

Learning from and strengthening regional infrastructure for involvement, engagement, and participation in health and care research



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on behalf of [Forum](#) and the [PPI Voices Yorkshire and Humber](#) network

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Image by [DanielRao](#)

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Plain English Summary

The National Institute for Health Research (NIHR) understands that some communities find it hard to get involved in health research. It wants to understand how to strengthen the infrastructure that supports community engagement. Humber and North Yorkshire (HNY) is home to people and communities with very poor health but is also the part of Yorkshire and Humber that has the least contact with health and social care researchers.

This collaboration between the HNY voluntary sector, the public and NIHR public involvement workers from the wider Yorkshire and Humber region aimed to start a new relationship between the NIHR and this underserved area, to begin to understand existing networks and to co-design a draft Framework for Community Engagement, that has the VCSE sector at its heart and closely links research with the new HNY Health and Care Partnership (HCP).

In focus groups, researchers, members of the public and communities and charity leaders discussed how they currently work with each other to undertake research and the problems they face. They talked about the engagement teams and networks that are already in place and how these might be 'joined up' by a regional Framework. Participants described their challenges in engaging with communities about research but were enthusiastic about the possibilities and opportunities that a Framework might support, such as collaborations between regional academics, communities and partners within the HCP. An ambition for the region of high-quality research that includes community driven research questions and local evaluations of new ideas was discussed, with clear agreement that research must make a difference to communities and to health and care services in the region.

These focus groups were followed by a co-design event to agree working principles and to begin to understand what the Framework would look like in practice. The information from this event was used to write the draft Framework in Appendix 4.

The next steps for this project are to continue to discuss the Framework ideas with the HCP and more research teams and VCSE groups in HNY. The Framework will need some funding to make it work, including people to build relationships with communities and to link communities with researchers. Finally the team will look for opportunities to put the Framework into practice, to test it and see if it will increase contact between researchers and underserved communities, and 'join up' and if it will improve the quality and usefulness of research in the region.

Introduction

In 2021 the National Institute for Health Research (NIHR) published its operational priorities. Best Research for Best Health: The Next Chapter¹ described 7 areas of strategic focus for the NIHR, two of which speak directly to the challenge of strengthening regional infrastructure for involvement, engagement and participation in health and care research: bringing clinical and applied research to under-served regions and communities with major health needs; embedding equality, diversity, and inclusion across NIHR's research, systems and culture. Despite this national steer, at a regional level the route and mechanisms through which this strengthening of infrastructure might be achieved are not clear.

Project Team

This project was a collaboration between the voluntary, community and social enterprise sector in Humber and North Yorkshire (VCSE), the National Institute for Health and Care Research (NIHR) and other health and social care organisations in the region. It was designed to begin a proactive relationship between health and care research and local communities, through the development of a co-ordinated approach via established VCSE organisations across the footprint of the Humber and North Yorkshire Health and Care Partnership (HCP)² which is the region's Integrated Care System.

The project was led by [Forum](#), a voluntary and community sector infrastructure organisation based in Hull and [PPIE Voices Yorkshire and Humber](#), which brings together members of the public and health and social care professionals from across the Yorkshire and the Humber region who have an interest in public involvement in research.

Humber and North Yorkshire

The HCP region contains a wide range of health inequalities. It is also a region with a limited NIHR presence relative to the other sub-regions of Yorkshire and Humber, although there are pockets of good practice in the two university cities of York and Hull. In recent years, the Clinical Research Network YH has made some progress and has portfolio research in the region, but this success is not reflected by other parts of the NIHR regional Infrastructure and other researchers, and large gaps in provision and opportunity remain. However there is a very strong community engagement (CE) through the VCS sector in the region³, estimated to include 14,900 organisations.

The launch of the HCP in July 2022 gives us an opportunity to focus on how researchers might collaborate with the ICS and communities, via the VCSE sector, to build an evidence-based health and social care system. Developing this infrastructure will allow future health and care research to be community led, responsive to the needs of local populations and facilitate increased access to those people who would not normally engage in research. A stronger relationship between the VCSE sector and health and care research will also allow the local voluntary and community sector to use research data to inform the design and delivery of future services based on robust evidence.

