

INVOLVE: A Practical Guide to Being Inclusive in Public Involvement in Health Research

- lessons from the Reaching Out programme

Written by Katherine Cowan, February 2020

Foreword

National Institute for Health Research (NIHR) is committed to focusing research effort on populations and areas where there is greatest need. It is also committed to carrying out more research in the locations where the relevant populations live and work (needs based, place-based research) and beyond clinical settings.

The purpose of the Reaching Out programme – a partnership between INVOLVE and the Research Design Service (RDS) – was to encourage the development of new public involvement and engagement relationships, and new or more effective approaches to building relationships, within communities in RDS localities. The emphasis was on parts of the community who are not usually, or consistently, involved in health, social care and public health research. In doing this work, the partnership hopes to enable public and patient involvement and engagement (PPIE) workers across NIHR and other settings to work together more to achieve common objectives.

Developing relationships with different communities and addressing power differentials are key challenges for all of us with an interest in ensuring a variety of communities are involved in our research. These relationships are the building blocks to involvement in research and ensuring that research reflects the needs of communities. This guide, which draws on the four projects which make up the Reaching Out programme, provides information on what researchers and organisations can do to enable a cultural change and lay the foundations for more inclusive involvement. In short, this guide can inspire those of us involved in research to truly *reach out* to, and develop meaningful relationships with, a variety of communities.

INVOLVE, March 2020

The Reaching Out programme is an important proof of concept that infrastructure focused around communities who are not usually involved in research can be set up, nurtured and leveraged for mutual benefit. As a public contributor I helped select the Reaching Out projects distinctly aware of how the learning and insight they provide will help shape future evolution in this space.

This guide helps distil and share knowledge from the projects but also highlights how leadership is required to prompt a cultural shift which enables a real difference on the ground. 'Reaching out' as a concept should be an indicator of good practice for the health research landscape, but it needs to be enabled if it is to have credibility.

Ngawai Moss, Public Contributor and INVOLVE Member

About this Guide

This guide is intended to be a companion document to *Being Inclusive in Public Involvement in Research*¹ a paper that suggests 12 prompts to researchers and public involvement practitioners, to encourage them to deliver more diverse and inclusive public involvement in research.

The guide provides practical examples, lessons and tips for preparing for and delivering inclusive involvement. These have been drawn from telephone interviews carried out in December 2019 with the leads of the four regional Reaching Out projects. Under each of the 12 prompts from *Being Inclusive in Public Involvement in Research* are key learning points with examples to illustrate them:

1. Check your power
2. Value the people you work with
3. Use language carefully
4. Consider inclusive locations
5. Listen and seek agreement
6. Get from A to B, perhaps via Z
7. Collaborate
8. Invest in the workforce
9. Commit to a relationship
10. Evidence, evaluate, share, reflect
11. Act small, think big
12. Be values based, socially innovate

This is intended to be of use and inspiration within the National Institute for Health Research, research organisations, charities and industry to support the inclusion of those who are underrepresented and who have not traditionally been involved in health, social care and public health research.

A separate full evaluation of Reaching Out has been ongoing and will produce an in-depth analysis of the methods and impact of each region's project.

Background to the Reaching Out programme

Reaching Out is a programme which was commissioned by INVOLVE and the Research Design Service in 2018. Its purpose was to encourage the development of new public involvement and engagement relationships, and new or more effective approaches to building relationships within communities in the Research Design Service localities. The emphasis was on members of the community who are not usually, or consistently, involved in health, social care and public health research. The aim was to support new or improved research partnerships and broaden involvement in research. There are four projects within the Reaching Out programme.

Overview of the four Reaching Out projects

Reaching Out **East of England** is a collaboration between the Research Design Service, Healthwatch Essex, Refugee Action Colchester and the Jaywick Sands Neighbourhood Team.

¹ *Being Inclusive in Public Involvement (PI) in Health Research: Things to think about: for researchers and practitioners*, INVOLVE, 2019 <https://www.invo.org.uk/wp-content/uploads/2019/02/Being-Inclusive-Health-Research.pdf>

The aim of the project is to create more diverse community-based research partnerships for ongoing involvement and engagement. The focus has been on involving **vulnerable children and young people**, including **refugees**. The primary activity to date has been to convene community partners and the young people with whom they work, and to allocate small grants to enable them to develop their own innovative solutions to facilitate honest conversations about mental health and wellbeing with children and young people in their own communities. A 'Young Minds Inspiring Health and Wellbeing Research Event' was then held where the young people shared their ideas with researchers and representatives from the NHS, local authority and community and voluntary sector. Researchers are drafting collaborative bids with young people to answer potential research questions which have emerged from the Young Minds work and a series of co-design thinking workshops are now being developed.

Reaching Out **North East** is a multi-disciplinary partnership between the Research Design Service and partners from the region's research, academic, public involvement and health and social care sectors. Its aim is to address under-representation of certain groups within its public involvement networks by building new and lasting partnerships with diverse communities. These specifically include **people from Black, Asian and minority ethnic backgrounds, mental health service users, pregnant women, rural communities, working people and vulnerable children**. The project started with a launch event to make connections and explore opportunities for reaching the six constituent groups. This was followed by targeted work to map and build relationships with different community groups and leaders. This has led to meetings, workshops, conversations and consultation events to better understand how people want to be involved, and to facilitate connections between the communities and research colleagues.

Reaching Out **South Central** aims to broaden the diversity of patient and public involvement in research by building long-term and sustainable relationships with underrepresented communities in Southampton. It is coordinated by members of the Wessex Public Involvement Network in collaboration with other National Institute for Health Research partners and public contributors. An analysis of the demographic makeup of the region's current public contributors revealed that several groups were under-represented, including **people aged 26-55, men, LGBT+ people, people from minority ethnic groups, people who follow a religion, people in employment** and those with **average or low educational attainment**. The team attended community-based events and met community leaders, advocates and representatives to begin to build relationships with these audiences. The first major outreach event was a storytelling workshop to understand and celebrate the diversity of the region. The team then helped to organise and attend a garden party at a local housing estate, bringing researchers along to chat to residents and find out more about their experiences, interests and needs.

Reaching Out **Yorkshire and Humber** is a collaborative project between the Clinical Research Network, the Applied Research Collaboration, the Research Design Service and York Travellers Trust. It is focusing on involving **Gypsy and Traveller Communities** in research, a group with the poorest health of any ethnic group in the population. The team is establishing ways to engage with and build trust between community members, researchers, National Institute for Health Research and other local institutions, such as universities. The aim is to provide a platform for community members to express their views about health and social care to relevant research teams and other partners, and to raise the profile of Gypsy and Traveller community organisations in the region. Activities so far have included regular meetings with the York Travellers Trust to plan and develop the project, and engagement with the wider community, to consult on priorities and communication preferences, at the Lee Gap Horse Fair, a key community event.

1. Check your power

Working with members of the public in research operates in a context of imbalanced power relationships between people, researchers and institutions. Even more so if your aim is to work with those who may be considered as vulnerable, discriminated against, marginalised or lacking power. Try to understand power relationships within your context, your role and how to operate to promote inclusion.

Reverse traditional power dynamics

- All four Reaching Out projects proactively took steps to reverse traditional power dynamics. They enabled the community groups to articulate their needs, determine their priorities and set the agenda for their involvement in ways, places and formats that suited them.

