



Healthworks
the community health charity

Community Voices on Local Health Issues and Research

‘It Needs People to Listen and to Talk’

Ellie Clark

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Contents

- Abbreviation Guide.....	Page 1
- Abstract.....	Page 3
- Background.....	Page 4
- Introduction.....	Page 5
- Methods.....	Page 7
- Findings.....	Page 10
- Conclusions.....	Page 23
- Recommendations.....	Page 28
- Reference List.....	Page 29
- Appendices.....	Page 35
- Acknowledgments.....	Page 39

Abbreviation Guide

NENC- North East North Cumbria

PPIE - Patient and Public Involvement and Engagement

ARC- Applied Research Collaboration

ICS - Integrated Care System region

NIHR- National Institute for Health and Care Research

CRN- Clinical Research Network

HAREF- Health Equality for Ethnically Marginalised Communities

VCFSE - Voluntary, Community, Faith and Social Enterprise

WHIST - Women's Health in South Tyneside

SMCOPA- South Mountain Chinese Older People's Association

Abstract

Within the North East and North Cumbria (NENC) there are large differences between people's health status based on access to care, health behaviours and wider social factors. These are called health inequalities.

People with certain characteristics protected by law, such as age, gender, ethnicity, disability, groups of people who are less able to access services (e.g. people who are homeless) and groups of people with a lower socioeconomic status (e.g. based on education level and employment) are more likely to experience these inequalities [1].

Based in Newcastle, Healthworks has worked across the region for over 27 years with disadvantaged local communities to tackle health inequalities and improve health and wellbeing. Healthwork's patron is Professor Sir Michael Marmot who is the Director of the Institute of Health Equity and a leading global voice on the social determinants of health. Healthworks works in partnership with the NHS, local authorities, universities and communities to devise cost effective solutions that secure good health impacts for conditions that inhibit quality of life.

This report is an initial mapping project to understand health issues that affect people within the region. Views on research and what good practice would look like were also explored. The accessibility of services, a lack of awareness of local resources, in addition to wider issues around finances and a lack of time were highlighted. This report provides some summary suggestions for actions to inform engaging with communities that are currently under-served by services and research.

Recommended actions included:

- The need for open access resources including offline options.
- Better partnership work with Voluntary, Community, Faith and Social Enterprise (VCFSE) organisations. Raising awareness about available resources and research.
- Evaluation of research from the point of view of people and better accountability for this. This could include more work on showing the outcomes of research.

¹ Ethan Williams et al., "What Are Health Inequalities?" The King's Fund, June 17, 2022, <https://www.kingsfund.org.uk/publications/what-are-health-inequalities#pathways%3E>.

Background

The North East of England is home to over two and a half million people; over a third of which live in the 20% most disadvantaged areas of England. Evidence shows that those living in the most disadvantaged areas face the worst health inequalities. The national NHS England Core20PLUS5 approach is aimed at reducing health inequalities and identifies that this population group requires focused attention.

In the North East region, healthy life expectancy is around 59 years. Almost 70% of adults are classed as overweight or obese and the number of adults who smoke, including pregnant women, is higher than average within England. Furthermore, fewer adults living in the North East achieve the weekly recommended level of physical activity or eat five portions of fruit and vegetables a day[2].

Long term strategies to address health inequalities require partnerships between local organisations that deliver services to the region [3]. There are a number of organisations and partnerships, both nationally and regionally, working together to address health inequalities. Ongoing engagement with and the involvement of the local population is an important part of this.

Within research this process is called Patient and Public Involvement and Engagement (PPIE). The experiences of groups of people who are most likely to face these health inequalities should be focused within work to address health inequalities. Over the course of this report, the term 'under-served' groups is used to better communicate the impact of historical, institutional and societal barriers on different communities. It also places the responsibility of doing better involvement and engagement within institutions.

²

Paul Court, "Making Health Services Work for Deprived Populations in the North East" NHS England, December 9, 2022, <https://www.england.nhs.uk/blog/making-health-services-work-for-deprived-populations-in-the-north-east/>.

³

David Buck, "Reducing Inequalities in Health: Towards a Brave Old World?" The King's Fund, August 13, 2017, <https://www.kingsfund.org.uk/blog/2017/08/reducing-inequalities-health-towards-brave-old-world>.

Introduction

Currently, there are a variety of different organisations undertaking PPIE within the NENC Integrated Care Systems (ICS) region. The main organisations involved in this are: Local VCFSE organisations, research centres within the National Institute for Health and Care Research and NHS organisations. PPIE is often undertaken by community partners and PPIE representatives or through open platforms advertising opportunities available [4,5,6,7,8,9].

Further work to diversify PPIE in the region has embedded a Health and Wellbeing Research Partnerships Coordinator in the VCFSE sector based on previous research [10]. Other approaches like 'Research Ready Communities' raises awareness of research and develops partnerships with under-served communities by creating local Research Champions within VCFSE organisations [11].

⁴ NIHR Applied Research Collaborative North East and North Cumbria, "Your Experiences and Ideas Could Change the Lives of Others," <https://arc-nenc.nihr.ac.uk/pice/>. (Accessed on March 21, 2023)

⁵ NIHR Newcastle Biomedical Research Centre, "Public Partnership Advisory Group," <https://www.newcastlebrc.nihr.ac.uk/patients-carers-public/public-partnership-advisory-group/>. (Accessed on March 21, 2023)

⁶ Research Design Service North East and North Cumbria, "PPI Information for Patients and Public," <https://rds-nenc.nihr.ac.uk/public-involvement/public-involvement-consumer-panel/>. (Accessed on March 21, 2023).