¹ <https://www.nihr.ac.uk/documents/best-research-for-best-health-the-next-chapter/27778#Introduction>

² <https://humbercoastandvale.org.uk/>

³ Chapman, Tony (2021) 'The structure, dynamics and impact of the voluntary, community and social enterprise sector: a study of West Yorkshire Combined Authority, West Yorkshire Harrogate Health and Care Partnership and Humber Coast and Vale Health and Care Partnership areas.', Project Report. PolicyPractice, Durham. <https://dro.dur.ac.uk/33980/1/33980.pdf>

This report uses the NIHR definitions of [public engagement, involvement and participation](#). A Glossary of terms is contained in Appendix 2.

Aims

1. Describe how the regional NIHR family and its partners engage with local networks and communities about health research and then build on that engagement in order to develop effective involvement and participation partnerships
2. Understand the driver, barriers and enablers that impact on existing PPIE approaches
3. Start a new relationship between the NIHR family and an underserved part of the YH region, within the Humber, Coast and Vale geography
4. Explore the engagement challenges within Humber Coast and Vale, and how the regional NIHR might adapt to facilitate more appropriate inclusion of underserved communities through the development of sustainable partnership working
5. Co-design an initial PPIE infrastructure and process map to maximise the impact of NIHR engagement with underserved communities across the Humber, Coast and Vale geography, and to build on that engagement to improve participation and involvement with health research
6. Scope a Community Research Champions model which provides a framework to support future research activity and enables ideas and themes for research proposals to be generated at a community level
7. Develop recommendations in order to spread this engagement process in the wider YH region.

Methods

The method was agreed through discussion with the authors and the Voices Network.

The engagement process included 3 stakeholder focus groups followed by a codesign event. The Voices network agreed the focus and approach for each event and the authors finalised the details.

Focus Groups

Three virtual focus groups were held: with current NIHR public contributors; researchers and other 'professionals'; VCSE Leads for the HNY Care Partnership. The VCSE Leads were invited by Jason Stamp, who is the Chair of the VCSE Group in the HCP. All other participants were recruited via the Voices network. An alternative questionnaire was offered to people who not attend the events (see Appendix 1) and one participant preferred a 1:1 interview with CS rather than the focus group.

The Topic guides (Appendix 1) were intended to be used to stimulate conversation. In the event, conversations were very dynamic and so the guides were only very loosely followed.

The focus groups with researchers and public contributors concentrated on the barriers and facilitators to good community engagement by researchers and the NIHR. Following advice from our VCSE Partner (JS) the VCSE focus group introduced the VCSE Leads to the NIHR and focused on the synergies between the opportunities for communities to engage with NIHR research and the HCP's requirement to address health inequalities. The discussion focused on the opportunities to connect with different ways of working and mutual benefits of engaging with the VCSE section about the NIHR research agenda. The Leads were asked about their context as VCSE Leads within an Integrated Care System, their perception of research and researchers and their history and experiences of working with health and social care (H&SC) research teams. Their needs as potential

champions for research in the VCSE sector were explored, together with the systemic requirements to enable reciprocal and impactful relationships between communities and H&SC research teams.

All focus groups and the 1:1 interview were recorded with the verbal permission of the participants. CS summarised the discussions and information from the questionnaire into a PowerPoint presentation.

Co-design event (zoom)

See Appendix 1 for the format of this event. JS and CS presented a summary of the focus groups. This was followed by a series of break-out and whole groups discussions which were recorded with the permission of the participants.

CS used the discussion recordings and notes to draft the Framework (Appendix 4). All participants were invited to comment, and CS, JS and GP agreed the final version.