*From the start we've said "This isn't about us, it's all about you, what do you think? What do you want to do? We are here to deliver something for you and with you". We've set it up on purpose so that the power dynamic that exists is very much in their favour. We've been very united as 'professionals' in having that approach. There's a big thing about taking your own ego out of the equation. It absolutely isn't required in this context. **Yorkshire and Humber***

*At our very first meeting [with the young people], the ice breaker I used was to try and put everyone on a level playing field. We didn't start off going round the room saying, "I'm the professor of whatever". One of the things we did was getting people to get in a line around their birthday, not their date of birth. The other thing was getting one person to say something about themselves – something they like doing, something that's happened to them – anyone else in the room who can relate to that comes and stands next to them and says, "I've done this". You then recognise that you have a lot of things that connect you. **East of England***

Be aware of how you and your organisation may be perceived

- The teams became aware of how their traditional professional approaches might appear to or impact on communities who do not usually get involved in research. They were mindful of first impressions, their manner, presenting style and appearance.
- They recognised the mental exhaustion that comes from being involved as a patient or member of the public in research, including networking with new people and being consulted in different ways. The practitioners considered how they might come across both institutionally and personally, and whether that might create barriers to people getting involved.

*I've been aware of how I present myself. I work in the university, which is a fairly relaxed environment anyway in terms of how you dress, but it's still formal, it's still that learning environment. Working with the migrant community and the mental health community, I've made a conscious decision to dress down, to not go with a PowerPoint, to not go with lots of print-outs but to just go and chat with people, which feels to me that it's less threatening or formal. I didn't want to be someone stood at the front in a suit, pointing at a PowerPoint, as I thought that would turn people off. **North East***

*I remember going into a Sunday lunch club and just thinking: "I don't know what I'm meant to do, I don't know where I'm supposed to sit, I don't know where I'm supposed to get a drink, I don't know who I'm meant to speak to" and realising that's exactly what you do when you bring a patient into a conference. **South Central***

Try not to grab or assume power

- The teams left their professional comfort zone in order to get into the communities' comfort zone. They did not assume power. They were willing to be humble and, at times, vulnerable in order to dismantle their own power as professionals and hand power over to the communities. This helped them secure trust and input.
- They were also conscious of past mistakes, where communities may have had negative experiences of research, and the need to acknowledge and address these in order to reverse imbalances of power and perceived hierarchies.

Definitely we needed [the community members] more than they needed us. We were very conscious that we were not in an environment or setting that we were familiar or comfortable with. We were very reliant on them to guide us and accept us and allow us to come into their community and work with them.

*I think that if there was a power dynamic, the power was with the community groups. We took ourselves out of our comfort zone, we were completely in their space and we were kind of without all the usual infrastructure that supports the work we do and that we're so used to. It was a very exposing experience for me a lot of the time. I felt that I was going into someone else's space and they had knowledge that I didn't have, they had an understanding of the community and how it worked that I didn't have. I felt like I was in a slightly vulnerable position. If we were to ask our community reps if that's their perception, it might not be, but that was certainly how I felt. **South Central***

2. Value the people you work with

Recognise and nurture the people who become involved in research. Many will have existing and emerging passions, assets and talents, not to mention different perspectives and opinions. Diversity is the engine of innovation.

Agree an appropriate reward for involvement

- The teams budgeted for the remuneration of the groups and individuals who were involved. This generally included time, travel and food. They clearly communicated their payment policies and processes to those taking part from the start and were open about limitations.
- They ensured that any forms of payment, including vouchers, were appropriate and useful for the recipient.

*We said there was remuneration available and they asked, "What type and how do you normally do it?" We've agreed now with each of the groups we work with what the process is. Generally, we've gone down the route of vouchers and providing refreshments. We have explained that this might not be the case ongoing, but during the development phase that is the case and that's how we're doing it for the time being. All that's happened is that different groups have requested different vouchers, so we make sure those vouchers are usable. There's no point in me giving Love to Shop vouchers to the kids in rural Cumbria because there's no big shopping centres nearby. So they asked for Amazon vouchers because they can use those online. **North East***

There are different ways to value, recognise and reward

- Reward and recognition of value also came in other forms, including certification of involvement and actively providing feedback and thanks, as well as provision of assistance, time and support for community activities.

I offered all the young people the opportunity to be a Community Fellow at the University of Essex. One of them, who was only 16, I wanted him to have that recognition – I had to get it signed off by the Vice Chancellor because he was under 18. So I've made sure that's on his CV. They also got certificates.

They got gift vouchers. So for every meeting they got a £15 Amazon gift voucher.

*After each major thing that they've done I've written them a personal letter detailing what they've done, with a couple of pictures, and copied it, if they've wanted me to, to their college tutor, so they know what they've been doing. It's those small gestures, it's a reciprocal relationship. **East of England***

Reciprocity is key

- All four Reaching Out regions recognised that reciprocity was important for securing people's involvement. Research will benefit from inclusive involvement and communities will benefit from that in the long-term, but the individuals also needed to get something out of it more immediately. They thought carefully about what people might get out of different types of involvement.

The team in **South Central** made a distinction between the different ways in which they involved their communities. They learned that the ways in which they demonstrated the value of those types of involvement needed to vary. For example, at a one-off community event held in a housing estate, residents were invited to engage with researchers by having a

brief conversation. Individuals had a chance to enter a raffle to win a prize, acting as an incentive to encourage people to engage.

We had to think about what we can offer to people that will be engaging and interesting and will in a tangible way make them feel like they're getting something out of the conversation that we're having with them. "How can we make our conversation with you meaningful to you right here and now?"

By contrast, the relationships they built with local community organisations and leaders were ongoing and long-term. While remuneration was offered, the team noted that some individuals were not always keen to take money and seemed to value practical help and assistance more highly. This included paying for materials and helping distribute flyers for the community event across a housing estate.

We almost had to convince the community organisations and representatives to take our money and to allow us to pay them. They were so passionate and dedicated and so used to doing things for free that we almost had to insist that we would pay them and that we would pay them the full price, because that was what we should be doing. And even then it was considerably cheaper than what we would [usually pay] for a conference or an event in a hotel or a university.

This has had a direct impact on the relationships built, trust gained and the ability of the research team to continue to involve groups that were previously under-represented.

Take safety and safeguarding seriously

- Valuing people also meant being aware of their wellbeing and safety. Some groups that the Reaching Out regions involved, such as children and young people, and vulnerable adults, required safeguarding procedures and clear boundaries to be put in place.

Although I knew I'd never be on my own with the young people, I got the enhanced DBS [Disclosure and Barring Service check]. The way the young people joined the group was that they were introduced by a community group that they were already connected with. All of the young people had an adult youth leader who was their point of contact. As project lead, I made it very clear that I was there to support them in the project but not with anything personal. So any issues that came up for a young person, I could refer that back to the charity. If there were any issues, I talked to my own line manager at work and shared anything I wasn't sure of. That's what was so great about one of the partners who worked with younger kids: they were able to be part of the project but supported through their groups. So when they came to the event they came with adults or their parents. We didn't have any situations where we were looking after them directly.