⁷ Sunderland City Council, "Sunderland Ageing Well Ambassadors," <https://www.sunderland.gov.uk/ageingwell>. (Accessed on March 21, 2023).

⁸ Voice, "Groups." <https://voice-global.org/groups>. (Accessed on March 21, 2023)

⁹ Cumbria Northumberland, Tyne and Wear NHS Foundation Trust. "The Involvement Bank." Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust. <https://www.cntw.nhs.uk/services/involvement/involvement-bank/>. (Accessed March 21, 2023.)

¹⁰ Voluntary Organisations' Network North East, "Meet Greta, Our New VCSE Health & Wellbeing Research Partnerships Co-Ordinator for the North East and North Cumbria | Voluntary Organisations' Network North East," Voluntary Organisations' Network North East. <https://www.vonne.org.uk/meet-greta-our-new-vcse-health-wellbeing-research-partnerships-coordinator-north-east-and-north>. (Accessed on May 11, 2023).

¹¹ NIHR, "Research Ready Communities Pilot Evaluation 2021/22," October 10, 2022, <https://www.nihr.ac.uk/documents/research-ready-communities-pilot-evaluation-202122/31642>.

PPIE takes time. There is some work that argues 'there will always be additional voices that can be heard – usually the ones that require researchers to reach out beyond their comfort zones. Context will also keep changing so research priorities must keep up'[12]. In the spirit of this, this report seeks to undertake additional work on understanding what local health issues are the most pressing in the NENC ICS region . Meetings with community members, took place online and in community spaces to facilitate open debate and discussion.

Additional work also involved understanding any previous experience with research and what best practice for future work between the public and research would look like. This included cultural and social barriers in engagement with research and how to try and overcome these. Most of the people who participated in this report worked within or had used services in the VCFSE sector.



12

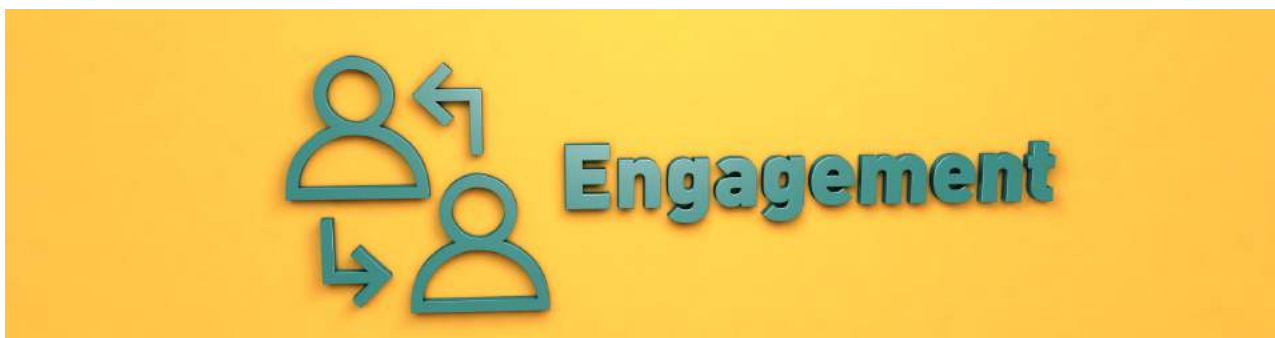
Claire Marsh et al., "Priority Setting for ARC Research – Can We Take a Longer-Term View?" NIHR Applied Research Collaboration Yorkshire and Humber, November 3, 2022, <https://www.arc-yh.nihr.ac.uk/news-events-and-media/blogs/priority-setting-for-arc> .

Methods

Participants

A collection of views was undertaken during October 2022 until May 2023. This engagement was done in a variety of ways to engage different people. Views were purposefully sampled to include under-served groups and people from services that worked with these groups. Representatives included individuals and charities that worked in and with the following people and community groups:

- Refugees/ Asylum Seekers
- Ethnic minority led charities
- Charities working with ethnic minorities
- Charities working with carers
- People aged 50+
- Women
- Men
- Disabled people
- People with mental illness
- Young people
- Places with high socio-economic deprivation [13]
- Local Charity infrastructure organisations



¹³ Office for Health Improvement and Disparities, “Local Health: August 2022 update,” August 2022, <https://www.gov.uk/government/organisations/office-for-health-improvement-and-disparities>.

Figure 2: List and Location of Charities, People and Groups Contacted within the North East North Cumbria Integrated Care Systems Region

Location Number	Contacted
Newcastle upon Tyne	5
Chopwell	3
Ashington	2
Sunderland	1
South Shields	1
North Shields/ North Tyneside	3
Walker	2
Byker	2
Benwell	4
Throckley	3
Cumbria	2
Durham	1
Hartlepool	1

Approaches to engaging people included attending VCFSE networking events, attending community groups and asking the opinions of those who worked in and accessed these places. Infrastructure organisations such as Healthwatch Cumberland, the Health Equality for Ethnically Marginalised communities (HAREF) network and individuals from various VCFSE sector organisations were also contacted. Individuals were invited to undertake a 30-45 minute online/face to face meeting. For these meetings, participants from VCSFE organisations were remunerated for their time with a £25 Amazon voucher.