Stakeholder Discussions

Participants

This engagement project comprised 3 focus groups (researchers, public contributors and HCP VCSE Leads), a short questionnaire for researchers or public contributors and a 1:1 interview with a public contributor; followed by a co-design event. These events included a range of stakeholders:

- 12 members of the public who were already involved with NIHR projects. These projects were not based in HNY
- 17 'professionals' from the VCSE sector, NIHR Infrastructure (ARC, RDS, CRN, CRF), AHSN, Universities of Sheffield and Hull and the HCP

Summary of Discussions

It became clear early in the discussions that fully achieving Aims 1 - 4 would take longer than the period of the project. At present the NIHR has very limited engagement in the region, and we identified many gaps in our plan of engagement. We were unable to engage at such short notice with many potential stakeholders, and we cannot progress to wide implementation before those first conversations have taken place. Additionally the VCSE sector has a very different concept of research and limited experience of working with academic research teams. The project team agreed that these network gaps and disparities in understanding underscored the need for the Framework and decided to continue the 'first step conversation' phase with wider stakeholders after the project period, using the Framework as a prompt for conversation.

Appendix 3 illustrates the range of the focus group discussions, which were summarised into key themes:

- Context
- Ambition and Opportunities
- Risks
- Resources
- Tasks

- Feedback to NIHR

Context for research in HNY

HNY is relatively underserved by NIHR research, with most activity being concentrated in the university cities of Hull and York. Research activities tend to be siloed and there is a lack of communication, both within and between sectors (such as H&SC and HEI).

There are increasing expectations around Community Engagement in all sectors e.g. the HCP has a legal duty to engage with communities. There were several examples given that illustrate the ongoing shift in thinking within HEI about community engagement⁴.

It was agreed that community engagement needs to happen (to establish and then sustain trusting relationships between HNY communities, the HCP and the research community) *before* any other involvement or participation with services or research. The groups recognised that there are many different definitions of engagement, but that the importance is highlighted by the shift in language over the last few years. Finally there were concerns that our current levels and quality of community engagement may not be consistent with the 2010 Equalities Act.

Research in the wider HNY system

There are pockets of excellent Community Engagement in HNY and discrete siloes of expertise. However, there are many challenges, uncertainties and information and language gaps about research. Examples include:

- The 'dark arts' of navigating across sectors to find champions and identify collaborators
- Lack of awareness of research within communities, together with low levels of trust
- At the present time it is unclear where the research function will sit within the new HCP
- It is unclear what each sector (VCSE, H&SC and HEI) means by 'useful research'. There was a clear gap described between the types of research undertaken by each sector
- The VCSE sector does not routinely commission research and illustrated the challenges they have faced. *'We've never got the relationship between VCSE and Academia right before'*.

Research in the system - Academia & NIHR

Specific challenges were described within the HEI sector. The NIHR was described as fragmented, with complex processes and a competitive 'marketplace' which does not support meaningful community engagement.

Universities are designed to capture big funding grants that include overheads, not local research that does not. This acts as a disincentive to work with local collaborators on local challenges. Within universities there are additional challenges that were summarised as *'finance, HR, legal risk and funding'*. Inequalities also exist between the regional universities. The 'redbrick' University of York was described as 'dominant' compared to the other universities of Hull and York St John. This inequality has implications for power sharing within the region.

⁴ Current initiatives in the University of Hull: Ideas Fund for community projects to support mental wellbeing; an asset mapping exercise; development of a civic agreement and a Knowledge Exchange Public and Community Engagement Strategy; impact acceleration award with the Medical Research Council; participatory research training for academics and external partners

If our ambition is to create a 'whole system' approach for community engagement it is important to recognise that academia outside of health not as focussed on community engagement as the health-related schools and has less knowledge, although they still have an imperative to engage.

Finally it was noted that researchers work in siloes and, although they disseminate results in the form of research publications, they rarely use other more accessible forms of communication, '*they don't talk to each other*'. Participants provided examples of duplication of work because of poor communication and lack of collaboration between teams and across sectors. This lack of communication also directly impacts on communities and there is need to address issues of competition between research teams for community engagement, and community fatigue

Ambition & Opportunities

It was clear from the focus groups that there is the potential for shared ambition for community engagement and research that impacts on services and communities themselves.