*I made a big effort to ensure they got taxis. Our meetings were in the evening and in the winter it was dark. I knew that one of them was vulnerable and had been bullied, so I made sure they always had a taxi home if they wanted after meetings. **East of England***

3. Use language carefully

Health research, and public involvement, is littered with jargon. Avoid it. Guides and glossaries exist to help you. Also, consider the language you use to communicate beyond simple translation: to avoid potential for misunderstanding, confusion and/or offence. Be mindful of how to describe each other in research partnerships. Some don't like certain terms (e.g. Service user). Others do. Some researchers prefer the use of titles. Others don't. Agree together.

Learn what language to use

- Working with communities who have rarely, if ever, been involved in research, meant that the Reaching Out teams needed to communicate clearly, appropriately and effectively.
- By taking a community-led approach to inclusive involvement, the practitioners created opportunities to explore language and understand what words to use and avoid. They developed mutually respectful relationships in which mistakes could be made and corrected.

When first approaching the Gypsy and Traveller Communities, the Reaching Out **Yorkshire and Humber** team were acutely aware of the potential sensitivities of language and the need to learn from the community itself.

On our way to that first meeting [with the York Travellers Trust] we had a long conversation about what we weren't going to say and how careful we would be not to put our feet in it. I'd not worked with the travelling community before and I felt very self-conscious about the words that we were using, the language we were using. That first meeting was great, it was such an eye-opener. They were really open, and we talked a lot about language and the way that their community uses language. It's very different from medical language. All of us said something stupid in that first meeting but said sorry and we learned, and they were really patient with us. We've been quite open about "If we say something stupid just tell us; we don't know, you're going to have to tell us the language." All the stuff around medical terms that they wouldn't use generally, they've been very generous in giving us the space to make mistakes.

The opportunity to meet and explore language with a community organisation, to hear their stories and experiences, was key to the team's learning. A strong relationship with the community leaders was developed and has become a foundation on which future work can be based.

We've all read things in the media, seen things on TV, we think we have an idea of what people will be like, and for me it was so different, and it was so nice to talk to people. We need to be clear that you can't make assumptions, you need to talk to a community to understand their perspective

*They said using the term 'mental health' could be a bit of a barrier, particularly with the refugee community, it wasn't necessarily something they felt comfortable about. So, they called it health and wellbeing, although in the end we did end up focusing on mental health and emotional health. **East of England***

*We decided to look at mental health, which [the Gypsy and Traveller Communities] call 'bad nerves' – that was a key area that they wanted to focus on. **Yorkshire and Humber***

Talking about involvement in research with people who have not been involved in research

- The Reaching Out practitioners found that talking about research was not always helpful. It made more sense to people to talk about health and about understanding community priorities. This then informed and led to conversations about research within a relevant, recognisable context.

*We said that research was going on in the region and we want to make sure that it's appropriate and relevant to people in the North East from a variety of communities, "Would you like to have your say in what research looks like?" We didn't sell it as patient and public involvement as I think sometimes that puts people off. It was more about coming to help us make research more relevant. **North East***

*I didn't use the word 'research' too much. I focused it more on health and wellbeing. We wanted to really hear what matters most to children and young people around their health and wellbeing. I didn't want to bombard [the local neighbourhood officer] with loads of information about the NIHR, and all that stuff we usually do. I basically said, "We work on the NHS social care research and there's this opportunity that is really unique to drive research from where the need is". I then said, "Tell me about what you do." **East of England***

*The [storytelling] event was described as an opportunity to celebrate communities of Southampton and the diversity of the city. Then there was a small link to the fact that we as a research team wanted to better understand the communities of Southampton and how we can work together. We focused our conversations around why this matters, rather than research. We spoke about things such as how if we only speak to one particular population in society, we're only ever going to make our health services appropriate for that one particular section of society. **South Central***

Be adaptable and responsive to different communication needs

- Language is important, but so are methods of communication and having the skills to deliver them, both in person and remotely. The Reaching Out teams had to adapt their standard professional approaches and adopt the preferences of their community groups. This included communicating via platforms such as WhatsApp and Facebook, using photographs and images as a means of communication, picking up the phone rather than emailing, and having in-person contact, both planned and spontaneous.

*They said, "Please don't email me, please don't phone, please write me a letter." And lots of the migrant women who were involved do have email, but they don't really read them because they're 'official', sometimes a little bit scary to open, especially if it's coming from an official address. So they wanted a WhatsApp group because they communicate by text. That was a surprise because when you're dealing with researchers and patients who are regularly involved, everything goes by email. **North East***

*We learnt that our formal and professional approach that we're used to – ie reaching out with a polite, professional email and expecting people to respond – didn't get any response. So we just started turning up at places. We found out about community events and just started turning up. **South Central***

*You might be communicating with a group of young people who are developing an app, or you might be communicating with adults with learning disabilities, and it's about that skill of being able to adapt your communication and develop your communication and facilitation skills. There's a lot of thinking on your feet and reacting to situations. When we had someone who didn't want to speak out loud, we had to think about how we could adapt that setting to enable her to participate and feel like she's part of the group whilst not making her stand out. **North East***

*It's about being able to listen, to talk, to be open and transparent, but also explaining everything. We're used to talking to researchers every day. We did notice after the first couple of meetings that some members of the group were a bit quieter, and we needed to be able to bring them in. One member emailed me and said they weren't going to be involved anymore because they didn't feel they were contributing as much. I reassured them that it was absolutely fine, you might not have much to stay at this stage, but you might later on. So we've created a WhatsApp group and they're so brilliant on that. So this person who was really quiet, we've used a different method of communication and that's working really well for them. **Yorkshire and Humber***

4. Consider inclusive locations

Think about where, when and how public involvement can be most inclusive. Universities, hospitals, science centres, libraries, community centres, arts venues, the street, online, radio, social media – the list of places is limited only by your imagination. What might work for one group of people working together, might not for another. Decide together.

Choose a venue that is right for the community

- All four regions worked with their community groups to identify and agree where to meet. The venue was key to people turning up and therefore needed to be appropriate, comfortable, welcoming, accessible and easy to find. Using community venues was another way of supporting those communities.

*For the first one we used the university because the young people themselves said they would like to go and see it. That was their request. When we asked them at the end, they said it was great and they loved it because it was a bit funky, on campus, near the students' union. But all the parents said, "No, you should come to us." So, I've held the last two meetings at a hub where families who have settled in the area come to as a resettlement centre. **North East***

*We've let them lead the way. For the next meeting we said, "When do you want to do it, where do you want to meet?" It's all about shaping it around them and really taking feedback from them. For the next meeting they said they wanted to come to us, they were fine to travel, so they came down and we put on some nice refreshments and lunch. It was literally just talking. We didn't have an agenda or anything, it was informal, but we were learning so much. **Yorkshire and Humber***

*The venue [for the storytelling workshop] doesn't look posh but it does its job and it's physically in the middle of where most of the community people we were inviting lived. Some people had been there before, others hadn't but they immediately felt comfortable because it's clearly a community space. What was really important for us was that people were comfortable, but also that we were walking the walk: we were actually investing in the community by being there for that event. The money we paid to be there was going straight back into community initiatives. **South Central***

Create formats that are inclusive and appropriate

- As well as making sure the venue was inclusive, the Reaching Out practitioners ensured that the format was inclusive. They paid attention to the practicalities such as materials, layout and food. What worked for one group may not have worked for another. They avoided traditional professional approaches, such as formal agendas and presentations. They worked with flexible, informal agendas and overarching objectives instead.

