [RGP1]. Contracting is also slow [RGP1].
* Could funders provide funding to institutions (e.g., a block grant) to cover its pre-funding work with community organisations [RGP1]? Funding held by institutions to facilitate working with community organisations, or by community organisations themselves, would make collaboration more likely than something that required researchers to apply for more funding [RGP2].
* For sustainability, responsibility for diverse research needs to be an instittional one. But what is an institution? A university, the NHS, a network, somethng else [RGP1]?
* Funding needs to be more flexible during a project, not just pre-award. The funding needs to be sufficiently flexible ot meet the expectations of community organisation partners [RGP1].
* The recommendations around funding need to include some concrete suggestions for how things could change. Seed-funding? Funding for early engagement? The recommendations need to identify the structural barriers, but also propose something that can be implemented [RGP2].
* It is important to think about local context: local institutions could have a relationship with local community organisations [RGP2].
* Good involvement needs both time and money [RGP2].
* It could be argued that pre-award work should be facilitated by research institutions as an early investment. Funders (e.g., NIHR) are not yet set up to do this, it would need a rethink [RGP1+RGP2 summary discussion].
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| EQUITY | **The Better Collaboration Better Health rapid review and focus groups**The BCBH rapid review and focus groups took the value of improved collaboration as a given. The research question was not whether it is valuable, but how to make long-term collaboration between researchers and diverse ethnic communities more likely. With regards to the effect on equity, again the starting point for the review and focus groups (and the research funding call) was that improved collaboration between researchers and diverse ethnic communities would improve the relevance of health research and the health services that are affected by that research to diverse ethnic communities. Through this, the expectation is that health equity would be increased but the review and focus groups did not aim to provide direct evidence that this expectation is true.  | Two groups of researchers and members of diverse ethnic communuties discussed the Better Collaboration Better Health findings on 7th Nov 2024. Their key insights are listed below. ‘GP1 signifies contributions from Group 1 and ‘GP2’ contributions from Group 2.* There were no specific comments on equity.
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| FEASIBILITY | **The Better Collaboration Better Health rapid review**The success criteria identified by the review do in a way give a strong steer to what is needed to make long-term collaboration between researchers and diverse ethnic communities feasible. It could be argued that the feasibility concerns would be to ignore the success factors that the review identified, especially perhaps those nine indicators that were most frequently mentioned (see section on anticipated benefits above).**The Better Collaboration Better Health focus groups**Barriers to collaboration (i.e., feasibility problems) were an important part of the BCBH focus group discussions. There were many suggestions for barriers to collaboration between diverse ethnic communities and researchers– see quotes and table below. **Illustrative quotes:***“True collaboration means involvement from the very start. It doesn't mean being involved halfway through or organisations coming to ourselves and to community members when they realise, oh, we've forgotten to ask this section of the community. It involves being involved from the very beginning, the service users, community organisations in the design of the research, because 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 to enable effective participation.” (MBME C4, CEO of charity organisation)**“It's a shame that even with the whole 10 years of being involved in this work, that some of the same issues are still there and I kind of think, but why, when they could just be so easy to solve. And again, if you have public contributors involved at earlier stages, and I don't think a lot of these issues would be so apparent or even happening right now.” (R03, PPIE coordinator)**“I have no previous involvement in health research...I did not even know how to get involved with health research before I saw the poster for this, in the community centre.* *I have had no previous experience of involvement in health research, even though most of my life I have experience working within the social care settings, with complex needs, so cared for and about people’s physical and mental health.” (MBME C1 participant)**“And I think usually, so for instance, if there's a steady ongoing study and the people who are recruiting do not know anything about the community they want to recruit from, sometimes it really becomes difficult. So sometimes having training, doing some training on inclusive research or how to engage in these communities and what the culture is like, like going there to speak to them, to study the place and how the culture is like over there really helps because you will be surprised to find out that regardless of how important your research is, if they find that you do not really understand your culture, their culture, it may deter them from taking part in the research.” (CAHN DEC FG participant P02, researcher)**“So investment and you know, support and backing and the understanding that relationships have to be built and you know networks kind of developed from that and again like you mentioned that element of trust as well if you want you know the doors to be opened to us and seeing more diverse groups being involved in health research and clinical trials then we need to invest in that both monetary and through our time.” (R03, PPI Lead)**“But it does feel like there's a lot of recreation of the wheel and everyone knows how important it is to try and recruit a diverse PPI group and diverse samples to whatever the project is. But if there was some sort of hub or network that people could access in the healthcare research space, I think it would be helpful.” (P1, SAfH, Researcher)**“Making awareness is the best thing, isn't it?**So people don't feel that the stigma is in there because people don't understand it.**That's not the point of sending things there.**So that's typically the education of stigma.**If you educate people and remove that stigma, then more people will be willing to participate and learn more.” (SAHA DEC FG Participant)***Suggested barriers to collaboration between diverse ethnic communities and researchers.**