All the groups agreed that a whole system cultural shift is needed, within the HCP footprint, so that community engagement and research work together harmoniously and can ultimately underpin H&SC service change across HNY. In this way research will provide added value for the region as well as meeting the Research Excellence Framework requirement for impact. This shift is beginning to be visible in the HEI sector, with the move towards civic responsibility in universities. In the University of Hull there is a current focus on skills development to drive innovation e.g. participatory approaches to research.

Colleagues from the HCP noted that two key challenges are how to make the hard choices of disinvestment and shifting resource and the need for evidence to underpin those decisions, and the more mundane task of commissioning for impact and not process outcomes. These challenges of disinvestment are compounded by the lack of system resource and research capacity in e.g. Primary Care, which receives little funding from NIHR in relation to acute care.

A key focus for any Framework is 'how do we align all the moving parts?' The ambition for the HNY Framework should be to provide a focus for CE activities as well as a platform for future funding. Several participants remarked that '*the future is about collaboration, consortia and partnerships*' and this was considered to apply to both research and commissioning. Opportunities were identified to capitalise on this notion of partnership working e.g. by using traditional research grants as springboards that can be augmented by community-led questions and flexibly or co-funded research, or to use routine or big data to follow up on research impact. There are opportunities to build capacity within HNY for research about HNY, based on community-led research, with behind-the-scenes academic support. However for this to happen resource needs to flow against system resistance into communities.

It was noted that 'new' research might not be needed, but that adapting research from other regions or specialties to the HNY context may be a more cost-effective solution. The nascent Hull Evaluation and Research Unit may provide a vehicle for such research e.g. providing rapid reviews of evidence in collaboration with the HCP and communities and linked to action plans that apply evidence to the local context.

Risks

A broad range of risks to any Framework were identified by participants:

- How to maintain quality of engagement, such that relationships are reciprocal and not transactional, whilst increasing diversity? This applies to all aspects of any research focused engagement Framework including communication, governance, accountability and transparency, ethics and scientific quality
- How to sustain any framework in the long term and manage expectations of communities and other stakeholders?
- Sharing power is hard. How can the Framework support power sharing e.g. during conversations about disinvestment?
- It was clear from participants that any Framework should support regional capacity building. Participants were clear that they *'don't want [HNY] to be 'colonised' by external universities'*
- To counteract to effects of fragmentation and silo working the NIHR needs a single point of contact in the region.

Current Resources

Current resources were identified as:

- Champions within the communities themselves e.g. within the VCSE sector, schools, H&SC staff and students
- People currently in community engagement roles across the HCP, VCSE and HEI, including the YH PPIE Voices Network of public contributors and PPIE Leads and the Ethnic Minority Research Inclusion (EMRI) Group within the NIHR CRN, INVOLVE@Hull, The Hull Ideas Fund team.
- There are opportunities to learn from ongoing work in HNY, the wider Yorkshire and Humber region and across the country

Tasks

Three sets of tasks were discussed in the contexts of identifying where research could add value and where the HCP could join up key strategic challenges. The two 'logistical' tasks included the identification of 1) resources – included the people, engagement roles, teams and Champions who were not included in this first stage of engagement and consultation, such as local, trusted and credible intermediaries within the VCSE sector. 2) sources of intelligence – included:

- Mapping projects such as the 2021 VCSE Report⁵ by the University of Durham, asset mapping in the regional HEI and HCP organisations and a mapping of NIHR and HCP priorities
- Routine feedback mechanisms from H&SC
- Big data and routine datasets
- Learning from wider regional teams e.g. the two other HCP in the Yorkshire and Humber region
- Learning from other research sectors such as the arts and humanities.