East of England Young Minds event

Having it in the art gallery was a neutral space based in the community. The agenda was very open. Obviously, we had to have some agenda, but we wanted the event to be as interactive, relaxed and informal as possible. The young people didn't want any speakers. We had one of the young people open the event, which was her idea, to tell her own mental health story. And after that we didn't have any speakers as such, but we had these four areas where the four projects were able to share what they'd done. All the delegates move around. It was very chaotic and noisy, but we had a lot of positive feedback. All the delegates had to get very involved. The other thing was the food. The young people chose pizzas, but we also put on some food that was made by one of the asylum seekers who had set up their own catering business. That mix of food was quite complicated, but everyone enjoyed it and that was important – the food is always very important in these things. We also made an effort to get

a really good facilitator for the event, someone from a youth justice background. We picked someone who the young people would feel comfortable with and who would be fun.

South Central Storytelling Workshop

To facilitate and deliver their Storytelling Workshop, the South Central team engaged an experienced creative storyteller from a not-for-profit organisation within the community. She was experienced in and able to create a respectful and empowering space in which people from different cultures, faiths and backgrounds could interact. She set the tone of the day and made it clear that there was a space for time-out, and people could share their own story or something more generic if they wanted to. There was no pressure. The facilitator used creative methods to help people express themselves. Some people chatted, some wrote their thoughts down, and some used visual or artistic materials, such as paints and collage, to input. Different contributions through different means were enabled. People were encouraged to tell their stories to each other, rather than being on the spot in front of the whole group. People could get to know each other with total autonomy over how much they shared. Employing an experienced professional, rather than trying to learn the skills as public involvement practitioners or researchers, was the right thing to do and was a vital first step towards building relationships and trust, understanding the community better and gaining insight into what they wanted in order to become involved in research.

Be adaptable and willing to do things differently

- Timing was important. Some meetings took place outside of office hours, during the evening and at the weekend. Being prepared to be flexible ensured members of the community could attend, although this had implications for the practitioners' working patterns.
- Going to existing community events – for example a horse fair and a housing estate allotment party - was an effective way of meeting and consulting with multiple members of the communities at once. These opportunities were made possible by establishing relationships with key community groups and leaders.

*[The researcher] contacted [the mental health group] and told them about her work, and they agreed that we could come along and talk to them about what we're doing. So we went along and had around 13 people at the first meeting. We had to think of different ways that they could be involved as not everyone was comfortable speaking out loud. We had lots of post-its, some people just drew pictures. It tested our skills: yes, we got people along to the meeting but how do you get them to engage in the discussion? **North East***

*Not everybody wants to join a PPI [Patient and Public Involvement] database or join an advisory group or have a long-term involvement in something. For a lot of these individuals that traditional way that we do PPI is not aligned with the priorities in their life. We had to find a different mechanism to make sure we're listening to their opinions and their voices. **South Central***

5. Listen and seek agreement

Dialogue simply does not happen without active listening. Listen carefully. Then act on what you have heard. Or give good reasons why you might not be able to.

Create opportunities to listen

- In order to be able to listen, the Reaching Out teams had to create inclusive and appropriate environments where communities could comfortably contribute and be heard. This included taking creative approaches: using art, for example, to encourage input and enabling people to contribute virtually if preferred.

*I did a little bit of a presentation just to set us on track. There were a lot of blank slides in that presentation because I wanted to put the message across that we are shaping this project together. It's a joint project. I'm genuinely really interested in people's stories and it was great to go out without a formal agenda and just find out about these different groups. **East of England***

*We acknowledged that as researchers in Southampton, we had not done a very good job of listening to communities in the past, and this was the first step in a journey in which we wanted to take to get to know you better and to listen to people to understand them. The normal motivations that keep the current audience involved don't fit the new audience. That's why the new audience aren't involved. Things like "I've retired and I'm looking for an activity", that attitude isn't necessarily fitting for a working-class person who's trying to feed their children. We needed to have had more conversations with those groups early on to work out what the offer should be. **South Central***

Show that you are listening and responding to feedback

- The practitioners were conscious of the importance of giving feedback and showing what has happened as a result of listening to a community. It was also important to manage expectations and be open if a request or suggestion could not be acted on. They gained trust by being honest and accountable.
- The teams had to be prepared to change their plans based on what they heard the communities say. The earlier the communities were involved, the easier it was to make plans.

*At the end of the meeting we asked if people [in the mental health service user group] would be prepared to talk to a researcher about their research, even if it was something that wasn't on their list [of priorities for research]. They said yes, they would, as long as they had a chance to see the topic first. I had a researcher approach me and she was talking about access to support services for people with depression following drug and alcohol problems. So I went back to the list and one of the things that they had suggested was research on access to services out of hours, so I went back to them and asked if it was ok for the researcher to come along. They could see that we had listened and now a researcher has visited them twice to define her project. **North East***

The listening process is ongoing

- The teams showed the communities respect by listening, confirming, acting and checking, and continuing that cycle of negotiation. This took time, especially when multiple voices were involved. It required patience and pragmatism.

We always said to [the York Travellers Trust], "We've got this pot of money, what shall we do with it? How can we help you in terms of your needs and how can we help you in terms of the things we should

be focusing on?" When we put the objectives together, we made sure we got input from them. We did change a few as a result. The knowledge they had really helped us.

They really appreciate that we'd given the time to listen to them. It was listening, we were learning from them. We sat there for two hours and literally just listened. They educated us, they told us what we needed to know. We all walked out of there feeling really inspired. Every conversation was gold dust.

[You have to] make it visible to them that you have listened. Even those small little tweaks, like when we showed them the objectives and they said, "We don't think that's feasible, we don't think that's going to be achievable", and then showing them that we'd made those changes. It helped with the trust, it perhaps showed them that we were serious about listening to them. We showed them we were good at feeding back. Taking constructive feedback is important too. You have to be quite thick skinned and not defensive!

*Any decision-making takes three times as long as it would do if it was just us. It takes so long to get from A to B. Because we're trying to be trustworthy, we can't just take a unilateral decision because that would defeat the whole purpose. **Yorkshire and Humber***

6. Get from A to B, perhaps via Z

At the beginning of working in partnership with members of the public, starting points might be different for different partners. In finding your clear purpose and planning for involvement be prepared not to start where you think is the beginning, be flexible and allow time to find the route together. Consider structural constraints as well as value the commonalities and differences in your partnership. Be prepared to have some discussions about sensitive subjects.

Involve people in the planning stages

- The Reaching Out projects took different approaches to identifying which groups to involve. Some were led by the makeup of their local community and the level of their unmet health needs. Others looked at who had been involved to date and compared that with the demographic profile of their region.
- The teams realised that involving people at the start of a project in the planning stages is important but not always easy, especially when involving people who have not traditionally been involved. Some projects were able to secure very early involvement while others had to create open, flexible plans that could be shaped later, after community members had been identified and engaged.