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| **DEC participants including PPI leads working with researcher academics** | **Researcher participants** |
| ***#DEC perceptions about researchers*** * Researchers do not want to include DEC in research
* DEC not given an opportunity to be heard – do not involve DEC from the beginning
* Researchers expect instant engagement
* Lack understanding about the diverse community/ethnic minority groups, lack of cultural competency
* Researchers assume and lump ‘engagement’, ‘involvement’ roles together

***#Researcher ways of workings**** Historic ways of working e.g. include male, older people from White backgrounds

***Language issues**** Not thinking about the person when talking about research, its benefits

***#Lack of access to research (physical aspects)**** Not knowing how or where to access health research
* Not knowing the location of researchers
* Research not accessible to people outside of London
* Digital/online modes are used for engagement which can exclude a lot of people e.g. people with disabilities

***Cost/Funding issues******£For individual community members**** Cost to travel to researchers
* Payments – not clear about tax implications for people on benefits
* Use of slippage money, not dedicated for collaborative work and this results in tokenistic involvement

***££For community organisations**** Funding issues can cause tension/friction, lead to competition/rivalry between DEC and researchers

***Wider system issue affecting all**** Smaller organisations unable to collaborate due to government funding cuts/difficult application process for funding

***Competing time/commitments of DEC prevents involvement in health research**** Invitation/involvement at times when people are working, have parental responsibilities
* Hospital appointments/long waiting times

***^Lack of information/knowledge about research******Previous negative experience of health research/health system******\*Researchers not of the same background as a DEC member so the research feels inaccessible*** | ***#Researchers not being inclusive/lack understanding about inclusive research**** No specific need suggested by researchers to recruit people from diverse backgrounds in research
* Not willing to translate study materials because of high research cost associated with it
* Using online means for advertising study/recruitment - people from deprived backgrounds may not have access to internet/social media
* Tokenistic involvement, diversity is an afterthought
* Using strict eligibility criteria within research

***Language issues**** Not impactful to affect engagement e.g. ‘living lab’ term to engage people from Black community
* Involving interpreters can filter the dialogue
* Term ‘research’, ‘data’ in general incites fear
* Lack of fluency in English language can affect getting useful contribution needed for a research question
* Dilemma of the need for translation or not done, usually a knee-jerk response

***Researcher perceptions about DEC**** Assumptions made that engagement/recruitment of DEC will take more time and will cost more
* Lack of clear understanding about what ‘research’ is in the community
* DEC are suspicious of public sector organisations – negative previous experiences

***^Lack of information/knowledge on where and how to access diverse communities**** Not knowing the population and where to look for them (experience of those new to research in comparison to grant holders)
* Not being culturally aware of DEC
* Lack of community gatekeeper involvement in research prevented community engagement

 ***Cost/Funding issues******For researchers (impacting diversity in research/collaboration)**** Means restricting study eligibility criteria to recruit diverse groups;
* Less/no involvement of public contributors during grant period
* Unable to carry out translation of research materials which limits the diversity in research
* Reliance on luck for pot of money but no dedicated funding available to involve people at the start (at planning stages prior receipt of grant funds)

***£For individual community members**** Lack of appropriate reimbursement/incentives to enable DEC engagement/participation in research
* Lack of timely payment
* Delivery of compensation is not timely (could also be applicable to community organisations)