⁵ Chapman, Tony (2021) 'The structure, dynamics and impact of the voluntary, community and social enterprise sector: a study of West Yorkshire Combined Authority, West Yorkshire Harrogate Health and Care Partnership and Humber Coast and Vale Health and Care Partnership areas.', Project Report. Policy Practice, Durham. <https://dro.dur.ac.uk/33980/1/33980.pdf>

3) More strategic tasks discussed included:

- Identifying priorities in communities
- Identifying challenges and levers for change within the HCP and universities such as the promotion of participatory approaches
- Each sector has multiple engagement strategies within its constituent organisations. Might it be possible to align engagement strategies from all sectors?
- A strategic approach to communication including ongoing conversations with communities to build relationships, feedback from projects and initiatives (referred to in discussions as the '*researchers' Achilles Heel*', and to reduce silo working within and between sectors
- The evaluation of the Framework

Challenges for NIHR

Participants noted the positive changes that are happening within the NIHR: the increasing expectations for PPIE sections in bids and the diversity of participants and contributors; the change in language to include community engagement in addition to involvement and participation. However, during discussions several concerns arose for feedback to the NIHR. Participants felt strongly that the real challenge for the NIHR is culture change to be more responsive, limber and flexible in its approaches to the funding of engagement, '*Practice what you preach! The NIHR doesn't help itself. It asks for a miracle but is old fashioned in its approaches*'.

Systems and approaches to Community Engagement within the NIHR

Participants highlighted that, in order to successfully engage with communities the NIHR needs to be more flexible and responsive in its structure, systems, processes and funding offers. Within projects the NIHR's interest in PPIE was perceived as 'front-loaded' and participants suggested that more emphasis and follow up of PPIE plans is required with projects to strengthen the perceived value of PPIE. The NIHR has a focus on the transferability and generalisability of research, but this does not support more context specific local evaluations of interventions. There are still opportunities for multisite research consortia, with context evaluations built in. Participants noted that time limits in research funding can bias results e.g. from a lack of follow up for impact.

Within the NIHR itself there is a strong need to reduce silo working and fragmented approaches to community engagement and PPIE e.g. between the NIHR Infrastructures within and between regions

The NIHR needs access into a diverse range of communities but there is a resistance within funding and host organisations to allow money to flow into communities (via charities and community groups). Participants highlighted that a small amount of money goes a long way for engagement and that the NIHR should not rely on community goodwill as this reliance runs counter to the concept of reciprocity. Goodwill runs out. It is also difficult to identify funding within the NIHR for community-led/based research. There is a perception that this is not the kind of research the NIHR wants to fund.

Permanent funding is required for regional outreach and community engagement. The current funding within programmes and projects is insufficient for the scale and quality of community engagement needed. New funding for engagement will liberate existing funds within programmes and projects for high quality involvement. Participants noted the successful Reaching Out pilots that facilitated equitable discussion of plans and power sharing, and flexibility on priorities over time and recommend the scaling up of these approaches.

External influence

Participants suggested that the NIHR might use its external influence, as major funder, to promote community engagement approaches within universities, royal colleges and H&SC. This promotion might include e.g. education for senior leaders & supervisors, who may not be fully aware of the complexities and implications of meaningful engagement within the complex H&SC and research landscape.

Achievement of Project Aims

It became very clear during this initial conversation with stakeholders that our aims were too ambitious.

We succeeded in Aim 3, to start a new relationship between the NIHR and the YH region but there is much more work to do to build on this initial foundation. Aim 5 and 6, to co-design an initial Engagement infrastructure based on production principles, and to scope a Community Research Champions model were likewise achieved and can form part of the ongoing conversations to build on these new relationships. There is more work needed to agree a roles and responsibilities and a process map for engagement. We have identified the next steps that will begin the process of implementing the Framework within HNY (Aim 7, see Next Steps).

Aims 1, 2, 4 were partially completed. Our limited range of participants were generous in sharing their opinions, experiences and examples but this is just the first step in fully understanding the challenges the region faces in engaging with research to improve health and social care.

Next steps

The key next steps for this Framework (Appendix 4) are to

1. Increase awareness of the Framework within the region including within the two York Universities, the HNY Health and Care Partnership, the VCSE sector, NIHR infrastructure in the wider Yorkshire region via the YH Voices network.
2. Identify resources to
 - a. increase awareness of the Framework
 - b. for staffing and activities. Some of these resources already exist but may need to be reconfigured, but new resource will need to be identified and ringfenced.
3. Create the infrastructure using existing and new resource
4. Finalise the process map for the Framework
5. Identify opportunities and test the Framework.