An information sheet was produced for both group work and individual meetings (see appendix 1). This was available in Plain English to give some background on what questions were going to be asked, why this was being done, by who and what would happen afterwards. General Data Protection Regulations around how data would be stored and how to withdraw from the research was also covered.

Questions asked included:

- In the local area, what helps you live a healthy life?
- In the local area, what makes it hard to live a healthy life?
- If you wanted to know more about taking part in research, where would you look for more information? Are there places in the community that could be useful for getting this information?
- What do you think good working between the public and researchers looks like?

Data analysis

Each participant gave their views through either an online or face to face meeting. Notes were written either by the interviewer asking the questions, by the participant themselves or together. Notes were sent back for feedback. Regular updates were emailed out to previous participants updating on what was happening with the report.

Most people gave their opinions as their own, others wanted to keep it anonymous including the place they worked at and others were happy for their views to be reflective of the organisation they worked for. Notes from each meeting were summarised then sorted into themes based upon each question. Prioritisation of themes was deduced by the most comments in each theme. For each theme within each question, quotes from different meetings were chosen to add context and detail.



Findings

Local issues that affect health

The following questions focused on what things in the local area help people and what creates barriers to people living a healthy life. What was healthy was left to the participant to define. Examples of specific projects that helped people live a healthy life are also shown below.

Question: In the local area, what helps you lead a healthy life?

Connecting with people within a local context and place

Connections with other people and within local places were important to health.

'The centre itself is important especially for older people. Without it some people wouldn't be here. Taxis can be contributed to for transport. Programming in the centre works so that people can stay all day doing different things and make friends who encourage them to come to the other activities'- A Community Centre in Walker

Workers who had similar lived experiences or an understanding of these experiences were a part of this.

'Services with a holistic approach supporting local communities and having strong knowledge and understanding of ethnic and diverse groups' and 'Understanding the needs of the community without complicated questionnaires' helps build that connection'- Imran



Accessing information at the right time

Knowing where to access support and information was also an important part of being able to lead a healthy life.

‘The local knowledge of services, knowing places in the community to help meet a person’s need’- Rebecca and Members of Women’s Health in South Tyneside (WHIST)

‘Taking a personal approach to your own health is important. It’s not a one size fits all, you need to find things that work for you. Prevention is better than just treating the symptoms’- Robynne from Hartlepool Health PCN

Places that support physical health

The importance of physical health and accessing green spaces came up often. These options being affordable was also highlighted.



‘Access to green spaces and facilities such as the gym and swimming pool. Things that are close and affordable’ – Richard

Case Studies of Projects that Help People Live Healthy Lives:

Physical Activity

'An example of good practice is Parkrun, it's well organised and accessible. You don't need much just some running shoes, you feel like you're taking part in an event and you can just walk it if you need to' - Richard

Data Access

'Reducing data poverty through the Good Things Foundation Data Bank project which is supported by Virgin Media, O2, Vodafone and 3G Network. They offer up to 6-months of free data and call contracts which support people in need and helps improve mental health. Being connected digitally helps reduce stress; the stress of navigating in a place you're not familiar with and staying in touch with loved ones.' – Imran

Tailoring Funding to Local Needs

'The Winter Wellbeing fund has also been helpful, it covers the basics for people, like duvets and slow cookers but we've also been putting air fryers in this selection. They are helpful for reducing energy and time cooking. There's a lot of fried food in the culture, using an Air fryer can help with reducing the amount of fat used when cooking things like this. I try to give this to the families I know will use this the most like the families with 5/6 kids' - Riverside Community Health Project on the behalf of the families and based upon the experiences of those who use their groups.

Accessible Information

'Creating pieces of work that help break down the unknown. For example, breast cancer screenings. We provided a video walkthrough and talk about how it will be done. This has been helpful in increasing uptake' – Koli



Question: In the local area what makes it hard to live a healthy life?

Accessibility of information

Access to language translation within services and the variable quality of this were barriers to living a healthy life.

'Translation is often not available and the meaning of messages can be lost or difficult to translate. Some advertisements displaying services like sexual health or breast cancer screening can be worded offensively or in a culturally taboo way which can cause avoidance or offence. If advertised in a certain area, it can cause people to avoid that service/ area'- Imran

'People's understanding of who does what. There's a lack of communication of these messages in an understandable way with approachable language. Where things are, how the system works together. How are the general public meant to know what they are entitled to get?' – Healthwatch Cumberland

Other participants discussed how both assumed digital competency and a lack of offline provision made accessing information and services more difficult.

'Some of the websites you use can be in your own language like the Universal Credit website but others don't have that option like the housing website. Some people can use a smartphone, you need one to do so much these days but not everyone can use one. Sometimes I have to help people with theirs and others don't want to engage with it at all. Some people will have one phone in the family which often the young person will use the majority of the time. You can't assume anything and you have to make things as simple as possible for people to understand'- Riverside Community Health Project on the behalf of the families and based upon the experiences of those who use their groups.



Assumed knowledge around healthy eating and limited information about healthy eating in a culturally inclusive way was also highlighted.

