Community Connexions engagement handbook : engaging with underserved communities

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Authors	Benoit, Céline;Ackom-Mensah, Hannah;Burt, Christine;Zakia, Fatmia;Siddiqi, Urfan
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Community Connexions engagement handbook

Engaging with underserved communities

Authors:
Céline Benoit, Hannah Ackom-Mensah, Christine Burt,
Fatima Zakia and Urfan Siddiqi

Let's listen, talk and act for healthier communities

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Community Connexions is a patient and public engagement programme that seeks to capture the lived experiences of underserved communities in Birmingham and the Black Country – Wolverhampton, Sandwell, Walsall and Dudley – to adapt our healthcare services to better meet local needs and inform future health research. The programme, led by the Birmingham Community Healthcare NHS Trust (BCHC) and Black Country Healthcare NHS Foundation Trust (BCHFT), is funded by CRN WM. Aston University acts as a key partner.

While the handbook was written by the Community Connexions Team and Operational Groups, it could not have been possible to do so without the feedback from the Steering Committee, which includes the following organisations:

- African Caribbean Community Initiative (ACCI)
- Birmingham City Council (BCC)
- Birmingham Voluntary Service Council (BVSC)
- Clinical Research Network (CRN)
- Citizens UK
- Flourish, the West Birmingham Community Healthcare Collaborative
- Healthwatch Birmingham
- Healthier Futures, Black Country and West Birmingham
- Ladywood and Perry Barr Locality Partnership
- Refugee Alliance
- The Royal Wolverhampton NHS Trust
- University of Wolverhampton
- West Midlands Combined Authority

We are grateful for the time and support from local and regional organisations, including those listed above.

And last, but certainly not least, we would like to extend our thanks and express our gratitude to all the community groups and individuals who have worked with us, who have taken the time to share their thoughts and who are passionate about tackling health inequalities.

Céline, Hannah, Christine, Fatima and *Urfan*

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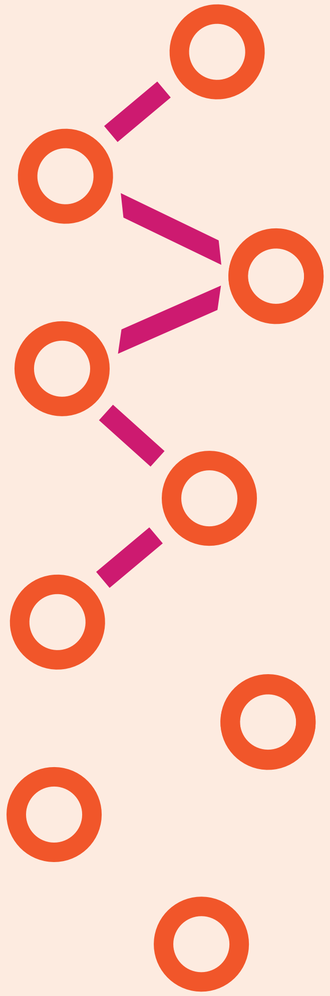


About the handbook

This handbook is the result of several years of community engagement among underserved communities, and of working in partnership with several local and regional community partners. It was created to complement existing resources on Public/Community Engagement and Patient Engagement. While there are many resources that look at modes of engagement (see section 9), we felt that none of those explored issues pertaining to the power dynamics that emerge when engaging with communities that have traditionally been disempowered by society. This handbook invites the reader to reflect on notions of power, so they can act ethically and help challenge social injustices. While the document takes examples from health and healthcare services, it remains suitable for use in any community engagement activity, regardless of your (research) topic.

Regardless of the reasons for which you choose to engage with underserved communities (i.e. whether it is for research, or not), this handbook invites you to reflect on your approach to community engagement so that you not only acknowledge but also challenge barriers to engagement. As you read this document, we encourage you to reflect on your role in reproducing/challenging barriers and existing power dynamics. We also invite you to reflect on what motivates you to do community engagement – never engage with underserved communities as a box-ticking exercise. Community engagement only works when those who take part are genuinely motivated and enthused by the prospect of working together.

This handbook has been written so that you can engage with relevant sections directly, though we do recommend that you read the whole document. The handbook can also serve as a guide for good professional and ethical conduct that can be adopted by the event organisers. It provides practical recommendations, and a checklist (see section 6) with which you should engage *prior* to any community engagement activity.

This document is a collaborative handbook – it serves as a basis for conversations about community engagement and we hope it will grow as you share examples and case studies with us. Similarly, if you have any questions about how to use this handbook, we invite you to contact us directly via email (BCHC.CommunityConnexions@nhs.net or bchft.communityconnexions@nhs.net) or on X, formally known as Twitter, (@BCHC_CommCX or @BchftCommunity).

1. Introduction

We know that health inequalities are caused by the social and structural determinants of health. As such, health inequalities are not only unfair, but they are also avoidable. It is therefore crucial that renewed attention is paid to these determinants of health and how we can work collaboratively to mitigate their impact on future health. As such, Community Connexions seeks to build a network of organisations and individuals that are committed to work collectively to tackle health inequalities, enhance quality of life, and help improve health outcomes within our local and underserved communities. Community Connexions also strives for greater inclusion of underserved populations in health research and clinical trials, tackling their under-representation which we know exacerbates health disparities.

1.1. Focus on power dynamics

This handbook is the result of several years of community engagement among underserved communities, and of working in partnership with several local and regional community partners. While a number of community engagement handbooks/resources already exist (see section 9), we felt that none of those explored issues pertaining to the power dynamics that emerge when researchers or organisations are engaging with communities that have traditionally been disempowered by society. This handbook was therefore created to provide organisations and researchers with the tools they need to effectively engage and serve underserved communities, regardless of the topic of research.

1.2. Key terms

The term 'underserved' refers to any group or community that has been inadequately provided for. Underserved communities are more likely to come from minoritised backgrounds. By minoritised communities, we refer to "any and all who identify in contextually situated, nondominant communities such as race, class, sexual orientation, language, dis/ability, religion, and gender" (Verner Chappell and Chanmann-Taylor, 2013: 243). Minoritised groups can also include children and young people, the elderly, those experiencing socio-economic hardship, refugees, migrants, those experiencing digital poverty and/or poor literacy, to name a few. Minoritised communities are more likely to face racism, oppression, discrimination, as well as social challenges and barriers. They are also more at risk of being marginalised, and disempowered.

As we discuss further down in this handbook, it is important to be mindful of the language we use as it can serve to reproduce existing power structures and inequalities. In this handbook, we talk about 'minoritised' communities, and not 'minorities' as we recognise that power is not evenly distributed in society, and that those facing barriers are not necessarily members of minority groups (in the numerical sense), but members of groups that have been disempowered and/or excluded. "Using 'minoritised' makes it clear that being minoritised is about power and equity not numbers" (Wingrove-Haugland and McLeod, 2021: 1).