***££For community organisations**** Limited economic incentives offered to NGOs/community organisations; only minimal expenditures covered.
* Inappropriate PPI costing in grants

***Wider system issues**** Short timelines of funding calls do not help with building relationships with communities
* Research topic areas come from NIHR and not necessarily the community
* Ethics and governance requirements are text heavy for study materials
* Perceived value of research might be different between DEC, Researchers/NIHR

***\*Research teams are not diverse******Long term collaboration might not be possible for all types of health conditions*** |
| ***\****Common views among DEC and researchers**#, £, ££, ^** Findings given by the DEC and researcher participants are linked/can help to explain/give better understanding about the barriers to collaboration from both sides.  |

 | Two groups of researchers and members of diverse ethnic communuties discussed the Better Collaboration Better Health findings on 7th Nov 2024. Their key insights are listed below. ‘GP1 signifies contributions from Group 1 and ‘GP2’ contributions from Group 2.* See comments from GP1 & GP2 about funding, especially the need for sustainable funding to support collaboration from the beginning of a piece of research.
* How do people become aware of research collaboration opportunities? Greater collaboration needs greater awareness of what researchers and diverse ethnic communities can offer each other [GP2].
* Researchers do not think about where collaboration takes place from the perspective of diverse ethnic communites. Using e.g., university venues presents problems for many. Think about what it entails, and go to where community members are likely to be comfortable [GP2].
* Working with diverse ethnic communities needs to be part of reseearcher training, especially of those early in their careers [GP1 & GP2]. It is likely that seeing the benefit of collaboration early in a career will mean that collaboration becomes a routine part of that researcher’s life [GP1].
* Community organisations could support early career reearchers with training and their research, but this needs funding [GP2].
* Ethnic groups are not the same. Some groups may have very different needs and persepctives than others. Migrant ethnic communities are different to ethnic minority groups generally, there may be greater language barriers, gender issues, lack of familiarity with UK health system and processes [GP2].
* Researchers lack confidence in how to engage with diverse ethnic communities. Without external pressure, this makes it too easy for researchers to stay within their comfort zones [GP1].
* Academia is very competitive, which makes it hard for academics to collaborate with each other, let alone anyone else. Collaboration with diverse ethnic communities needs to be recognised as expected and important within an academic career [GP1].
* Some universities expect ethical approval for any contact with diverse ethnic communties, which both presents a barrier to consultation and collaboration as well as fundamentally changing the role of community members from partner to participant [GP1].

Two groups of researchers and members of diverse ethnic communuties discussed the Better Collaboration Better Health draft recommendations on 28th Nov 2024. Their key insights are listed below. ‘RGP1 signifies contributions from Group 1 and ‘RGP2’ contributions from Group 2.* Don’t put all the responsibility on PPI [public and patient involvement] to improve diversity in research. Funders and others also need to provide training, guidance etc. It’s not just about more diverse PPI [RGP1].
* Training should cover things like how to develop anti-racist research, working with diverse ethnic groups, taking an intersectional approach to research. Training is important and should also involve community organisations [RGP2].
* Nothing is being done to identify community champions (at community organisations) to support greater involvement by a particular ethnic community [RGP2].
* Recommendation #7 should be a bit clearer. Funders need to develop black and ethnic minority researchers. Funders shouild be trained too, especially with regard to intersectional approaches to research [RGP2]. Projects working with ethnic minority communities should be led by researchers from ethnic minorities. If this is not possible, at least move to diversify the research team [RGP2].
* Research design needs to be aware not only of participant characteristics, but also the discrimination and oppression that having some characteristics can lead to [RGP2].
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**Recommendations**