'Not everyone learns about healthy eating at school. People come from other countries with different experiences. Having an induction or orientation for people about healthy food options. Having a health visitor that's part of the community, a person that comes to the house to talk about different health problems, local mental health options and information. Who can signpost to different services and does this as a family approach, to help everyone be informed.' - Kuveri

'Chinese patients are confused over their intakes on how to incorporate Eastern food and Western food to help them to manage conditions like Type 2 Diabetes etc - better. Accessible information is important that's available in the language people speak, lots of information is available from sources like the Hong Kong government. Chinese communities from London and Manchester must have resources that can give advice on dietary changes for Chinese people that is mixed with western culture' – Sow Fong Cole and the South Mountain Chinese Older People's Association (SMCOPCA).

Health is not the priority

Wider issues around safety, transport and a lack of time were barriers to living a healthy life. In particular, limited finances and the cost of living were linked to accessing healthier food options.

'Not enough money or lack of budgeting for food, everything is going up. There's not a lot of facilities/ shops here to get healthy food' - A community centre in Walker

Groups such as people who need a support worker and people claiming benefits were more likely to face financial barriers and be affected by the rise in the cost of living.

'People who are on benefits like PIP don't necessarily just use this for travel, it's used often on people other than themselves. PIP has also been absorbed into the increased cost of living' - Adam

Messaging about health and wellbeing was also highlighted as not considering the impact of wider socio-economic factors.

'Public health makes them feel as though it is their fault. Behaviour change without acknowledging the inequality' - Rebecca and Members of WHIST

Others considered habits within families and within their local area as barriers.

'Habits, being stuck in a rut around how you do things normally. Seeing who's around, what you're looking up to can have a big effect on what you aspire to do. There's not a lot of motivation or aspiration for people to do things differently'- Cherri

Stigma and a lack of trust

Participants talked about how those that could benefit the most from local services in the local area did not engage or were not aware of local services. The attitudes of professionals and people's perceptions of professionals created barriers to engagement.

'People, especially professionals can come across as preachy or having an agenda- 'you get paid to tell me what to do'. People don't necessarily want to talk about their health with professionals other than the doctor' – Leah

'Professional attitudes are also a problem and add more barriers to people accessing things like cancer screenings e.g. assumptions being made about patients which results in them not being invited to certain screenings' – Sunderland Older People's Council

Certain health topics were considered taboo in different cultures and can also impact engagement with services.

'Cancer screenings can also be a taboo subject. Some people believe that if you talk about it, it is going to happen or you bring it upon yourself. Belief around there not being any treatment options. This can bring up issues around attendance to follow up appointments. As soon as the word is mentioned, people disengage or switch off' – Koli

Isolation and transport as a barrier

A lack of services in local places made it necessary for people to travel. Issues around public transport infrastructure and its affordability were often mentioned within rural places.

'Although it's a small city, things are spread out across Newcastle and the surrounding areas. This makes services more difficult to get to and there is a lack of well-resourced local areas. One person has to travel from Dinnington as there isn't the services they need available in their area'- Sally

'People are forgotten about. The community is here, but there are no services.'

'There's also the isolation of being put somewhere where you don't know anyone'- Kevin from Throckley

This impacted social networks and neighbourhoods.

'The cost of travel and navigating multiple buses can be difficult for lots of people such as those who are elderly, neurodivergent and who have different health challenges and language barriers' - Imran

The gap in knowledge between the service and the person

Assumptions can be made about the people accessing services and information.

'You can't assume anything. We tried to help someone by making them a pie but they didn't have any cutlery to eat this with, things you take for granted or don't think about others might not have'- Leah

This also impacted navigation through care pathways.

'Low income refunding is only available for patients attending appointments at the hospital not for their carers. So, if a person from Berwick has to go and stay in hospital in Cramlington that's 54 miles away. If their carer doesn't have the transport they can't necessarily bring what the person might need, they might not be able to come and see them or stay with them as that's hours on the bus. This builds guilt and impacts both the mental health of the carer and the outcomes for the person they are caring for' – Lisa from Carers Northumberland

Delays and waitlists in services

Delays in accessing services for physical and mental health impacted the likelihood of engagement and were considered to have longer term impact on worsening health outcomes.

'Youth workers are trained in signposting but not in supporting young people with complex care needs that involve safeguarding and social care. Waitlists delay accessing care and creates further pressure on youth club staff who haven't got the support they need to deal with these situations. Poor mental and physical health are present before anti-social behaviour becomes an issue. Prevention is talked about but the delay in getting the support you need only makes these issues worse for young people in the future' – Chanise, Youth Worker, Chopwell

'Waiting lists for services in general are barriers but especially for our service these can negatively impact the likelihood of engagement' - Chris

Research experiences and good practice

The majority of participants had previously had some experience of research. Follow up questions focused on people's experiences of research and what they considered good practice. What was considered research and what was considered involvement and engagement was defined by the participant.

Question: If you wanted to know more about taking part in research, where would you look for more information? Are there places in the community that could be useful for getting this information?

Difficulty in raising awareness

Often VCFSE organisations were directly approached to take part in research. There was a lack of awareness about research and where to find opportunities to get involved among service users. This also included frontline staff.