Similarly, we talk about underserved groups, to highlight the fact that some community groups have been left disempowered and disenfranchised. The term 'underserved' (or 'under-served') "reflects the perspective that the research community needs to provide a better service for people in these groups – the lack of inclusion is not due to any fault of the members of these groups" (NIHR, 2020). As such, we recommend moving away from terms such as 'hard to reach communities', 'hidden communities', or 'underrepresented'. If Community Connexions has taught us anything, it is that underserved communities are far from hard to reach, and are more than ready to collaborate in research and community engagement activities.

1.3. Adopting a sustainable approach

Regardless of the reasons for which you choose to engage with communities (i.e. whether it is for research, or not), this handbook invites you to reflect on your approach to community engagement and question the power dynamics that are at stake. The aim is not only to act as ethically as possible, but also to help challenge social injustices. Too often organisations and individuals engage with underserved communities to collect data for a project, and then leave once they have what they need. Instead, the handbook recommends adopting a more sustainable approach to community engagement and moving away from transactional relationships, especially as traditionally transactional relationships tend to reflect the power asymmetries between those who do community engagement (and who benefit the most from taking part in community engagement activities), and underserved communities (who tend to give data away and get little in return). The handbook can also serve as a code of conduct, since it provides practical recommendations, and a checklist (see section 6) with which you should engage *prior* to any community engagement activity.

Useful terminology:

Minoritised communities are community groups that do not identify with dominant/normative identities, and who have been disempowered and/or excluded by society. Minoritised communities are more likely to face racism, oppression, discrimination, as well as social challenges and barriers.

Underserved populations: While there is not a single, simple definition that can encompass all under-served groups, the term reflects the perspective that the research community needs to provide a better service for people in these groups – the lack of inclusion is not due to any fault of the members of these groups. The term 'under-served' reminds us of this perspective in a way that alternative terms such as 'underrepresented' do not (NIHR, 2020).

2. What do we mean by ‘community engagement’?

‘Community engagement’ does not mean the same thing to everyone. Depending on the context, it can be understood in different ways – for example, for some it may equate to a one-off public consultation on a specific issue, while for others it may mean sustained face-to-face engagement with specific communities to maintain trust and communication.

In some organisations, other terms may be used (such as ‘public engagement’, or ‘patient and public involvement and engagement’). These may sometimes be conflated to mean community engagement, but this is not always the case.

Therefore, *prior* to approaching any community group, you must ensure that you and your community partners agree on a common understanding of what community engagement means for you all, and what it entails. We recommend that you share your answers to the following questions, and come to a shared approach:

i) What kind of **relationships** do we want to build together?

ii) What will the engagement **activities** look like? How **long** will they last?

iii) What are the **aims and purposes** of this collaboration?

iv) What do you think the **outcomes** will be?

v) What **outputs** do you think will come out of the engagement activities? What will you do with them?

vi) What are the **benefits** of the collaboration, **for all parties involved**? Make sure that there is no asymmetry, and that everyone involved will benefit from community engagement.

These initial questions are important to take into consideration. Agreeing on a common understanding of community engagement is an important step to ensure you start the project on an equal footing.

Below are examples of ways in which community engagement may be understood. This is not an exhaustive list – we instead capture what has come up frequently in our project as we engaged with underserved communities. Instead, the below demonstrates how important critical engagement is needed *prior* to starting any type of community engagement activity.

2.1. ‘Community’

Underserved communities tend to be organised by ‘types’ so that trends/patterns within communities can be identified. This is especially common if you lead on a research project. Below are the main ‘types’ that we have identified:

i) **Communities of interest:** people are brought together because they share the same racial and/or ethnic background (e.g. Nigerian Commonwealth Community Health Profile 2022), a common religion (e.g. Sikh Community Health Profile 2022), a common language, or a shared socio-economic status. Communities of interest remain diverse (e.g. age, sexual orientation, disability).

ii) **Communities of experience:** people are brought together because they share very similar experiences (e.g. carers). The sense of belonging may be strengthened by sharing similar experiences within a specific context. Communities of experience remain diverse (e.g. in terms of gender, social status, race).

iii) **Communities of identity:** people are brought together because they identify with the same identity marker (e.g. lesbians – see Lesbian Community Health Profile 2022). While communities of identity often share cultural references, spaces, literature, art and language, they remain diverse (e.g. in terms of age, ethnicity, location).

iv) **Communities of place (or place-based communities)**: people are brought together by geographic boundaries. In healthcare, this can be useful to understand how a particular locality is being underserved, how local residents are impacted, and what (hyper) local solutions have been implemented (if any). The communities of place remain diverse (e.g. in terms of age, gender, religion).

This is not an exhaustive list, and the terms listed above can be interpreted differently depending on contexts. It is therefore important that you make sure that you and your community partners agree on what you mean by ‘community’.

Before you organise communities into ‘types’, it is essential to note that *no community group/type is homogeneous.* Diversity *within* each group must always be acknowledged. Therefore, when you share your data/findings, refrain from making sweeping generalisations, and do not claim that any group share the same characteristics. Instead, explain how your data/findings shed some light on broader issues, which may need further exploring. You may identify patterns, or trends, but when you present them, beware of the language you use – do not make claims that present underserved communities and minoritised groups are an undifferentiated mass.

If you choose to organise your communities in 'types', the concept of 'super-diversity' will be useful to you, as it aims to acknowledge the limitations of such an approach.

Super-diversity

"Super-diversity, a term coined by Steven Vertovec (2007), refers to the 'diversity within diversity'. It is about acknowledging that organising people by countries of origin, ethnicity, language, or religion is rather one-dimensional. Instead, we should look at taking a multi-dimensional perspective.

For example, rather than considering one category (e.g. ethnicity), it may be more useful to reach out to communities that share a range of other variables such as age, country of origins, sexual orientation, social status, location, etc. (e.g. Bangladeshi women living in Lozells, Birmingham or Hindu men living in Dudley, Black Country)."

Similarly, engage critically with any secondary data you may have used to learn more about the groups with which you want to engage. Ensure you start your project with an open mind, without jumping to conclusions and assuming what the needs/priorities of your community partners may be. For example, data on the deaf communities may be presented in a one-dimensional way in some secondary sources. This may suit the purpose of the publication you are accessing, but it does not mean that the data can be used to generalise the needs/priorities of the deaf communities.

"There is such a diversity of deafness, you have those who come from hearing families, and those who don't, those who attended mainstream schools and learn English, but some people struggle with English and are better with BSL. It really depends on the background of that person. Have they been taught the language? Have they been taught how to speak? Have they had elocution classes? Education will have a major impact on people's experiences. So there is no one-size fits all to meet the different needs. There are some deaf people who speak very, very well. It really depends on their education. What we need is people to understand what we need from them, and people being willing to learn. Only that way can we work with people."