**Recommendations: funding and incentives for collaboration**

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| [Recommendation](#TypeofRecommendation_C) #1 | **Current research funding arrangements in the UK are a substantial structural barrier to routine collaboration between researchers and diverse ethnic communities.** **Funding needs to be available pre-award to support to co-design of research; simper ways of making direct, and timely, payments to community organisations, not just individuals, are needed; sustained, routine collaboration needs funding that is not connected to individual projects.**  |
| [Justification](#Justification_C) | This recommendation was universally judged to be the most important of our eight recommendations to support increased collaboration between researchers and diverse ethnic communities. More and better collaboration between researchers and diverse ethnic communities will not be possible without changes in how and when funding is made available, and how that funding can be used. Collaboration requires trust, and trust takes effort to build and sustain, which requires funding. Moreover, trust requires an equal partnership, which implies a joint enterprise between researchers and diverse ethnic communities working together from the very start of a piece of research. Funding to support early co-creation work prior to the award of a project grant is currently extremely limited. While in the past universities and other research institutions may have had funds to support pre-award work, this is no longer the case. What funding is available is modest in scale, piecemeal and involves applications processes that may not be successful. Funder payment models used for universities that run on payment in arrears do not work for community organisations, which do not have the financial capacity to do work without being paid up-front. Moreover, while funders and research institutions such as universities are becoming familiar with paying individuals for patient and public involvement, direct payment to community organisations is much harder, and harder than in was in the past. Both funders and research institutions need to make direct payment to community organisations more straightforward. Community organisations do not have finance departments that can cope with systems developed with large organisations in mind.  |
| Comments | Some potential funding models to support this recommendation were suggested and are listed below no particular order. The models are not mutually exclusive, and all would need to support other features of Recommendation #1 such as simpler and timely payments to community organisations.**Model 1**Funders provide a block grant that institutions can apply for to support pre-award collaboration co-design work between researchers and diverse ethnic communities. This funding could also support co-design work with other under-served groups in addition to ethnic minority groups. ‘Institution’ here could also mean community organisations, meaning that community organisations could apply for the funding on their own behalf, meaning they are then funded to work with research organisations on co-design and collaborative health research. **Model 2**Funders provide pre-award funding to research teams that have promising ideas based on e.g. an expression of interest or Stage 1 submission. Not all of this funding will lead to a successful proposal (e.g. at Stage 2), but it could be considered as an investment in more informative research for those that are funded. More careful selection of proposals put forward to later stages (because progression to later stages comes with pre-award funding) may also reduce research waste by having fewer research teams spending time on proposals that ultimately are unsuccessful. **Model 3**Funders offer early engagement or seed funding schemes that do not come with substantial grant submission processes, and which are flexible regarding how they are used beyond being used to support engagement with diverse ethnic communities (and other under-served groups). These schemes could also support direct application from community organisations.**Model 4**Funders consider non-traditional funding routes such as variants of community commissioning or participatory budgeting to directly support diverse ethnic community organisations’ ability to both contribute to research agendas relevant to the communities they represent and to support and work with researchers to design and deliver projects addressing questions on those agendas. **Model 5**Institutions such as universities reallocate some of their existing funding to support pre-award co-design work. This does happen already, but on a small-scale and is institution dependent. UK universities are in a difficult financial situation at present so it is unlikely that they could scale-up current initiatives without there being a mechanism to get back some of their investment, perhaps as a budget line in successful grants. This would require funders to accept a general ‘Diversity-related pre-award budget’ in grants, similar to some FEC costs now that are accepted as the cost of doing business with the institution.   |

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| [Recommendation](#TypeofRecommendation_C) #2 | **Funding should be used as a tool to mandate that researchers work together with diverse ethnic communities.**  |
| [Justification](#Justification_C) | Researchers respond to conditions placed on the award of funding because, simply put, they have to pay attention to the conditions to get the money. Funding and the funding processes can therefore be tools to change researcher and institutional behaviour regarding working together with diverse ethnic communities. For example, funding calls could mandate collaboration and look for evidence of this within the submitted proposal. Institutions and researchers that were better at doing this would be more successful at getting research funding. Collaboration with diverse ethnic communities needs to be recognised with academia as an expected and valued part of an academic career. It should be noted that funder-mandated requirements would need to come with money to support meeting the requirement, including pre-award co-production work (see Recommendation #1).  |
| Comments | A mandate would not, on its own, be enough to lead to substantial increased collaboration between researchers and diverse ethnic communities. As mentioned above and in Recommendation #1, financial support is needed to allow pre-award collaboration, and to sustain beyond funding from a single project. Researchers also lack confidence in how to engage with diverse ethnic communities, reducing their ability to meaningfully comply with mandates. Lists of community organisations that are able to help would be useful. See Recommendations #5 and #8.  |