*We really wanted [the Gypsy and Traveller Communities] to have a say about what direction this project goes in. We started off with a blank canvass. When we were putting the project together we really struggled. We didn't know what we were going to do. We knew that we wanted to work with the gypsy community, but what did we need to do? That really needed to come from the community, we all agreed on that. So we put a rough idea together of what our plan was, but it was quite broad so it could be shaped by the community. **Yorkshire and Humber***

*I drove out to Jaywick, the most deprived ward, and knocked on the door of the Neighbourhood Team there, and it evolved from there. I was lucky as the first person I met was leading a project involving children and young people, so that's why we decided to make our focus children and young people. **East of England***

Be open to possibilities and new opportunities

- In order to reach people who had not previously been involved in research, the teams had to think creatively about where to find people and how to connect with them.

*I'd meet with someone and they'd say, "Oh there's a meeting on Tuesday night with the local youth service on youth crime in Colchester", and I made sure I went to as many of these opportunities as possible. I went to that meeting thinking I'm not sure it's exactly relevant, but when I got there, it was like being in a sweet shop: there were youth workers, the local borough council and I got to meet some really key people. Normally we don't get those opportunities. That meeting was after hours in the evening, and normally you might think it's got nothing to do with research it's not a good use of my time. **East of England***

Be prepared to make changes

- Building relationships and engaging new communities took time and was a learning process, and inevitably with that new insight and learning, plans needed to adapt or change altogether, strategically, logistically and practically. The ability to be flexible and responsive was key.

At the meeting we held up a plan: for every group in the room we were going to hold four meetings a year and that's what we costed for in the grant. I don't think we should have done that. We should have waited and allowed the groups to develop, as they now have and let them lead how we would take it going forward. We tried to be too directive at the beginning and we quickly became aware that we can't say how the group is going to run. The community needs to say, "This is how we want to be engaged by you". **North East**

We delayed our first workshop by six weeks. We knew that we could fill the room, but we knew we wouldn't be able to fill it with the people who we needed to reach. So we chose to delay and then spent some time just going into communities. This was one of the biggest learnings that we've come away with. There was a real naivety in our planning about the amount of time we would require and the amount of investment you need for relationship building. **South Central**

7. Collaborate

As well as individual people, many community organisations have a huge amount of knowledge and expertise about public involvement. Some specialise in working with specific communities e.g., black and minority ethnic groups, asylum seekers, etc. Understand and work with organisations to enable communities to lead and own their involvement in research.

Find local community groups to collaborate with

- In order to reach individuals who had not previously been involved in research, the Reaching Out teams identified and collaborated with community support groups and organisations that were already working with and representing them. They took time to approach people, recognising that collaboration needed to be based on trust and mutual understanding, as well as shared goals and values.
- Most Reaching Out teams took an iterative approach to finding community organisations. Drawing on existing contacts and online searches, they set up in-person meetings and other networking opportunities, often in new and unexpected settings. Original contacts led to new contacts, which led to more new contacts. This took time but enabled them to grow their contact databases.
- Collaborating with community organisations helped the teams to learn about the needs of those communities. Gaining insight into their challenges, preferences, attitudes and experiences enabled the development of tailored involvement and engagement approaches.

*I started by doing a bit of googling and thinking, “Right, who are the potential people in this locality that would be good to go and meet?” I had Jaywick in my mind and I was aware that Jaywick is one of those places that everyone wants to go to, all the TV programmes. I was aware that I needed to tread very carefully. That’s why it was important that if I did go there that I didn’t impose an idea on them, that it came from them. Luckily, I found a key person, a Neighbourhood Officer in the district council, and went out to meet her. It took a bit of persuasion; I think they were cautious of people. The Neighbourhood Team was the first partner, and they introduced me to other relevant groups, which included a refugee group that was supporting children and young people’s health and wellbeing. **East of England***

*We had an intern who was googling, searching, Facebooking all the community groups in Southampton. And then we mapped those groups in the area and crudely ranked them as to whether or not they hit our target demographics. So if they were a group of male single parents, that would hit both our male and our working age range categories. **South Central***

*They’re not hard to reach but it takes time to engage them. First you have to work out where the communities are, who the contacts are – that can take time and it’s usually by chance or snowballing. **North East***

Gaining credibility and trust

- Once the community organisations’ trust was gained, they helped to facilitate introductions and provide access to people who had not previously been involved in research. Being associated with individuals and groups that were known to and trusted by the communities gave the Reaching Out teams credibility.

What worked really well [at the Lee Gap Horse Fair event] was that York Travellers Trust was there. At first it was just us setting up and we were a bit nervous, but as soon as the guys from York Travellers Trust came over, people recognised their faces and they came up and they were then happy to talk to us. It was interesting to see that because otherwise people were just walking past. When

they saw someone they knew, they came over. [The Trust] leader was somebody who has a lot of visibility and credibility within the community. **Yorkshire and Humber**

The charity introduced us to somebody who was a trusted person within several communities. He had taught lots of the migrant families to speak English and had really helped them. We went and spoke to him and he thought that lots of the communities that he was involved with would be really interested in the work that we were doing. [He] put the feelers out and managed to find 18 women who wanted to come along. **North East**

Give something back to the community

- The practitioners were all aware that community and voluntary organisations often face challenges in terms of capacity, finances and the nature of their work. Their collaborations were also an opportunity to reciprocate by offering practical help and support to those organisations. It was important that the collaborations were mutually beneficial.

The **East of England** project collaborated with a number of partners, giving them funding to run small-scale projects to engage children and young people, to learn more about their health and wellbeing needs, and to develop longer term relationships for the research team to draw on in future.

At the art group, [a young person] came up with this idea, Mood Mosaics, and I thought that would be an amazing way to capture what matters to children and young people. And at that point I thought, "Hang on, we don't need to necessarily organise all this through our big partnership group. Maybe what we could do is to get some of the partners to come up with their ideas and then get on and do them." So at the next partnership meeting I asked them all, "If we were to give you up to £2000 each, what could you do to engage the children and young people in your community to effectively talk about their health and wellbeing?" So, we ended up with four mini projects that were designed and run by the partners and, more importantly, by the young people. At the next Partnership Group meeting they came prepared and we had lots of art material and spent that meeting with the four groups, planning out their pitch. After the meeting they went off and we set up a process for governance for them to apply to us for the money - very light touch but I wanted an audit trail. They summarised their ideas. We then allocated them the money and let them go off and get on with their project.

I knew that practically speaking, with the resources we had and with me project leading it no more than one day a week, I wouldn't physically be able to manage a really massive project. It had to involve a smaller number of partners, who'd open the door to more people. It was the best thing that could have happened because I then didn't need to micromanage anyone and we got so much more out of everybody. We ended up with four really creative and different ways of reaching out to children and young people. They used their own ideas to engage their own communities.

Be prepared for challenges

- Not all groups have a positive perception of 'authority' or the public sector, or see the relevance of research. Challenges when engaging groups ranged from differing priorities through to hostility. The teams had empathy and understanding for these kinds of challenges and recognised them as a potential barrier to inclusive involvement.

I went to one particular group and they did not like me or the fact that I work for NHS or government - I was the root of a lot of their problems because I work for authority. I got a tough time and I didn't know how to handle it and I didn't know how to handle the questions. It was an enlightening experience. I'm not an outwardly confident or egotistical person so it might have been surprising for them to see someone going "Oh I don't actually know what to do right now", and not to give them politician-style responses.