'Better communication of outcomes and more interactions with frontline staff. Finding better ways to filter down research/ information as this message isn't getting across. Everyone needs to be on the same page, one way to do this could be sending notifications to all staff on clinical systems sending things out like information and comms to raise general awareness' - Robynne from Hartlepool Health PCN

'Staff would look for more information via the internet. It's different for members, I'm unsure they would know where to look for information on where to get involved in research'- Rebecca and members of WHIST

There was also difficulty in raising general awareness about local services in the area.

'We ask how do we get this information out then people mention put information on Facebook or send out paper newsletters. Even when we do this people don't follow the Facebook page or throw the newsletter away' – Leah

Working in partnership with established networks

Some participants already worked with local infrastructure organisations and had partnerships with researchers.

'The West End has a lot of good connections. Having people who are knowledgeable about research embedded within the local area can be helpful with connections and finding out if there's anything that might be of interest' – Ruth from the Pendower Good Neighbourhood Project

'Durham Community Action and the Rural Design Centre are currently developing a framework for rural community research networks as part of a UKRI funded development project with the aim of securing ongoing funding to set this up. This is part of the work to build research capacity within the VCSE sector and communities'– Nicole from Durham Community Action

Consideration of the people you're trying to involve

Trying to make sure things fit around the person and acknowledgment of the burden that being part of research can bring were highlighted.

'Co-production and working collaboratively are the buzzwords of the decade. But if it's not in the particular interest of the person, it can feel exploitative/ there is going to be a sacrifice for the person getting involved. Even though people say yes, it can still be burdensome' – Lisa from Carers Northumberland

Others experienced empowerment from directly being involved in research and have gotten involved as it aligned with their values.

'Getting involved help me to build more contacts with the outside world, I'm the kind of person that if something needs to be done I'll get it done, 70 is the new 40. I've always had this consciousness and awareness; statutory services are good at doing things to people but we need to flag up the life experiences of the people themselves'- Sunderland Older People's Council

In person or local outreach

Having a presence in the community and having people who act as promoters were mentioned as effective ways to raise awareness. Making sure to not add to frontline worker's workload is also important to consider.

'Being directly approached by researchers, making sure it's not filtered down via the CEO or by group email. But make sure to not increase the workload of frontline workers who don't have time to think about extra things. You need community organisers, people who are an informal promoter of the group who are proactive in getting posters out and talking to people about things going on' – Adam

Place based Facebook groups/ social media spaces were suggested as places to target as they allowed people to choose when to engage.

'Community Facebook groups; they are place based and fairly active and this allows you to choose when to read it. In person at local places such as the local library, community centre and café. Places where people are waiting and sitting down. Making sure it's on the person's terms. People are less likely to engage with cold calling or knocking on people's door as it inconveniences a person' - Richard

Charity-led research and experiences

Participants had experiences in service evaluation, conducting their own research projects or undertaking projects with or on the behalf of external research groups/ the local authority.

'Contact and ask people directly who are in the centre/ using services. (Conducted work on North Tyneside Health and Wellbeing Board's Equally Well topic discussion with local people). I didn't have a PowerPoint as I wanted the focus group to feel relaxed and not intimidated. I printed handouts although they weren't needed (and didn't need print outs.) I ended up doing most of the writing. Emphasis was on the importance of people's opinions and views. It was based at the same time same place for 6 weeks. A new topic was used each week. There was some drop off but a core group of people really engaged with the work. At the end of it the people of the core group were sent the report and a thank you note' -Cherri

Question: What do you think good working between the public and researchers looks like?

Communication and seeing outcomes

Taking time to consult with trusted people and prepare resources in additional formats in advance were emphasised.

'Ideally, the participants will be given prompting questions in Chinese, beforehand; allowing thoughts for questions' – Sow Fong Cole and Members of SMCOPA

'Materials were already put into easy to read/ plain English. Doing this as the norm means people don't have to flag up that they don't understand something. Find out what people need and don't make assumptions' – Sally

People seeing what had changed from their involvement both within research and wider healthcare service consultation created buy in and helped build trust.

'It can be hard for people to share potentially distressing stories and then not hear back about what happened. Not getting a follow up letter or update about what's happening can be disheartening. People tell stories to make changes or help others/ stop them going through the same thing'- Sally

'Show the outcomes of what happened, help people to see the point of the work and that something has changed. Share that ownership, that you are part of the change and that they are part of it' – Healthwatch Cumberland

Further accountability for researchers to continue to engage with communities and for evidence of this to be present within research outputs was also highlighted.

'Lots of effort is taken to conduct research, there should be as much effort put into communicating outcomes of what actually happened and how things changed. Spending money on what matters to communities and on prevention; making changes on the ground. Funding reward criteria being based on previous involvement work with communities. When people are writing their final report emphasis what you did with the public and what the public contributors think and what their feedback was. Accountability for public involvement'- Kuveri

Building relationships

Taking time to connect with people and use trusted connections were an important part of continuing relationships.

‘Visibility in groups, going along to groups and community centres and talking to people, listening to their needs’ – Chris

‘Ensure continued contact with the community. Use people who are a part of that community to conduct the research. Make sure to build capacity within the community itself. Make sure it's simple English, focus first on what's working within the local area and build on this’ – Claire and Roy

Being sensitive to different people's circumstances and valuing the expertise within communities was an integral part of building connection.