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| [Recommendation](#TypeofRecommendation_C) #3 | **Researchers need to work with community organisations and members to better understand what motivates community members to contribute to research.**  |
| [Justification](#Justification_C) | Money is essential to support collaboration, but it is not sufficient to build trust and support collaboration with diverse ethnic communities. Researchers need to work more closely with diverse ethnic communities to understand what the additional incentives are, but these include working with communities from the start of projects, addressing research questions that are of direct relevance to community members, having endpoints and outputs from the research that are important to community members and sharing results with the community (see Recommendation #8). Researchers and research institutions could also provide support to communities that is non-financial. For example, institutions could offer training in research and data collection methods or offer institutional research structures such as ethics committees to local community organisations to support their own work.  |
| Comments | Building, and keeping, trust requires an ongoing relationship where diverse ethnic communities are involved from research conception through to completion, that results are shared with communities and that the relevance of the results to communities is clear. Sustained relationships are currently difficult because funding comes piecemeal, usually linked to individual grants. Relationships are formed, lost and then reformed as projects get funded. Institutions such as universities rarely offer (or have) resources to sustain relationships between projects.  |

**Recommendations: responsibility for collaboration**

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| [Recommendation](#TypeofRecommendation_C) #4 | **Collaboration between researchers and diverse ethnic communities should be an institutional, not only individual, responsibility.**  |
| [Justification](#Justification_C) | Generally, where collaboration between researchers and diverse ethnic communities takes place, it does so because of the enthusiasm of individuals, not institutions. These individuals are also often researchers who are early in their research careers, rather than as a task for senior staff. Even where senior research staff are involved, collaboration is an individual initiative not an institutional one. Collaborations that rest on the goodwill of individuals are vulnerable. For collaboration to be routine and sustainable, responsibility for collaboration needs to be placed at the level of the institution. Additionally, collaboration needs financial support to sustain it beyond individual projects and individuals, otherwise trust and motivation will wane. Participation by researchers in this institutional collaboration should be acknowledged by the institution and others as an important marker of academic career progression. Finally, improved diversity is about more than more diverse public involvement. Funders and others need to provide training and guidance to researchers to ensure that their whole approach to research design, conduct, analysis and reporting considers equity, diversity and inclusion. See Recommendation #5.  |
| Comments | Community organisations could also identify community champions at their organisation who are responsible for supporting greater involvement of their community in research locally.  |

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| [Recommendation](#TypeofRecommendation_C) #5 | **Institutions need to better support their researchers to collaborate with diverse ethnic communities.**  |
| [Justification](#Justification_C) | Working with diverse ethnic communities should be part of the training of all researchers, especially early career researchers. This would raise the importance of working with diverse ethnic communities, making it more likely that it will become a natural and routine part of a researcher’s way of working. Training should provide researchers with the confidence to engage with diverse ethnic communities, highlight local diverse ethnic community organisations willing to support research, cover intersectionality, be anti-racist and raise awareness of the discrimination and oppression that having some ethnic characteristics can lead to within the UK. This training should directly involve community organisations and will help to change and improve research design so that it becomes more ethnically inclusive. Community organisations are willing and able to contribute to training and development, but this needs to be funded. At present many early career researchers, especially PhD students, come to community organisations looking for help but with little or no resource to pay for it. Additionally, contact may be made well into a project and after the community organisation has any opportunity to influence the design of the study. This makes collaboration haphazard, modest in scope and poorly integrated into researcher training.  |
| Comments | None. |