*The impact of what we do in PPI is quite far removed from what some of these community groups are doing on the ground. That's a broader issue for PPI: it is quite an intangible process to get involved with and it relies on being able to see the long-term impact of things like research, which can be really long-term and may not have that much direct impact or influence within a small community. A lot of the community groups that we wanted to work with were hugely stressed in terms of capacity and working with really vulnerable people, and had a huge range of immediate and pressing issues, almost life and death for a lot of people - being able to put food on the table for their children and things like that. Community groups that represent those kinds of people find it very difficult to see the benefit of contributing to research that is maybe five, 10 or 15 years away from having an impact on the NHS and on practice. **South Central***

8. Invest in the workforce

Effective public involvement requires investment in personnel, whether these are researchers or in defined practitioner roles.

Inclusive involvement requires the right skills and personality

- The Reaching Out projects required personnel with advanced knowledge of public involvement, skills in facilitation and communication, and the willingness to be authentic with people.
- The role of the project lead was key for establishing more inclusive involvement mechanisms, and for developing a delegated, sustainable long-term plan for its delivery. While one or two people were dedicating to building trust, they needed to share their responsibilities across their research teams, in order to be confident that the relationships would be maintained and valued as an ongoing resource for inclusive involvement.

*I think it needs a dedicated person to facilitate this kind of relationship building and brokering. It needs to be someone who's a people person, someone who's genuine. **East of England***

*Being personable in those environments is so key. The researchers we brought along to our event, they were the same, they're naturally personable. They're confident talking to random people. **South Central***

Establishing the foundations for inclusive involvement takes time, effort and resource

- Planning for and delivering inclusive involvement was time-consuming and created significant workload for all four projects. Activity to develop contacts and relationships required repeated efforts and did not always lead to an immediate, tangible outcome.
- The support of senior leadership was vital. For this type of work to be sustainable, an understanding of its demanding nature is required. Resource must be committed to help manage the time, workload and responsibilities that the practitioners will face when developing inclusive involvement opportunities.

*We went to a church to deliver a talk after a sermon. We turned up half an hour early for tea and coffee, we sat through the service and then we spoke at the end. And I remember being questioned by a colleague: "How long did you speak for?" 10 minutes. "OK so why did it take 3 hours?" There was a disconnect in understanding. We can't just waltz into a conference, talk for 10 minutes then walk out the other door, like those conveyor belts that some academics do. That wouldn't have worked. People wouldn't have respected it. [To not commit additional resource to inclusive involvement] perpetuates the idea that outreach work in communities and relationship building is something that can be tagged on to an existing job, and I don't think it can. If organisations want to take diversity and outreach seriously it needs to be recognised for the amount of resources and capacity and skills it takes. **South Central***

*The impact of the workload to get these groups up and running is not to be underestimated – it's huge. If it is given priority, it will become part of people's role. It's in all our working plans to work with more diverse communities, but I'm not sure there's an appreciation of how much back-work there needs to be done to make that happen. Maybe that needs to be factored in when people are planning to increase diversity. **North East***

Be prepared for the work to be rewarding as well as challenging

- The Reaching Out practitioners described satisfaction, pride and professional and personal growth from their work to make involvement more inclusive. Nevertheless, the work was challenging, logistically and emotionally, with people working beyond their contracted hours in new and unfamiliar settings.

*This is whole new territory for me. It's been incredibly useful to learn about working with a community. I'm learning and I'm just going with the flow. **Yorkshire and Humber***

*It can sound quite intimidating and it was intimidating, but it was also probably the most rewarding thing I've ever done and the most inspiring thing I've ever done. So I would want people to know that while it may be quite a difficult journey, it's so going to be well worth taking. **South Central***

9. Commit to a relationship

Inclusive research often revolves around effective relationships. Consider how you might first meet, nurture the first flush of friendship, acknowledge that things might not always go smoothly, that long term relationships can flourish, and that sometimes, things come to a natural – or planned – end.

Take time to establish the relationship

- The Reaching Out practitioners all described the time they took to get to know various community groups and individuals, finding out about them, listening to them, learning and gaining trust. They acknowledged where involvement in research had been inadequate in the past. This was a vital aspect of demonstrating their commitment to the relationship.

*It took us the best part of nine months to develop relationships with people working with migrant populations, so they trusted us and they agreed to let us talk to some families. Even once you've identified the right person to talk to, that trusted individual within the community, you've got to build the relationship with them for them to understand that you are a trusted individual, that they will allow you access to their community. The first year has been all about developing relationships, you're not actually doing PPI: you're selling PPI, you're selling yourself and you're selling your organisation as a bona fide organisation that people should get involved with. If you take that time, it's more likely to have a long-lasting impact. **North East***

*We spent a long time just talking. We did talk about the project, but it was really more about getting to know each other and I think we've got a trusting and trusted relationship now with [the team] from the Travellers Trust. But that was a long time before the project officially started. **Yorkshire and Humber***

*In those two weeks putting the bid together I went and met a lot of people, I bought a lot of coffees and I went and physically drove around meeting people, going to evening meetings that looked relevant in the community and just listening as much as I could, while thinking, "Who are the best people to involve?" **East of England***

Be honest, authentic and genuinely interested

- Gaining trust and demonstrating commitment required the practitioners to be willing to be genuine and honest, developing authentic connections with the community individuals. They brought their personality and authenticity, not just their professional persona. This sometimes felt exposing but also led to stronger relationships and firmer foundations on which to base future involvement work.
- The teams actively demonstrated their commitment to the relationships they were forming. This included reading about and immersing themselves in different cultures, offering practical assistance to community groups and investing resources in groups and projects that were important to those communities. This showed the communities that the teams were serious about working with them and not just using them for their own gain.

It was very much about us as individuals, having a personal face, building relationships. People were interested in talking to us, we were not nameless people sending emails, we were actually turning up in their communities and taking a much more human approach to it. If we were offering ourselves as a pair of hands, that was more valuable. I helped [the community leader] flyer the estate and she was overwhelmed by that. It was not only about time, but also recognising how long it takes to get people to turn up to events, we recognised the work she had to put in to get people to come to the event. That was one of the things that helped solidify our relationship. We took time to find someone to read blood pressure, as they were interested in that, we took that off their hands. It was about getting stuck

*in, trying to be part of what they're doing and contributing in a way that is meaningful to them. **South Central***

*It's about having the confidence to treat people as people, and not just as research subjects. It takes a leap of faith to put yourself out there. **Yorkshire and Humber***

Acknowledge past mistakes

- Some communities may have had negative experience of being involved in research or other consultation exercises. The Reaching Out projects were conscious of this and were careful to make plans to maintain a long-term commitment to their communities to ensure those communities felt respected and had a positive experience, rather than feeling used.

*In our local space there's been quite a lot of work done with that community. But when we started talking about it, although there'd been quite a lot of research done, the community didn't really have a good experience of research previously, we didn't want to repeat those mistakes and that's why we took a more community-led approach. It's the classic tale of somebody comes in full of enthusiasm, does a piece of research and then disappears, they never see them again. So they just end up feeling like lab rats, just a convenient piece of data, they don't hear about what happened. It's superficial, tokenistic public involvement. With the exception of the odd individual, people have just parachuted in and then parachuted out again. **Yorkshire and Humber***

*Researchers' projects and funding dies. Then everything goes. The mosque has loads of good examples of researchers having relationships with them for the duration of the project and then they disappear. **South Central***

Lay strong foundations to achieve positive future outcomes

- All the practitioners acknowledged the importance of the early investment in the relationships with community groups, leaders and individuals. The level of work to demonstrate that commitment in the early days will pay off in terms of long-term trust, health working relationships and the future involvement of people from those communities.