Acknowledgements

We'd like to thank everyone who has contributed to this draft framework; the public contributors and colleagues from the academic, VCSE and NHS and social care sectors. We are very much looking forward to expanding this list of partners as we go forward to implement this for the region.

Appendix 1: Topic Guides and Agenda

These guides were intended to be used to stimulate conversation. In the event, conversations were very dynamic and so the guides were only very loosely followed.

DRAFT QUESTIONS FOR VCSE INFRASTRUCTURE ORGANISATIONS

1. What is your current perception of research and how does this link to your work in the VCSE at a local level?
 - a. Does research make a difference/help you do your job? How
 - b. What do grassroots think about research?
 - i. Communities themselves
 - ii. Charities etc
2. As a VCSE infrastructure organisation, have you ever commissioned a piece of external research?
 - a. What was your experience? What worked well?
 - b. What didn't?
3. Do you have regular contact with health and social care researchers?
 - a. Where are they?
 - i. Red-brick vs post92?
 - ii. Part of networks?
4. Have you supported or participated in any health and social care research projects in the past two years?
5. What do you think needs to be in place to help researchers connect more effectively with local communities?
6. What do you think are the potential barriers to participation for local communities?
7. How can a more joined up approach to research benefit local infrastructure organisations and the wider work of the VCSE in the Integrated Care System?

DRAFT QUESTIONS FOR PUBLIC CONTRIBUTORS AND RESEARCHERS (Focus groups and questionnaire)

We would like you to think about 2 examples of projects where you have engaged with and/or involved the public in Yorkshire and Humber.

Please tell us, in your own words

1. What worked best about the project's public involvement/engagement?
2. What could have worked better, and why?
3. What do you think are the major 'red flags', or challenges in public engagement, involvement and participation in Yorkshire and Humber?

Co-designing PPIE Framework for Humber & North Yorkshire

Co-designing Draft Framework Event - Agenda

23rd May 2022

<https://us06web.zoom.us/j/88225579245?pwd=U2FVN2NnUTITOVovc3hlamVRbzhTdz09>

Meeting ID: 882 2557 9245, Passcode: 945376

- | | |
|-------|--|
| 9.00 | Introduction Recap & Context Common Themes |
| 9.30 | Recorded break-out discussions <ol style="list-style-type: none">1. Implementing principles2. Roles and responsibilities3. Process mapping |
| 10.30 | Comfort break |
| 10.45 | Recorded feedback and discussion – 20 mins per group |
| 11.45 | Next steps |
| 12.00 | Close |

Appendix 2. Glossary of Terms

The National Institute for Health Research has collated a glossary of research terms [here](#). Additional terms found in this document include:

HCP – Humber and North Yorkshire Health and Care Partnership. This is the integrated care system for the region.

Integrated Care System – partnerships of organisations that work together to plan and deliver joined up health and care services <https://www.england.nhs.uk/integratedcare/what-is-integrated-care/>

Appendix 3: Summary of Discussions presented at Co-design Event

To open this presentation right click the picture, then select Presentation Object, then Open.

NIHR National Institute
for Health Research



forum

Conversation Themes

Appendix 4: Community Engagement Framework for Humber and North Yorkshire

Community Engagement Framework for Humber and North Yorkshire



Produced by: Jason Stamp, Christine Smith and Graham Prestwich
on behalf of [Forum](#) and the [PPI Voices Yorkshire and Humber](#) network

June 2022

Image by [DanielRao](#)