‘Between the worlds of academics and communities there's a void. From the university side, the lead on a project can be so far removed from the work, they don't have an understanding what people's lives are actually like. Poverty is complex and it affects people in all different ways. Affluence comes with doing things that some people wouldn't dream of doing or would never be able to do. Having people there to bridge this, being embedded within the communities and who understand the practical things like the importance of tea, coffee and cake’- Ruth from Pendower Good Neighbour Project

Value people's time

Remuneration for people's time with payment, food or the researcher's own time was considered good practice.

‘Giving time, the people involved in research could give their time to volunteering projects or give financial rewards for people taking part. Making sure to acknowledge people and thank them personally. Ensure there's enough funding to provide teas, coffee and biscuits for any groups’- Cherri

‘Provide lunch. Being aware of people's time and circumstances and remunerating them for this, people's time is precious’- Leah

Other options such as remunerating charities rather than the individuals was also suggested.

(Asked further question about remuneration) 'It can attract a certain type of person, those who are on low income or need the money. They can make their experiences fit into to the study due to the incentive, it can lead to the same faces being seen. It can also impact people's benefits which can lead to sanctions.

How does recruitment fit with using charities as representatives? Instead of asking 200 people, ask a charity that can give you more data and speak on the behalf of more people e.g. who they talk to and who uses the service. The remuneration for the charity can help it keep running and perhaps be more beneficial for the individuals' – Lisa from Carers Northumberland

Person / charity led

More informal approaches to engage people were advised including going to places where people are waiting. However, having clear reasons as to why you are going into groups and classes was important.

'There needs to be a good reason why people are being asked to get involved why the people and their views are important. That people know exactly why you are there' - Riverside Community Health Project on the behalf of the families and based upon the experiences of those who use their groups.

Addressing issues such as the power dynamics between research and communities was also highlighted. This included enabling there to be more power in communities around who makes the decisions in research and what are the outcomes of this.

'Shifting the power balance in funded academic research. This would be where communities define research priorities, based on what matters to them'- Nicole from Durham Community Action

'Got involved with HAREF as the charity I'm involved with is an ally. I heard about an opportunity to get involved as a peer researcher. To conduct this research, they used a methodology called Peer Research, which I think is a more appropriate research method for community research than the mainstream research methods used. If we could include the use of peer research methodology when appropriate as a recommendation, we could probably set thinking in an alternative direction' - Kuveri

Conclusions

Being able to meet people in a variety of ways and the flexibility of the timeline for this work allowed a wider variety of people to be contacted.

To help people live healthy lives, face to face, easily accessible information and services were considered key to this. Accessible was defined as things being affordable, easy to physically access, based in the local area, having adequately trained staff present and being available in different formats (hardcopy, Plain English etc, different languages).

In the local area, barriers were likewise focused on information and service accessibility, with assumptions being made about how people access these. Wider factors such as a lack of time and money were overarching barriers that many participants highlighted.

Previous regional NENC engagement work undertaken by the Multiverse Lab [27], also found themes of tackling poverty were present in the health and social breakthroughs people wanted to see in their lifetime. In terms of research, people from the NENC ICS region, in particular those involved with the VCFSE sector, often had experiences with research and service evaluation. But public involvement and engagement within these projects was often not explicitly mentioned.



Additional questions were also asked about what good working between researchers and the public looked like:

Good working between the public and researchers

- Ensure that work is person-led, through early involvement, being clear on why you are there, asking about what people need and doing meetings face to face and in community settings. Be mindful of frontline workers' workloads.
- Building long lasting relationships takes time, they are built on respect/ common ground. Try to engage people who aren't already engaged.
- Communication needs to be simple, consider if alternative formats for resources / information are needed. Highlighting outcomes to those who took part needs to be prioritised. Keep research accountable and evaluated from a community perspective.
- Value people's time through remuneration; give time to groups, share skills, food and/or payment such as vouchers/money. Consider the role charities play for remuneration.

The recommendations for good research practice from this report support conclusions from existing guidance on how to meaningfully involve under-represented groups [14]. With current work underway on turning the Community Development Toolkit into a regional code of practice for involvement and engagement with research [15].

14

NIHR, "Improving Inclusion of Under-Served Groups in Clinical Research: Guidance from INCLUDE Project," NIHR, August 7, 2020, <https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435>.

15

Reaching out partners et al., "Community Engagement Toolkit," April 6, 2022, <https://www.rdsresources.org.uk/ce-toolkit>.

Most of the results reflect views from individuals linked to the VCFSE sector. Although most organisations had some sort of experience in research, it was echoed that for service users there was a lack of awareness around research and where to find opportunities to get involved in research. How to increase awareness in involvement and engagement with research will need to include increasing awareness of local resources and working with VCFSE partners.

Participants mentioned the importance of face to face outreach and suggestions for useful community assets. This included places where people wait, local Facebook pages and community notice boards. Further engagement with a wider range of healthcare professionals particularly frontline staff could also help with this.

There was also a consensus among participants on the need to involve trusted people within different communities in research, this echoes previous findings [16,17]. This will be important for issues like considering different cultural contexts when delivering health messaging. Research methods like Peer Research, 'in which people with lived experience of the issues being studied take part in directing and conducting the research' can be used to ensure research is led more by communities and under-served groups, generates richer data and can empower those involved and their communities [18].