*It is time-consuming getting out there and building the relationships initially, but I think once you've done that it then reaps huge rewards. Once the relationships are built – obviously you've got to invest every so often – if you meet the right people, they will spread the word much more effectively than we can. There's been so many connections and sparks from this small project. **East of England***

*They can tell us what they don't want, they tell us what they do want, and we didn't have that at the early stages, so that's good. I think that because we spent so much time getting to know them, I think that's really helped build a solid space to stand on while we start to tackle some of the more difficult bits. **Yorkshire and Humber***

10. Evidence, evaluate, share, reflect

Capture and evaluate your public involvement, publish it if you can. Theory of Change approaches can work well to evaluate involvement, and help with establishing partnerships and common purpose.

Contribute to a growing evidence base for inclusive involvement

- Awareness of the value of inclusive involvement in research is growing, but the evidence base for delivering it is relatively small. There is an opportunity for practitioners in this field to document their experiences and help others learn and undertake their own approaches to involving people who have not traditionally been involved in research. Sharing mistakes is as important as sharing successes.
- All four regions are contributing to a large-scale external evaluation carried out on behalf of INVOLVE. They have been collecting data, recording reflections and logging experiences from the start of the process.
- With many organisations wanting to be more inclusive in their activities, learning from projects that have involved seldom-heard communities has relevance and applicability beyond the health research sphere.

We've created an impact log, and we use the Google drive for that, and everyone has access to that. Everything we do, we reflect back on it, doing individual reflections on what we've learnt and seeing what others have said. We're able to capture things through that and see what people are learning and see what we already do and what else we need to do to help people. The more we go along and the more we do, we'll definitely capture more learning.

I'm working with our university engagement team and talking to them about the Reaching Out project, what we've found really works. There's a lot of open doors when I start to talk about this stuff, it's fitting in with wider university priorities. I've already started sharing learning around the practicalities. We usually have a teamwork event for the Research Design Service, and I did a presentation about the challenges we'd come across.

*It was really useful because now we're starting to do more public health research, public health is really high on the agenda, they're starting to use different methodologies, it is more community, place-based research, asset-based research. Some of the learning coming out of this project has been really transferable to those kinds of projects. The principles we've developed, the little bits of learning we're coming across are really useful when people are planning their PPI and their engagement. **Yorkshire and Humber***

Capture learning informally through reflection and feedback

- In addition to the formal evaluation, the projects have captured ongoing learning in a variety of different ways, both formal and informal. These include newsletters, feedback forms, shared-drive activity logs, photo-documentation, blogging and via Twitter - #reachingoutpartners.

The **South Central** team set up a blog at www.reachingoutsoton.com. It used the platform to document its activities, archive photos, share successes and tips and reflect on challenges, providing a learning resource for both internal and external use. Topics included:

- *Some personal reflections on the project so far*
- *Investing in Outreach. Building relationships takes more than an email... Time, a friendly face and authenticity are key*
- *Storytelling event and the challenges of creating inclusive spaces*
- *The parallels with tenancy/resident engagement*

- *Allowing 'Reaching Out' to adapt and develop is about letting communities own the direction of the project*

*One of the things that's been quite useful for getting feedback is after the events I always make an effort to email everyone and say thank you. You often then get an email back saying thank you back, which contains some feedback on what we've done. Within our meetings we always have space for reflecting. Right from the first meeting we established a set of principles with our partners and one of those was about saying thank you and feeding back. So, I think we've had that culture within the project. It's been built in as a principle. **East of England***

11. Act small, think big

A small social change can make a big difference. Supporting people, researchers and members of the public, to develop confidence, learning and skills is valuable for further change and growth.

- The Reaching Out projects all started with a simple aspiration: to make public involvement in research more inclusive. They all aimed to be informed and led by the needs of people who have not traditionally been involved in research.
- They needed to be innovative and creative to connect with and listen to people who do not find traditional, formal or academic involvement mechanisms suitable. It was not necessarily about increasing numbers of people involved, but rather enabling deeper, high quality involvement with new, diverse audiences.
- Basic friendliness, helpfulness and the act of listening actively and respectfully have set the projects on a trajectory to achieving a new level of inclusive involvement, engaging with communities who have never previously had a chance to influence research.
- Conversations lead to connections, which can lead to activity and eventually impact. While the long-term impact of the Reaching Out projects cannot yet be measured, all four regions observed how some simple changes had already made a difference to how they do public involvement, to their research and to the communities and individuals themselves.

Making a difference to how patient and public involvement (PPI) is done

*We now have a database of a more diverse population who would consider being involved in the future in the work that we do. It's changed how we do PPI. We used to have two consumer panels a month, a very general PPI panel. Since we started working with lots of these other different communities, we now only have one of those consumer panels a month, because if it's more appropriate, the researchers go to the individual communities to talk to them rather than going to our generalist panel. So that's changed a little bit of our working patterns. **North East***

*Our notion of 'good PPI' is very much built around institutions and organisational structures in the way that we work, which is a suitable mechanism for a certain type of person to engage with. It may not be suitable for a different group of people. One of the things that we recognised was that trying to stick to this traditional idea of how you do PPI doesn't necessarily allow you to access different groups of people. It has completely changed how I talk to researchers about PPI. There are projects where I wouldn't even bother to recommend that they get a patient on their steering group, if they're working with a community where I know that's never going to happen, and I would completely focus them on arguing the case for more ad hoc engagement with the right audience. I also think that I am able to articulate more clearly to the researchers about how to resource this, costing for PPI staff time or for other people's time. This has influenced how I talk to researchers about how they plan for PPI. **South Central***

*There's something about raising the profile of this kind of approach. We've done it, it is something people can do, there is some really key learning about the time that it takes and the trust, but hopefully being able to raise the profile will give people the confidence to go out and do it, reassure them that it has been done, it can be done with the different methods that we've used. **Yorkshire and Humber***

Making a difference to research

We went along [to the migrant women's group] and explained about PPI and then the researcher started to give her ideas about the research she was planning, which was all about access to cancer screening. And the women stopped her and said, "What's cancer screening? What does that mean?" It

became apparent that there's a whole load more work that needs to be done before that about general access to healthcare. So that research is now no longer happening. The researcher said, "I can't jump to that when there are other issues that need researching first." The women could see that they were having an impact immediately on what research was being done and what the money was being spent on. One of the women who's been to all three meetings, she's now a co-applicant on the consortium that's putting in a bid on the health avatar project. So she's gone from not knowing anything about PPI to being a co-applicant on a £7 million consortium bid. **North East**

Through the introductions that have been made there are all sorts of other connections being made. The new ARC [Applied Research Collaboration], they're involving some of the community partners in some of the work they're doing. One of the young people is now involved in our university service user group, involved in teaching. She's also got involved as a national research ambassador for one of the health conditions she has. **East of England**