Source: Deaf and Hearing Loss Community Health Profile 2022, p. v

It is *your* responsibility to ensure you avoid reproducing existing inequalities, and power imbalances by not representing communities/groups as being composed of individuals who all share the same characteristics.

As you seek to engage with underserved communities, you must ensure that you:

i) Never assume that everyone from one community or group shares the same views or the same experiences,

ii) Never explain group characteristics/behaviours as being biological/innate, rather than as being informed by society/shared experiences.

In order to avoid these pitfalls, you must be mindful of the language you use. We recommend using 'communities' (plural) rather than community (singular) to acknowledge diversity within types/groups (e.g. 'the Bangladeshi communities', instead of 'the Bangladeshi community'). We also recommend you check with your community partners what words are viewed as appropriate or inappropriate. The advice remains valid, even if you think you share the same community 'type'.

Example

"Within the Deaf community, capital D and lower-case d are used to categorise those with hearing loss conditions. A capital D is used to represent those who were born deaf or experienced hearing loss before spoken language was acquired. Within the UK, D/deaf individuals' primary language is British Sign Language, and they perceive themselves as part of a linguistic and cultural minority.

The 'lowercase d' deaf refers to the physical condition of hearing loss. People who identify as deaf with a lowercase 'd' don't always have a strong connection to the Deaf community, don't always use the sign language, and may prefer to communicate with speech. Developing deafness or hearing loss later in life after communicating in spoken language is one of the many reasons why a person may choose to identify as deaf with a lower case 'd'.

Source: Deaf and Hearing Loss Community Health Profile 2022, p. v

Finally, remember that language continuously evolves, and that terms we once used may have become obsolete/inappropriate by the time you are ready to engage with community partners. For example, while 'BAME' (Black, Asian, Minority Ethnic) has been used extensively in the last few years, the term is now being rejected by many because i) it emphasises certain groups over others (i.e. Black and Asian), ii) it excludes other groups, and iii) it masks disparities between different groups. As a result, the term can lead to misrepresentations, and misleading interpretations of data – an issue on which we reflected in section 2. Never assume you are using the right terminology, and always double-check with your community partners the vocabulary with which they are most comfortable.

Useful terminology:

Transactional relationships are relationships in which the researchers zoom in and out of communities as and when they need something from them. As a result of transactional relationships, the researched communities often describes a sense of disconnect with the researchers who do not follow up with the results of their research; the researched ending up feeling used (NIHR, 2022).

Equal relationships are relationships where the researched communities are seen as partners. Such partnerships involve compatible goals, where there is mutual benefit, and a reciprocated interdependence (NIHR, 2020).

2.2. 'Engagement'

Community engagement describes the myriad of ways in which we reach out to community members. Regardless of how community engagement is defined, to be equitable and ethical it must be defined as "a two-way process, involving interaction and listening, with the goal of generating mutual benefit" (NCCPE, 2020). As mentioned in the introduction, too often we have seen transactional relationships, where one takes, and another gives. It is essential that we move away from such relationships, where the researcher/community engagement lead benefits more than underserved communities. Transactional relationships serve to reinforce power imbalances, and should therefore be deemed unethical. Instead, you should seek to establish **equal relationships**, where the researched communities are seen as partners. Such partnerships involve compatible goals, where there is mutual benefit, and a reciprocated interdependence (NIHR, 2022).

> *"We've all been with people saying they are listening but they aren't. Lots of initiatives come into place, a report comes along, and then another report comes along… [but] we don't see changes happening."*
>
> *"I've too many times poured my heart out and been told that this would affect change, but actually it's too much hassle for the community leaders to make any changes and nothing is changing. It's just a waste of time."*

2.2.1. Engaging ethically with underserved communities

Working on an equal footing

Ethical considerations are not to be treated in isolation – it is not just about seeking ethical clearance from your organisation to conduct research/community engagement activities. Instead, ethical considerations ought to inform your whole approach to engagement. In the past, there has been a tendency to work *on* people, rather than *with* people, even when communities were involved in projects. Working *on* people should not be deemed ethical, as it reproduced power imbalances. It puts the researcher/engagement lead in the driving seat, and contributes to disempowering underserved communities. While there is an increasing trend to work *with* underserved communities, we suggest that this is not always enough and that we should see more work done *by* underserved communities (i.e. projects where they are in the driving seat).

In order to reposition underserved communities as active producers of knowledge about their lives, and to recognise them "as subjects rather than objects of research" (Alderson, 2001: 3), it is crucial that they are involved in the project as soon as possible, so they can take an active role in formulating the research question (if applicable), and that they are fully involved when thinking of appropriate engagement methods and topics to cover, when analysing the data, and when communicating the results. They also ought to be involved at every stage of the design process, on an equal footing with the researcher/engagement lead. This not only serves to ensure that power imbalances are not reproduced, but also that the project is not conducted by someone who sits outside the community, and who may hold assumptions about their participants.

Research/engagement *with* – and especially *by* – underserved communities directly involves people and addresses their "silence and exclusion". As you seek to do community engagement, you should see this as an opportunity to capture voices that have traditionally been silenced, which becomes "an ethical issue in itself". By articulating silenced voices, your project should recognise the active role of your participants, value their opinions, and empower them to take part in the development of society (Benoit, 2020). In order to redress the imbalance in power, underserved communities ought to be empowered to conduct the research/engagement activities on their own terms.

To be ethical and address power asymmetries, you must work with your community partners as soon as you begin your project. Community partners should be involved from the very beginning and should help shape the research questions/aims and purposes of your activities. Do not just engage with the community partners when you seek to collect data, but involve them in every single stage of the project, from beginning to end, whether this is a research project or not. Community engagement should be co-produced, and co-owned. It should not be about an individual or an organisation tapping into a community group for data and leaving.

> *"Black and ethnic minority group communities, we are just a tick-box. One of the saddest ways to engage communities, which I think is a failure!"*
>
> *"Research happens around us. Organisations […] ask us to engage, but they never feed-back on the outcomes and objectives and consistently fail to share the data"*

Useful terminology:

Cooperation: Working *with* rather than *on* people. This means a two-way conversation on an issue that is of interest and importance to all those involved (Beacon North East, n.d.).

Equality: Equality entails mutual respect and appreciation between all parties. This means respecting and valuing all contributions, regardless of background. Experts by experience, community researchers, community partners, academic, researchers – all ought to be treated on an equal footing (Beacon North East, n.d.).

Co-production: By engaging with community groups, all new knowledge that is created is 'co-produced'. This means that all parties work together on an issue, without privileging one type of knowledge over another (Beacon North East, n.d.).

Social Justice: Community engagement (research) projects have social justice outcomes. This means that the projects are for a social purpose, seek to have a real impact for those involved, and go some way to reducing inequalities and improving lives (Beacon North East, n.d.).

Community engagement is not just about collecting public insights and data to develop or inform (research) projects. Community engagement is also about building relationships with communities that have been traditionally underserved, excluded, and unheard. It is about tackling power asymmetries and working together to challenge social injustices.