16

Ann McNulty et al., "Health Inequalities in the Age of COVID-19: Towards Fairer Health for Disadvantaged Communities,"

https://www.connectedvoice.org.uk/sites/default/files/reports/Health%20Inequalities%20in%20the%20Age%20of%20COVID-19%20Formatted_0.pdf. (Accessed on March 21, 2023).

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Mabel Lie et al., "Gateways Not Gatekeepers – Reaching Seldom-Heard Groups to Gather Public Health Community Insights," *European Journal of Public Health* 32, 3 (2022),

<https://doi.org/10.1093/eurpub/ckac130.030>.

18

Caroline Yang and Zoe Dibb, "Peer Research in the UK," The Young Foundation, October 23, 2020, <https://www.youngfoundation.org/our-work/publications/peer-research-in-the-uk/>.

Examples of this include the NIHR 'Research Ready Communities' project which used participatory research methods to understand community assets and have conversations in these settings about research with members of the public [19]. Other projects used Peer Researchers to explore stigmatised topics like mental wellbeing and created recommendations for service improvement [20]. Training researchers who are from the same community as the participants and who are embedded in existing local partnerships allows for research to engage a wider audience. Further work using participatory methods like Peer Research can help with centring research on what matters to people and their communities.

Other options to embed public perspectives in research and service design have looked at how PPIE can be evaluated from the perspectives of people involved in advising research and service design. The NIHR ARC 'Dialogue and Change award' was given to projects that had 'meaningful and sustained communication' with public members throughout the process of research, service design and review.

Overall, there is evidence of good practice with meaningfully involving under-served communities in research in a variety of ways, more work should be encouraged to undertake research that uses these practices. However, what underpins this is trying to create partnerships that are an equal exchange between VCFSE organisations and researchers. Exchanges could include funding, donating time and mutual skills, or working together on overarching goals such as raising awareness which was a key issue identified by people in this report,

¹⁹ NIHR, "Research Ready Communities Pilot Evaluation 2021/22."

²⁰ Connected Voice, "Peer Research on Mental Health in Our Communities," November 1st 2021, <https://www.connectedvoice.org.uk/news-and-information/newsletter/peer-research-mental-health-our-communities>.

²¹ NIHR Applied Research Collaborative North East and North Cumbria, "The Dialogue and Change Award," NIHR Applied Research Collaboration North East North Cumbria, <https://arc-nenc.nihr.ac.uk/pice/the-dialogue-and-change-award>. (Accessed on March 21, 2023).

²² David Buck, "Reducing Inequalities in Health: Towards a Brave Old World?"

²³ The Health Foundation, "Health Equity in England: The Marmot Review 10 Years On - The Health Foundation," February 2022, <https://www.health.org.uk/publications/reports/the-marmot-review-10-years-on>.

²⁴ The Food Foundation, "The Broken Plate 2022," The Food Foundation, July 19, 2022, <https://www.foodfoundation.org.uk/publication/broken-plate-2022>.

In terms of local health issues, factors intersected to create disadvantage in access to services. Some factors identified in this report included; finances, access to healthy food, education, transportation, the location of services, waitlists for services and digital access. Previous evidence suggests the health gap between wealthy and deprived areas is widening [22] and that health inequalities have stayed the same or have worsened over the past 10 years [23]. This particularly impacts food access, as it has been reported that ‘the poorest fifth of UK households would need to spend 43% of their disposable income on food to meet the cost of the Government-recommended healthy diet. This compares to just 10% for the richest fifth’ [24].

Stigma/ a lack of trust in services was also highlighted. This is unsurprising given the historical and continued presence of institutional discrimination against black people and other ethnically minoritised groups [25,26]. Guidance from NIHR projects like INCLUDE [27], mandatory staff training in cultural competency and ensuring the perspectives of members of under-served groups are part of future plans will be crucial to this in addition to diversifying people involved in research structures and institutional leadership.

The views within this report are representative of some of the voices of communities and people within the North East and North Cumbria but this report reflects only a small snapshot of the health issues affecting people in the region. It’s important to ensure research is aligned to what matters to people. Although research has the potential to address some specific issues highlighted in this report such as the accessibility of research. Long term structural changes coming from central government, as previously described in the Marmot review 10 years ago [28], are fundamentally needed to address health inequalities.

25

Oluwaseun B Esan, et al., “Mapping Existing Policy Interventions to Tackle Ethnic Health Inequalities in Maternal and Neonatal Health in England: A Systematic Scoping Review with Stakeholder Engagement,” NHS Race and Health Observatory, December 8, 2022, https://www.nhsrho.org/wp-content/uploads/2022/12/RHO-Mapping-existing-policy-interventions_December-2022.pdf.

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Kalwant Bhopal and Clare Pitkin, “‘Same Old Story, Just a Different Policy’: Race and Policy Making in Higher Education in the UK,” *Race Ethnicity and Education* 23, 4 (2020): 530–47, <https://doi.org/10.1080/13613324.2020.1718082>.

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NIHR, “Improving Inclusion of Under-Served Groups in Clinical Research: Guidance from INCLUDE Project,” August 7, 2020, <https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435#citations>.