**Recommendations: developing research projects**

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| [Recommendation](#TypeofRecommendation_C) #6 | **Diverse ethnic communities need to be involved in research design discussions from the beginning of the research**.  |
| [Justification](#Justification_C) | The current model for collaboration between researchers and diverse ethnic communities is that researchers have a research idea, which they may then choose to discuss with diverse ethnic communities. This assumes that only researchers know what needs to be researched. Diverse ethnic community members are often invited to work with researchers well after the work has started, when many decisions have already been made. Indeed, funding may already be in place, which limits further the scope for change.A better model would be for research projects to be developed together with diverse ethnic communities from the very start, especially through collaboration with community organisations. Early discussion would also help to ensure that researchers recognise and account for the diversity of views and perspectives within different ethnic communities rather than thinking that there is a single perspective held by minoritised groups. Diverse ethnic communities also need to be involved in all aspects of a project. In other words, design, conduct, analysis, writing and reporting. Dissemination of results direct to communities is also an area where diverse ethnic community organisations can have a role. Sharing results directly with communities is likely to increase trust in research by those communities (see Recommendation #3).  |
| Comments | A constant criticism by members of diverse ethnic community organisations is that researchers involve them too late to make important changes to research design and conduct. This limits the impact their involvement can have on the utility of the research results for members of the communities they represent. Involving diverse ethnic communities from the beginning of research as genuine partners in the research is an essential component of improving the ethnic diversity and relevance of research. Note: there can sometimes be a tension between what drives researchers (e.g., getting a publication) and what community organisations have to do (e.g., run a food bank). The published output may not be as important to community partners; there is a day job to do. It is important to make sure expectations are matched. Is a person bringing lived experience to a discussion, or is the person there to represent a community? Some people may be more comfortable with one than the other, or it may be just one of these that is needed. Everyone needs to be clear what is expected of them.  |

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| [Recommendation](#TypeofRecommendation_C) #7 | **Some projects may be better led by community organisations rather than researchers or co-led by both.** |
| [Justification](#Justification_C) | Current collaboration models and funding mechanisms favour researchers as leaders and community organisations as co-applicant partners. Depending on the topic, it may be better for community organisations to lead and researchers to partner, or for both to co-lead as equal partners. Many community organisations include staff with research experience, and trust levels between community members and community organisations are often much higher than that between researchers and community members. Community organisation leadership may itself promote greater research collaboration and participation of community members. Allowing community organisations to lead or co-lead projects would in many cases mean changes to how funding can be awarded to enable non-higher education intuitions to be the lead organisation. Moreover, community organisations have access to types of funding (e.g., lottery funding) that may be less open to researchers. Once again, researchers would be partners but not formal leaders in projects taking these funding routes. Funders also need to develop black and ethnic minority researchers. Ideally projects working with ethnic minority communities should be led by researchers from ethnic minorities. Where this is not possible, efforts are needed to at least diversify the research team. Funders themselves need to be trained, especially with regard to intersectional approaches to research.  |
| Comments | Researchers should not be considered the automatic choice for leadership of ethnically inclusive research. Genuine co-leadership as equal partners is often likely to be the best choice, and funding mechanisms should acknowledge and facilitate this.Researchers in the UK are not as ethnically diverse as the general population; this is especially true of those leading the research. This affects the perceived relevance of the research, and the perspectives that are considered when choosing research questions and designing research delivery. More diverse public contributors will help, but the ethnic diversity of researchers themselves needs to increase.  |

**Recommendations: bringing researchers and diverse ethnic communities together**

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| [Recommendation](#TypeofRecommendation_C) #8 | **Researchers and diverse ethnic communities need a platform to facilitate collaboration and the sharing of results.**  |
| [Justification](#Justification_C) | Researchers and diverse ethnic communities can struggle to identify who to talk to. A member of a community organisation may recognise a research problem and know that research expertise is needed but be unsure of who to approach to get that expertise. Similarly, a researcher may know that the involvement of one or more particular ethnic groups is essential, but not know how to achieve this.An electronic platform that brings together researchers and diverse ethnic communities would make this easier. In particular, the role of community organisations as a bridge between researchers and diverse ethnic communities could be made more obvious to researchers, as well as providing the means to approach community organisations. The platform could also be used to share results with communities, along with the impact collaboration has had, including changes that have come about because of collaboration. The platform would be an opportunity to publicly acknowledge the contribution made by community organisations and members. The platform could also encourage community organisation involvement in analysis, interpretation and publication.  |
| Comments | A full-scale platform was considered exciting but a more long-term priority than the other recommendations, especially the funding related changes of Recommendation #1.  |

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