> *"How can you trust the people who always get it wrong to put it right? How do we, not just us in this little group, but how do we, generally, ensure that our voices and the change that we're being told in this new structure, and the change that we're being ensured is going to come, are coming from us, and not from the people who always got it wrong? For me, there's something about not being just at the table but it's about the hierarchy. We're at the bottom, and things go upwards. Turn it on its head. […] If we're talking about structures in this new set-up, we're talking about new ways to meet our needs."*

2.2.2. Working with children and young people

Children and young people under the age of sixteen can be considered a minoritised group as they have historically, culturally, and socially occupied a minority position within society in terms of influence, and access to power (Benoit, 2020). Children and young people not only tend to be excluded from formal power, but also from research and community engagement agendas. Not including children and young people "tends to rest on assumptions that children are passive", and rely on adults to make sense of the world they live in. This results in the marginalisation of children and young people, both in research/community engagement, but also in society at large.

Issues around maturity and competency, and around 'being' and 'becoming,' have also been used as a reason to exclude children and young people from research/community engagement. Are children human beings or human 'becomings'? How does this affect competency to take part in research/community engagement? Are their voices to be trusted? These questions are dated, and we need to move away from the idea that children and young people are in the process of 'becoming' and are therefore 'immature' or 'incompetent'. On the contrary, everyone is both in the process of 'being' (present self) and 'becoming' (future self), and the children and young people who have worked with us have demonstrated high levels of competency. Children and young people are also experts by experience.

Working with Children and Young People at the BLESST Centre

Getting ethical approval to work with children and young people can be a long and difficult process, which can be off-putting. However, it would not only do them a disservice to exclude them from research/community engagement, but it would also be unethical as it would serve to reproduce power imbalances as their voices remain silenced and their views excluded. Before you start your project, reflect on whether children and young people should be involved in your project. If not, what is your rationale for solely capturing the voices and lived experiences of adults?

2.2.3. Principles of community engagement

Community engagement is also about (re-)building trust, sustaining relationships. It takes time. It does not always lead to what may be perceived as 'real outcomes' (e.g. collection of data), but it is key in solidifying relationships, and for working on an equal footing. "We cannot engage with communities until we have built communities" – you have to build relationships with the community groups, so that citizens feel at the centre of the relationships, and so that you can start relocating power *within* the communities themselves. This is also an essential step to take to tackle existing barriers to research.

> *"Why are they approaching us, they have never been interested before"*
>
> *"There is often a 'them' and 'us' view, with the notion that 'they' have the power"*
>
> *"How does this engagement help 'us'?"*
>
> *"We are tired of saying the same things over and over – nothing ever happens"*
>
> *"We never see the individuals again or hear about any progress"*

Community Connexions has used this rhetoric to develop some key working principles:

i) The ultimate aim is to work with community groups to **co-develop** a research idea, and **co-create** community engagement activities

ii) There has to be **equity** – we come together as equals

iii) **Transparency** and **communication** are key

iv) Organisations/individuals involved in community engagement work must make the time to **maintain contact** with their community partners, even if there is no ongoing (research) project

v) Every time an event is being held, the **outcomes** of the (research) project must be **communicated clearly** – no matter how small

As such, community engagement should not be viewed as a one-off exercise, but as developing and sustaining communication and trust with community partners. The role of Community Connexions' Community Development Workers (CDW) has been key for public engagement as they have spent time developing and nurturing relationships with underserved communities across Birmingham and the Black Country. It is thanks to their work that the Trusts can then reach out to groups to conduct research projects that are mutually beneficial.

Engagement with communities takes diverse forms. It may mean maintaining contact by regularly engaging with community members. This could be a phone call to check on people, or a WhatsApp message to share information, encourage and ensure that things are going well. It could also be a newsletter to keep community members up to date with the work they do/the support they offer.

In other cases, community engagement may mean seeking out voices from specific community types to better understand them and/or to inform research agendas. For Community Connexions, we engage with different community types to better ascertain: i) the barriers they face to live healthy lives, ii) the reasons why they do not engage with health research.

2.2.4. Modes of engagement

There is no single way to effectively engage with communities. Instead, it is up to you and your community partners to decide which model of community engagement is best suited for your project. You may need to adapt/change models as the project develops. There are different ways to engage with communities, such as seminars, workshops, lectures, public talks, or joining community group meetings (e.g. coffee mornings or other collaborative community events). We recommend adopting formats that work best for both you and your community partners.

We have found the following approaches successful when engaging with underserved communities:

i) Listening events

These can be organised online or face-to-face. For Community Connexions, we took on supportive roles during a series of listening events, in collaboration with local charities or community organisations who led the listening events. The sessions were hosted in a venue of their choice, at a time that suited community members. They lasted approximately two hours on average. Participants were asked to share their views on the NHS or their experiences of accessing healthcare services. Refreshments and food were always available. In some cases, we needed to have interpreters with us to ensure no one was excluded.

Collaborative listening event at Saathi House by BCHC & BCHFT

For Community Connexions, we worked with many women who attend their local community centre. If we had not teamed up with the community centre from the onset, we would have not been able to include their voices as many of the women were either not allowed or not comfortable traveling elsewhere. This showed that if a listening session is organised outside of the safe space of the local community centre, many underserved voices would have been further silenced.

ii) Health Hack events

Pioneered by the Ladywood and Perry Barr Locality Partnership, 'Health Hacks' are projects that address certain health issues like oral health, obesity, and asthma. Connecting schools and health professionals to address these difficult issues, Health Hack events are a chance for pupils (secondary, but also primary) to learn about and address a thorny issue within healthcare. They are a chance for health professionals to tap into fresh, creative thinking, educate the community and to engage deeply with and inspire pupils from a range of backgrounds.

Community sandpit event hosted at Aston University

iii) Listening table events

These are hosted as face-to-face listening events held in public/private or open spaces. The aim is to encourage one-to-one friendly engagement with community members to chat, listen, seek consent to record data where possible, and find out about each person's stories and experiences about access to health services, their health priorities and knowledge of research.

Community Connexions' "listening table" at The Bob Jones Community Hub, Wolverhampton

iv) Community sandpit events/workshops

Co-design is at the heart of sandpit events. The aim is for organisations and/or community members to come together, listen to some key findings/data, and propose solutions to implement to tackle barriers. Aston University, together with Community Connexions, hosted a community sandpit event where community-led organisations came together and led on a series of projects to support health and wellbeing in East Birmingham (find out more here).

Community sandpit event hosted at Aston University

The list of by no means exhaustive, and it is up to you and your community partners to decide what models of engagement are best suited to your project and your participants. Regardless of the approach you choose, as the researcher/facilitator, it is your responsibility to ensure a **safe space** is created. It is not only about ensuring that the event takes place in a safe environment (i.e. a safe location, and at a time that is adequate), but also about creating an environment where people can be comfortable and feel that they can speak freely, without fear of being judged. Prior to starting the event, it may be worth reminding participants that they are the experts by experience, that you are here to listen and learn from them, and that mutual respect is expected from everyone present.