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The Health Foundation, “Health Equity in England: The Marmot Review 10 Years On - The Health Foundation,” February 2022, <https://www.health.org.uk/publications/reports/the-marmot-review-10-years-on>.

Recommendations

Firstly, more work with existing partnerships is needed to raise awareness of local resources, what research is and what PPIE is. To enable this to be effective and include under-served groups, people's and VCFSE's expertise needs to underpin specific future strategies around how to do this. This could include, where appropriate, participatory methods and evaluating research from a patient and public perspective.



Actionable points to focus on are shown below:

- The need for open access research resources for VCFSE organisations
- Better partnership work with VCFSE organisations. Raising awareness about available resources and research.
- Evaluation of research from the point of view of people and better accountability for this. This could include more work on showing the outcomes of research.
- Working together to reduce replication and better use resources.

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Appendices

Appendix 1: Information sheet examples used for engaging with people and VCFSE organisations



Information sheet for groups

People's views on local health issues and how researchers can better involve the public in research.

What is this about?

To understand people's opinions on local health issues and on participating in research.

Do I have to take part?

No this is voluntary; you don't have to take part and can withdraw at any point without giving a reason. To consent: Please tick the consent form and put a memorable word next to your name.

What does this involve?

Either one member of the groups asks the questions below and records the answers this could be through voice recording/ writing down comments/ drawing.

Or Ellie from Healthworks comes along and asks the group. It will last about 10-15 minutes. This can be done by post-it notes to write comments and/or draw pictures on. Ellie can also record/ write on the behalf of others.

Questions asked:

- In the local area, what helps you live a healthy life and what makes it hard to live a healthy life?
- If you wanted to know more about taking part in research, where would you look for more information?
- Are there places in the community that could be useful for getting this information?
- What do you think good working between the public and researchers looks like?

Why are we doing this?

This focus group is part of work to:

- Increase the number of people to have a 'voice' in research.
- Increase the understanding of issues and challenges all people face.
- Increase trust between people, research, universities and the NHIP.

What will happen afterwards?

Ellie will write up the notes taken during the focus group and share with group members and the community group organiser for feedback. These notes will be part of a report alongside other community groups. Comparison between these notes and professionals' notes will look for similar themes.

What are the benefits of doing this?

- For researchers and services: This can save time, effort and money in improving services and strategies. The goal is to improve health outcomes and address health inequalities.
- For the public: There are no specific benefits to taking part. Your experiences will help inform researchers about local health strengths and barriers and the public's views on research.

What if I don't want to continue?

You are welcome to stop or withdraw your consent at any time. I will use a memorable word to represent group members, please email me and quote your memorable word and I will remove you from the notes. Please tell me as soon as possible if you want to withdraw as this may not be possible with the finished report.

Further information

This is a discussion-based activity with a small amount of writing. Information people share will be recorded. This will be dealt with under GDPR (General Data Protection Regulation) and Healthworks' policies and procedures.

You can access our Privacy Policy here:

<https://www.healthworksnewcastle.org.uk/privacy-policy/> When you tick the consent box your information will be held securely. This will not be shared with any third party unless we are required to do so by law. If you have any queries about how we will use or store your data, please contact us by calling 0191 272 4244 or visiting www.healthworksnewcastle.org.uk

Information sheet for individuals

Do I have to take part?

No this is voluntary; you don't have to take part and can withdraw at any point without giving a reason just email Ellie.

What does this involve?

Answering questions about yourself/ your experiences of the people who use your service, about health in the local area and getting involved in research.

Questions asked:

- In the local area, what helps you live a healthy life?
- What makes it hard to live a healthy life?
- If you wanted to know more about taking part in research, where would you look for more information?
- Are there places in the community that could be useful for getting this information?
- What do you think good working between the public and researchers looks like?

Why are we doing this?

This is part of work to:

- Increase the number of people to have a 'voice' in research.
- Increase the understanding of issues and challenges all people face.
- Increase trust between people, research, universities and the NHIP.

What will happen afterwards?

These notes will be part of a report alongside other community groups. Comparison between these notes and professionals' notes taken earlier will look for similar themes between the two. You will be asked if you'd like to give your contact details to hear about what happens next and other research opportunities in the North East and North Cumbria.

What are the benefits of doing this?

- For researchers and services: This can save time, effort and money in improving services and strategies. The goal is to improve health outcomes and address health inequalities.
- For the public: There are no specific benefits to taking part. Your experiences will help inform researchers about local health strengths and barriers and the public's views on research.

What if I don't want to continue?

You are welcome to stop or withdraw your consent at any time. Please tell me as soon as possible if you want to withdraw as this may not be possible with the finished report.

Further information

This is an online form with a small amount of writing. Information people share will be recorded. This will be dealt with under GDPR (General Data Protection Regulation) and Healthworks's policies and procedures. You can access our Privacy Policy here: <https://www.healthworksnewcastle.org.uk/privacy-policy/> This will not be shared with any third party unless we are required to do so by law. If you have any queries about how we will use or store your data, please contact us by calling 0191 272 4244 or visiting www.healthworksnewcastle.org.uk

Contact Details

If you have any comments or suggestions email Ellie or call Healthworks.
Ellie Clark, Public Involvement and Engagement Co-ordinator, Healthworks, Email: Ellie.Clark@hwn.org.uk, or call HealthWorks Health Resource Centre reception on 0191 272 4244

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