Making a difference to people and their communities

I tried not to put too much pressure on them. I said, "You can have a space, let us know what it is you need." I feel that really worked and enhanced our project – it wasn't something that we planned from the beginning it was something that emerged from the partners, from us letting them take the lead with their own communities and trusting them with some resources to do that. The young people with the art group, they said, "We might have failed, you let us take risks with our own ideas, we didn't know if they were going to work". They really appreciated it and gained confidence from us enabling them to do that. Some of the young people are so vulnerable and I think it's given them such a boost to their confidence, and they've seen how they've been able to make a difference, which they want to do, and they don't seem to have that opportunity in other aspects of their lives. Because of the little project that they did, Essex Council for Voluntary Youth Services has been successful in attracting two more lots of funding. **East of England**

There's an opportunity to have a wider impact outside of our speciality. That's something that we've got a responsibility to do. Ultimately, we hope that this project will lead to better research and to better healthcare, and that people will want to work with [the Gypsy and Traveller Communities]. We know that there are some real needs in this community, we know that projects need to happen, and it's about joining that up. It's about raising the profile and saying, "These groups are here, they're available to be involved and here are the different ways you can do it." **Yorkshire and Humber**

Making a difference to public involvement practitioners

Our own learning has been above and beyond what we could have ever predicted. Also it's so inspiring to work with communities and to learn from them. And it's inspiring to hear the researchers' reactions and to think about the impact it will have on research. **South Central**

I've got as much out of it as I've put into it. It's been the most satisfying piece of work I've done for years; I've absolutely loved it. I can see the impact that it has. **East of England**

12. Be values based, socially innovate

Avoid diversity and inclusion becoming a box-ticking exercise by adopting a values and outcomes based approach. Support the ideas of the diverse and the many, not the few.

Establish your values and principles for inclusive involvement first

- Embarking on a programme of inclusive involvement brought a degree of uncertainty about process. The Reaching Out teams were open to how they would work with new communities but were clear about their values. The work was underpinned by the principle of being community-led, and the intended outcome of each project was genuine involvement of people who have not traditionally been involved in research, even if they had not yet established how to make that happen.
- The projects were guided by their inclusive values from conceptualisation to delivery and long-term planning. This enabled them to make decisions about what to do, what to change, to identify what has worked and what has not, and to be innovative. They had the freedom for things to go wrong, and to draw on that as a means of learning and improvement for the future.

The **Yorkshire and Humber** Reaching Out team underpinned their plans for working with Gypsy and Traveller Communities with a set of community engagement principles that were developed in line with the National Occupational Standards for Community Development. These were to be:

1. Asset based - our project will recognise, mobilise and build on community and individual assets.
2. Community Driven – community members will shape the project and have a key role in management, delivery and decision making.
3. Relationship oriented – all activities will aim to build trust and relationships. We will seek to acknowledge and challenge power dynamics which exist within the project.
4. Locally relevant – We will work with local communities to find outputs which are relevant to their lives and experience.
5. Sustainable – We will promote empowerment and learning within communities to enable ongoing work beyond the life of this project.
6. Reflective – We will promote individual and collective learning through reflection. We will be open to changing our processes in response to that learning.

It's really about recognising, mobilising and building on the individual community assets. It's about building trust. From that first conversation [with the York Travellers Trust] we said, "What do you think needs to be done? What are the areas that you think we need to be focusing on?" They were really open about the health issues that they have, they talked about their personal experiences. We wanted to mobilise the knowledge that they actually have. They have worked with the community for so long, they've got the knowledge, they've got what we need.

I feel quite strongly that the time that we've spent has definitely gone in our favour, because we've been very clear right from the beginning that it wasn't about us, it was about what they wanted to do. We were offering to support them to do a piece of work that is about them and for them. Yes we'll get publications out of it, but that's not the end point of the project.

Work with the community to change and adapt your involvement processes

- Collaborating with partner organisations from within the communities enabled the Reaching Out teams to find people to involve, but also required them to be open to new

ways of working. This ranged from adapting and tailoring their traditional approaches to involvement, to changing their working patterns and style of networking.

- The practitioners realised that their existing involvement structures were suitable for those who were already involved, but not for those who were under-represented. They had to think creatively about how to innovate and provide alternative opportunities that would be practical and give confidence to those whose voices were not being heard.

It was really important to me that the bid was driven by the community. Effectively I went out and facilitated that. They shaped it because they identified where the need was, which was children and young people. The whole point of this exercise was to engage new communities and basically get to know them and build those links. Anything else was a bonus. The challenge we set them wasn't about gathering data on health and wellbeing needs, it was about enabling us to reach out further into their communities and have conversations. It was all about the relationships. I thought we could frighten people off if we weren't careful. East of England

Conclusion

This guide has captured some of the experiences and learning from four different projects which had the same aim: to engage and develop relationships with people who have not traditionally been involved in health and social care research. The projects have all laid the foundations for their organisations to deliver more inclusive involvement in the future. They have demonstrated how community-led, innovative approaches can work. The Reaching Out programme has shown that this requires a willingness to embrace change on many levels, including ways of working and expectations of how public involvement is done. It has also highlighted the importance of ensuring that involvement in research is a mutually beneficial experience for both the researchers and the people who get involved.

Inclusive involvement cannot be a tick-box exercise. It requires an investment of time, expertise and resource in order to identify people, to develop a shared understanding of their motivations and preferences, and crucially to gain their trust and enable the building of relationships. Learning and good practice in this area is growing. Organisations and researchers that are already delivering a more inclusive type of involvement in research should aim to capture that learning and share it across the health research community and beyond.

As patient and public involvement becomes more mainstream, it presents an exciting opportunity: to work in new and innovative ways to ensure that involvement is genuinely inclusive of the diverse communities whose needs research seeks to meet.

Acknowledgements

Caroline Barker, Strategic Lead Patient and Public Involvement, University Hospital Southampton R&D (including NIHR Southampton Clinical Research Facility and Biomedical Research Centre)

Megan Barlow-Pay, Public Involvement Advisor, Research Design Service South Central

Gary Hickey, INVOLVE

Tracey Johns, Project Lead Reaching Out North Essex, Public Involvement Lead NIHR Research Design Service East of England

Samaira Khan, Public Involvement Lead, NIHR Research Design Service Yorkshire and Humber

Jo Lally, Senior Research Methodologist and PPI lead, Research Design Service North East and North Cumbria, Newcastle University

Ngawai Moss, Public Contributor, INVOLVE member

Christine Smith, Public Involvement Lead, NIHR Applied Research Collaborations Yorkshire and Humber

Kate Sonpal, INVOLVE (to December 2019)

Bella Starling, author, *Being Inclusive in Public Involvement in Research*

INVOLVE is a national advisory group funded by the National Institute for Health Research (NIHR) to support public involvement in NHS, public health and social care research.

If you would like to know more about what we do, please contact us:

INVOLVE

Alpha House
University of Southampton Science Park
Southampton
Hampshire
SO16 7NS

Web: www.involve.nihr.ac.uk

Email: involve@nihr.ac.uk

Telephone: 023 8059 5628

Twitter: @NIHRINVOLVE

If you need a copy of this publication in another format please contact us at INVOLVE.

Email: involve@nihr.ac.uk

Telephone: 023 8059 5628

This publication is available to download from: www.involve.nihr.ac.uk