Remember that regardless of the engagement model you choose, public engagement always "requires public members and 'professionals' to be involved on an **equal footing throughout every stage** of the design and delivery of the research" (Johns and Paylor, 2018).

> *"You want to feel part of the community and you don't want to be treated differently."*

2.2.5. Closing the loop

Working with underserved communities require you to think about the power dynamics at stake. How do you engage with your community partners on an equal footing? What do you need to do to not reproduce existing power asymmetries? One of our key recommendations is that you always think about closing the loop, or about the 'last mile' – i.e. what happens once you have conducted your community engagement activities? If you simply leave, your project will be viewed as exploitative.

> *"I think it's exploitative to be invited to events like these by the NHS, all the time, and nothing is done with that information. We divulge some of the things that happened in our lives, share our pains and relive trauma, to try and educate people. And what we get is: 'Isn't it terrible?' "*

Whether you are conducting a research project, or a standard community engagement project, it is essential that you maintain communication with your community partners even after you have collected data. Communicate what happened to the data, what obstacles you encountered, what the next steps are, etc.

Community engagement should aim to make sure that everyone feels included, listened to, and involved in decision making. Additionally, it should be culturally competent and an initiative for shared learning.

3. What do I need to do before engaging with communities?

The model below is based on the principle of co-production.

Co-Production

Co-producing a research project is an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge. […] Co-production […] represents a more collaborative and egalitarian approach – one where the agenda-setting and key decisions are shared between researchers and public contributors. In this way, we can think of co-production as offering an approach that is different to how public involvement has tended to be implemented, i.e. an approach that is situated more firmly towards the collaborative/horizontal end of the public involvement spectrum.

Source: NIHR, 2021

Essentially, co-production of research means that "research [is] carried out 'with' or 'by' members of the public, rather than 'to', 'about' or 'for' them" (NIHR, 2021). Community partners are therefore active participants in the research process. It moves away from mere consultation (where power remains in the hands of the researcher(s)/practitioner(s)) to genuine engagement from the onset (where power is shared). We recommend you read more about co-production, and what this entails before starting any community engagement project. Some resources are listed in section 9, though this is not an exhaustive list.

While we understand that constraints can come in the way (i.e. some funders asking for a research question prior to community engagement activities), we want to stress the importance of sustained relationships with community partners, which not only lead to true collaboration (i.e. identifying issues that need investigating collectively, and/or letting communities lead the research agenda, rather than the other way around) but also mean that by the time a call for funding applications are circulated, you already have built strong relations with your community partners and identified some key issues that would need exploring.

As such, you should plan the steps below collaboratively, with relevant community partners from the onset (e.g. community members, community-led organisations, schools, faith groups, or charities). The key to successful community engagement is co-production from the start. As discussed in section 2, co-production starts before you hold any community engagement activities. If you aim to engage with underserved communities, you must bear the issues around power dynamics in mind.

> *"How do move away from the experts reporting on us, to us reporting on us? […] How can we be taken seriously. How can we be involved at an early stage in designing services? How can people not view us as amateurs but as experts by experience?"*
>
> *"We need to make sure it's community-led and community-informed. That needs to come from community-based reporting."*

Step 1: engage with existing knowledge

Make sure that the answers to your questions are not already published, or readily available somewhere (e.g. reports, data collected by a community group or organisation) so that you are not guilty of reinventing the wheel, or engaging with community partners who feel that they have already expressed their needs/priorities.

Read and talk to different stakeholders (e.g. NHS Trusts, organisations, charities, schools) about your topics – they may have data they can share with you, and which you could analyse.

Although it can feel daunting or time-consuming, this is a necessary step! Too often, community members are asked the same questions over and over again. As a result, they can feel disheartened and unheard. This can result in further disengagement from the communities in the future, and can deteriorate relationships with your organisation.

Step 2: identify your community partner(s)

Who will you work with? Why do you need to reach out to specific groups?
What existing relationship do you have with the community partners you have identified?

Who will you be working with you to help you develop the project and work on the next steps collaboratively?

Step 3: identify your aims and objectives

What is your project about? What are you trying to achieve? What are you trying to assess/measure? How can the project be genuinely co-produced? What impact would you like to have?

Step 4: identify your engagement model

Once you have identified what data is available and what is missing, you can start planning your community engagement activities. How would you like to engage with your selected community types?

There is no one-size-fits-all model. It is up to you and your community partner(s) to decide how best to engage with your chosen community groups. Seek advice and work with your community partners to co-produce the adequate engagement model for your project.

If you want to hear from underserved voices, a series of listening event might work better than a health hack event. If you want to co-create solutions to tackle barriers that lead to poor health outcomes, a community sandpit event may work better than a Listening tables event.

Step 5: think about generating mutual benefit

Remember that community engagement must generate mutual benefit. What will the participants gain from taking part in your project? Often projects focus on the long-term benefits (e.g. a research agenda that takes underserved voices into account), but what about more immediate benefits? Again, work in collaboration with community members/gatekeepers to identify what would be most appropriate for your chosen groups.

Sometimes, it is important to include short-term as well as longer-term benefits. As part of our Community Connexions project, we gathered data to help shape the research agenda but were aware that the direct benefits to the communities who worked with us would not be noticeable. We therefore agreed to include a community sandpit event to our engagement method so that we could also co-create solutions that would be implemented at a hyper-local level within the next few weeks. You can read more about the project here. Whatever model you choose, make sure that it is not transactional, and not exploitative.

Step 6: plan the event(s)

Identify who in your team is best placed to lead on the event(s). Who will ask questions? Who will facilitate? Who will take notes? Remember – you are not working alone but in partnership with community partner(s). What role will they play during the event? Make sure you plan this together, and that the roles are fairly allocated. Be mindful of who does what – do not allocate yourself the most important/valuable tasks (e.g. do not always allocate facilitating events – an active role – to the researcher(s) and note-taking – a passive role – to the community partners).

Plan the event in a place that is convenient for participants (do not expect participants to travel long distances), and at a time that suits the participants (e.g. avoid early mornings if you want to talk to mothers of young children, as many will be busy getting children ready for school then). For Community Connexions, many of our partners felt more comfortable with us after they met us in an environment that was familiar to them (e.g. their local community centre or religious building). This showed the importance of in-person on-site visits – which have proved highly beneficial with our community partners.

Think about logistics: will you need refreshments/catering? If yes, make sure it caters to the participants' dietary needs (don't offer juice and chocolates to a community group sharing their experiences of living with Type 2 diabetes). Do the dates/times chosen work for everyone (e.g. check religious festivals and other cultural celebrations and make sure there are no clashes).

Will you want to take photos/videos? If so, you will need to seek consent. Make sure you have a form ready to hand out to participants. If this is a research process, make sure you also obtain ethical approval (you may want to embed consent for photos/videos on the same forms to avoid handing out several forms, which can be off-putting). For accessibility purposes, you may choose to seek oral consent (rather than written, as not everyone can write/sign) and collective consent (rather than individual, as less intimidating especially for some underserved communities). Bear in mind that if you are working with children and young people under the age of 16 you will need to take extra steps to get ethical approval as they are deemed a vulnerable group. Getting ethical approval to work with children and young people can be a long process, and can be off-putting for many. However, it would not only do them a disservice to exclude them from community engagement, but it would also be unethical as it would serve to reproduce power imbalances as their voices remain silenced and they remain excluded. If you are conducting a research project, do not start work until you have received ethical approval.

Step 7: think about the power dynamics

Make sure your event is as inclusive as possible. Remove barriers that would exclude community members (e.g. ensure unrestricted access to the venue, offer to have a British Sign Language interpreter on site, offer childcare services).

If your communities of interest do not speak English as a first language, you will need an interpreter.

If the event is online, you will need to think of ways to ensure digital inclusion (e.g. sending direct links to meetings rather than passwords and access codes), providing a list of local public spaces where they can access IT equipment and hold a meeting.

During the event, you will need to make sure that the participants know they are on an equal footing – it is not just about sharing power between yourself and your community partners. What about the participants you recruited together? Think ahead: how will you and your community partners ensure that everyone will benefit from engaging in your project?

Think about access: who are you going to talk to? How will you get access? Who are the gatekeepers? This is a key question to ask as gatekeepers can give access to community groups/participants, but can also restrict access. How may you be reproducing power dynamics within the communities? How do you know the gatekeepers are representing the interests of the majority and not the few? Who has the power? Who are the assets?

You may also find it useful to engage in some preliminary training before starting your community engagement project. Examples of useful trainings include: unconscious bias, intercultural communication, equality and diversity. If you do not have a budget to attend such trainings, there are free resources online.

Step 8: think ahead – what will 'the last mile' look like?

Too often, public engagement activities end after the project leads have collected data. Participants do not know what happens to the project nor the data, and can feel alienated by the process. How will you and your community partners close the loop? How will you make sure your project is not exploitative?

Remember that the aim is not to disappear once the project is finished. The goal of community engagement is to sustain any existing and new relationships you have made. How will you and your community partners do so? Make sure that you adopt an engagement model that suits the different parties (i.e. not just yourself). For example, avoid circulating newsletters via email to keep in regular contact with your community partners if you know that they spend little times on computers/emails. Instead, choose to disseminate updates and keep in touch with other platforms that are already being used by the groups, such as WhatsApp.

Step 9: mental health first aiders

If your project covers sensitive topics – or can lead to sensitive topics being discussed – you and your community partners may hear stories that are distressing. Some participants may also feel distressed re-telling their own stories, or listening to another participants' story. Make sure you think about how best to support everyone's wellbeing and mental health. For example, you may want to have trained mental health first aiders available during/after the event(s).

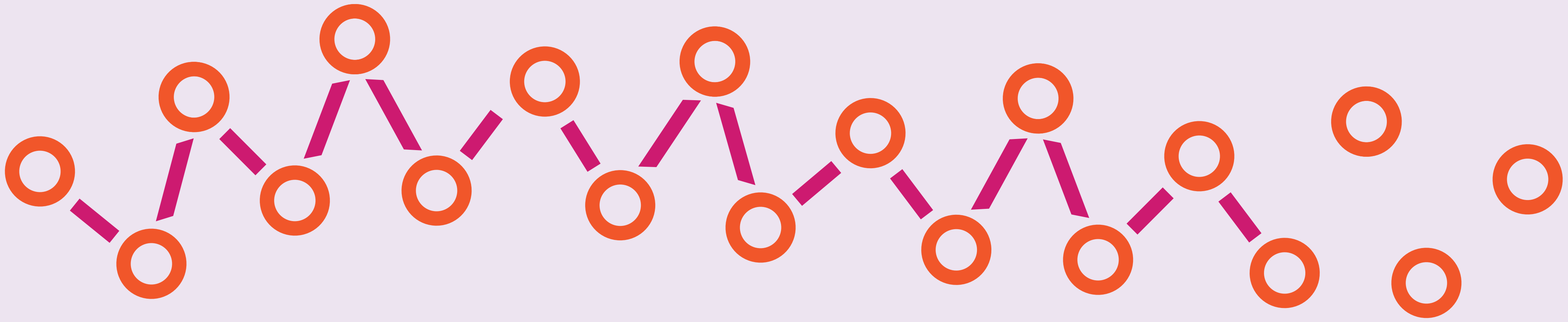
Step 10: advertise the event(s) and recruit participants

Advertise your event(s) in relevant spaces, in appropriate language (plain English – no jargon, and translated where needed), or with additional audio-recordings of key information. Bear in mind that the average reading age, even in mother tongue, is 10 years old. Identify places for awareness creation, e.g. bus stops, pharmacies, online/social media forums (including WhatsApp or Telegram).

Communicate well with participants, and send a reminder prior to the events. Remember that not everyone communicates in the same way. Some may prefer communicating via WhatsApp rather than emails, others over the phone rather than in writing. As such, you may want to think of different ways to reach out to people.

4. What do I need to do while engaging with communities?

- **Introduce** yourself and your team (which includes community partners). It is highly probable that community partners should take the lead and do the introductions – check what is the preferred approach. In the subsequent bullet points, 'you' refers to the researcher(s) and the community partner(s), since you are acting collaboratively.
- **Explain** what the event is **about**, what your project is about, what you seek to **achieve**, and what will happen **next**.
- If this is a research project, seek informed **consent** from the participants – you may want to use a GDPR statement, clearly outlining what the intention of the engagement is for, and then seek consent and signature for taking part (embed an option to gain consent for videos/photos).
- If this is not a research project, while technically you do not need participants to give formal consent, it remains good practice to clearly outline the intention of the engagement, and then seek informal verbal consent from the participants. If you wish to take **photos/videos**, you will need to get written consent and signatures from participants.
- Give people the opportunity to ask **questions** before you start. Take your time answering all questions and addressing all concerns, even if this is taking longer than anticipated. If this is taking longer than planned, this means that you need to review your introduction in the future and that the project, and its aims and outcomes were not clearly explained in the first place.
- Make sure everyone is at ease – signpost participants to the closest bathrooms, refreshments, **housekeeping** information (e.g. quiet space for people with autism), etc.
- Make it clear that everyone will be treated with **respect** throughout the session(s). Make it clear that this is a **safe space**, where everyone has a voice and where no stories are dismissed.
- Plan an **icebreaking activity** if needed (but do not mention that the activity is an icebreaker). Some groups start with informal icebreakers to get the conversations going. Others start the session with a story (e.g. the story of someone who shares their experiences of antenatal/maternity care – or another relevant story for your groups), and facilitate a discussion about the story that was shared, naturally leading to people relating (or not) and sharing their own stories. Remind participants that all stories are valid, and that there are **mental health first aiders** if relevant.
- **Listen**. Do not judge. Never jump to conclusions.
- Put aside your stereotypes and assumptions. Go to the events with a **blank page** and put your participants in the driving seat. Find out how you can support them and provide what they need.
- Too often we start with labels or misconceptions, and come up with pre-conceived ideas of what people need. Often, the problem is with our **lens**, not with underserved communities.
- If you sense discomfort, move on to another topic. Do not probe. Do not cause harm. Getting data will never be more important than **respecting people's boundaries**, and their health and wellbeing.



5. What do I need to do after engaging with communities?

Work with your community partners to close the loop. Communicate with participants: what happened to the data? What happened as a result of the events?

You will encounter barriers. Identify which ones, and communicate these with others. Sharing and learning from works and what does not work is incredibly useful – it will enable yourself and others to build on good practice, and learn to plan for obstacles along the way.

Transparency is key: participants would rather hear that you were unsuccessful in your targets, or that the goalpost has moved, rather than never hear from you again. Explain what you will do next to address the issues you have encountered. They may have ideas to support you!

It's a trade-off – you will not be able to give everything that communities need/want but community engagement is about making these decisions together and keeping the communication channels open all the time.

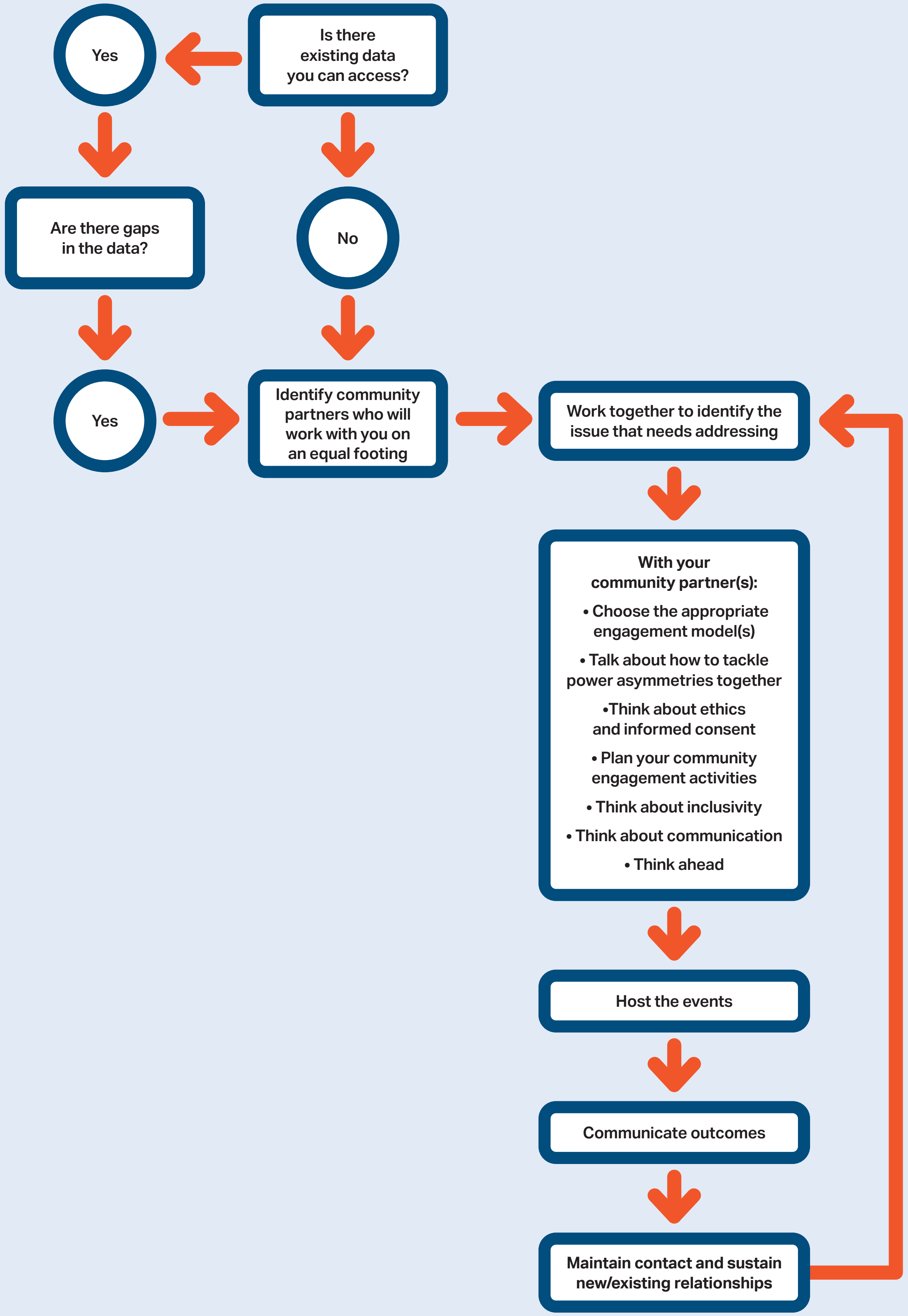
It is not all about data and figures – value qualitative data. See stories as valid data.

Sustain engagement – do not walk away from the communities after your engagement activities. Think of ways in which you can sustain engagement. Will you send regular updates via a newsletter? Or an audio message or a blog/vlog? How will you co-create your next project with them?

How do you lay the groundwork for the community partners and participants in the project to develop? How do you provide the next steps for them, and provide continuous development? For instance, can you help community partners become community researchers, who can be in the driving seat from now on? Can you point them in the right directions and support them during their training, as they see fit?

Your community partners should be given the opportunity to become more involved in research, and be able to set and lead the research agenda. This aligns with the need to train and develop more community researchers in order to address current power asymmetries in research. The aim is to equip local people with the tools to do research and collect data on their own communities, especially underserved communities. Community researchers should be trained, mentored, and remunerated when collecting data. Developing community researchers, and working with them "are likely to lead to effective implementation of research results, enhanced local capacity and greater equity in intellectual power-sharing" (Garnett et al., 2001: 571). As discussed in section 1, your aim should not just be to collect data but to challenge power asymmetries and social injustices – this can only happen if we help build capacity for more community researchers who can lead on the research agenda.

6. Take-away document: Decision Tree



7. Take-away document: Checklist

Here is a checklist that you and your community partner(s) may find useful when co-producing engagement activities with underserved communities. We recommend using this template *prior* to any community engagement activity.

Actions	Initials + date for record:
1. Ensure you are not duplicating efforts Does the data already exist somewhere? If it has been published, can you rely on secondary material? If it has not been published, can you approach NHS Trusts, local organisations or other groups that may already hold relevant data? Only if the data is not already available should you move to stage 2.	
Explain why you need to proceed to stage 2:	
2. Identify your community partner(s). You will not do work/research on communities but will seek co-production. Who will you work with? Who is more likely to be interested in the project? Who is more likely to benefit from collaborating on the project?	
List your community partner(s) + rationale:	
3. Together with your community partner(s), identify the issue(s) that need addressing What do you collectively want to find out about? Why?	
Write your research questions + aims and objectives of the project:	
4. Together with your community partner(s), reflect on the best engagement model(s) What engagement activities would be most appropriate for your groups? Why? Which ones are you ruling out? Why?	
Explain what engagement model you have chosen + rationale:	
5. Together with your community partner(s), think about power asymmetries between the researcher(s) and the community group(s) How will you make sure that you are not abusing power/reproducing power inequalities? How will you make sure that communities that have been traditionally underserved are not exploited? How will you make sure that the project will generate mutual benefit for all parties involved? Who needs to be included, and why? Who is excluded? What power imbalances may be reproduced/challenged in the process?	
List the mechanisms you will put in place to challenge existing power asymmetries and social injustices:	
6. Think about ethics and informed consent If this is a research project, you will need ethical clearance from your organisation. Ensure you include your community partner(s) and provision to take photos/videos during events so that participants do not have to sign multiple forms. If this is not a research project and you do not need ethical clearance it is still good practice to i) seek informed consent, and ii) ensure you are allowed to take photos/videos etc. as appropriate. Remember that if you will need to take extra care when working with children and young people under the age of 16, which should inform the ethical decisions you make.	
Explain how you will ensure that your participants will be able to give informed consent before taking part in any event:	

Actions	Initials + date for record:
7. Together with your community partner(s), plan your community engagement activities Where will the activities be held? When? For how long? Will you bring food? If so, ensure this is not at a time when communities are likely to be fasting. Make sure the food is not only culturally appropriate but that it is also healthy (e.g. do not bring sugary snacks when speaking to a group of people with Type 2 diabetes!). Clearly label food/refreshments (e.g. free from…, or clearly list all allergens).	
State rationale for date/time + location of the event(s): List what you will need on the day:	
8. Together with your community partner(s), think about inclusivity This relates back to the issue of power. It is also about ensuring that you are being inclusive: is the venue accessible to all? Do you need interpreters (incl. British Sign Language)? Do you need childminders to look after young children? Will you need mental health first aiders? Etc.	
List potential obstacles to inclusive participation alongside the actions taken to remove the obstacles:	
9. Together with your community partner(s), think about communication How will you advertise the events and make sure communities are aware of them but also know enough about the project so they can give informed consent? How will you make sure you do not rely one just one gatekeeper to relay the information back to communities? Do you need to translate anything? What formats do you need to use? Etc.	
List of resources needed + rationale:	

Actions	Initials + date for record:
10. Together with your community partner(s), think ahead What will happen once your project finishes? How will you close the loop and sustain existing/new relationships with community groups? What will you do to make sure you do not just leave once you have what you came for? These issues relate back to the notions of mutual benefit, and shared power.	
Explain how you intend on closing the loop and ensuring your project is not exploitative:	
11. Host the events Make sure you only act as a facilitator – the participants and community partners are in charge. Make sure the community partner play an active role – do not allocate them passive roles.	
Write your agenda/itinerary below:	
12. Communicate outcomes Make sure that you maintain communication with your participants and community partner(s). What are the findings? How will they be used? How have they been used? How have they been received? Be transparent. Reflect on the best formats possible and whether translation is needed. Ensure you do not rely on one gatekeeper to pass on information. Communicate clearly with all stakeholders to manage expectations around the timelines: how long will it take you to write a summary of the data collected? When will you share information with other stakeholders? When do you expect change to happen? Etc. Most participants do not mind waiting as long as they are kept in the loop.	
Explain how you will communicate findings and timeline:	

Actions	Initials + date for record:
13. Sustain relationships and support the development of community researchers Once your project is finished, it does not mean that your collaboration with your community partners ends. What will you do to maintain contact and sustain new/existing relationships? How will you help ensure that community groups can remain involved in the research process and take on a more proactive role in research? Will you be able to support individuals so they can develop and become community researchers?	
Explain how you will sustain new/existing relationships:	
List the training opportunities for community researchers in your local area (include contact details) + requirements needed to complete the training:	

8. Further guidance – ethics

Ethical clearance will come from your organisation/institution, and you will need to use their own template and follow their guidelines. In this section, we make some suggestions which may be useful when seeking ethical clearance:

i) In your Participant Information Sheet include a line such as: “If you do decide to participate, you will be asked to sign and date a consent form or to give your oral consent to a researcher.” Seeking oral consent rather than written consent means that you will not exclude communities that cannot read/write.

ii) In your Ethics Application Form, include the following paragraph:

“When possible, consent forms will need to be signed by the participants prior to data collection. Should participants prefer not to sign the form, they can give their oral consent. When possible (such as for interviews) individual oral consent will be audio-recorded and the participant will be informed about this. For focus groups or listening events, consent from all individuals in the group will be given orally and recorded in writing by the researcher to certify the group consent.”

iii) If you work with children and young people, you will need to reflect on how to do so safely and ethically. We strongly recommend that you seek informed consent from the children and young people themselves, even if you have already obtained consent from gatekeepers such as parents/guardians, teachers, etc. This can also be done verbally, though you will need to ensure that the language you use is appropriate and not a barrier to consent and engagement so that children and young people are empowered to consent and take part in the project on their own terms.

When seeking informed consent, we recommend including authorisation to take photos and/or videos.

9. Useful resources

This is a non-exhaustive list of resources you might find useful as you prepare for community engagement:

- Beacon North East (n.d.), Co-Inquiry Toolkit
- General Practice Data Trust Pilot Study: Report on Patient Focus Groups, 2023
- NCPPE Resources
- NICE's approach to public involvement in guidance and standards: a practical guide, 2015
- NIHR A Map of Resources for Co-Producing Research in Health and Social Care, 2020
- NIHR Guidance on Co-Producing a Research Project, 2019
- NIHR Improving inclusion of under-served groups in clinical research: Guidance from INCLUDE project, 2020
- NIHR Reaching Out: Building relationships to increase research impact, 2022
- NIHR Reflective Questions to Support Co-Produced Research, 2020
- NHS England – The Engagement Cycle, 2018
- NHS England – Working in Partnership with People and Communities: Statutory Guidance, 2022
- Rogers, C. and Ludhra, G. Research Ethics: Participation, Social Difference and Informed Consent, 2011

Although the focus is on health and health inequalities, this handbook and the suggested resources above remain relevant for different fields of research.

BCHC.CommunityConnexions@nhs.net