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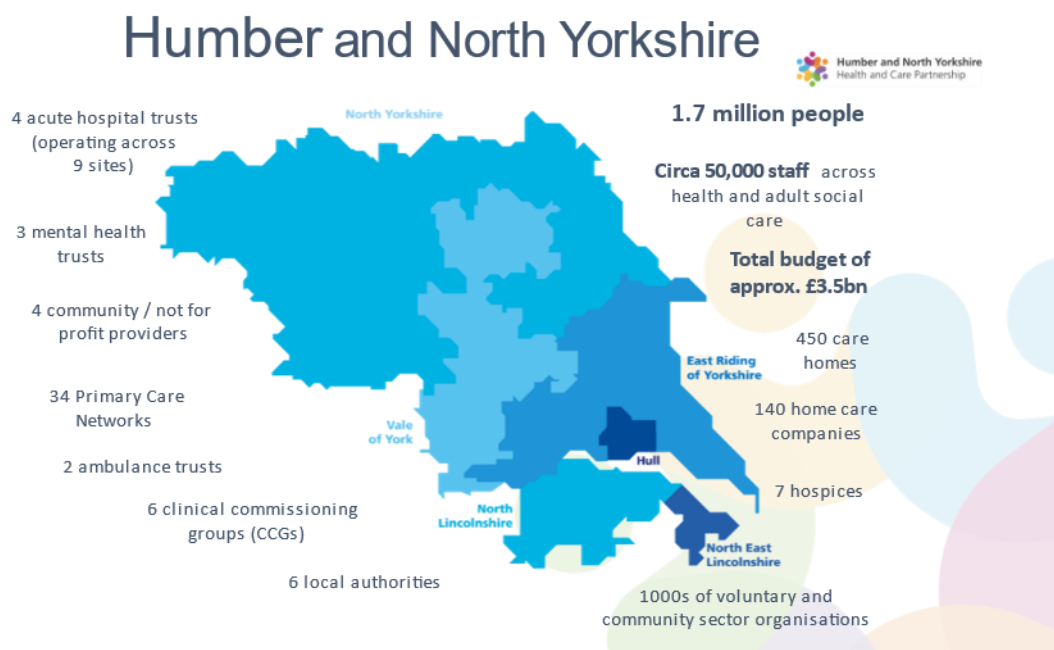
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Background

Humber and North Yorkshire is a region with high levels of health inequality. It is also a region with low levels of health and social care research compared to South and West Yorkshire. In recent years, the National Institute for Health and Care Research Local Clinical Research Network has made some progress and has undertaken research community engagement work, but large gaps in provision and opportunity remain.

In Humber and North Yorkshire (HNY) we want research, which is both informed by and based on public and patient priorities, to shape our health and care system and inform service transformation. Today, in 2022, we have a limited research infrastructure, with pockets of good practice focused on the two university cities of York and Hull⁶. Many of the diverse communities in the region are disconnected from the research infrastructure and there is no common regional framework to link research and services with our communities. However, regional universities have a strong sense of place and are shifting their practices to work more closely with communities and HNY has a very strong community engagement (CE) infrastructure through the voluntary, community and social enterprise sector (VCSE) in the region⁷ (Figure 1), estimated to include 14,900 organisations.

Figure 1. Health and Social Care Landscape in Humber and North Yorkshire²



The National Institute for Health Research (NIHR) has recognised that it has inconsistent community engagement and limited participant and public contributor diversity within much of its research and that working more closely with grassroots communities and infrastructure organisations to improve

⁶ The University of Hull Ideas Fund focuses on community-led projects to promote mental wellbeing. These projects are hosted by communities – shifting the power balance as academics are partners of the community-initiated ideas.

⁷ Chapman, Tony (2021) 'The structure, dynamics and impact of the voluntary, community and social enterprise sector: a study of West Yorkshire Combined Authority, West Yorkshire Harrogate Health and Care Partnership and Humber Coast and Vale Health and Care Partnership areas.', Project Report. PolicyPractice, Durham. <https://dro.dur.ac.uk/33980/1/33980.pdf>

the equality, diversity and inclusion within its research, will increase the impact of its research and influence investment and development to reach a wider mix of communities.

With the launch of the new HNY Health and Care Partnership⁸ there is an opportunity to focus on evidence-based system and service transformation. We want to work with the VCSE sector to connect communities with relevant researchers, universities and HCP partners, and to integrate research and communities into the decision making about health and care services without duplicating effort. The Framework will act as 'hub' helping connections to be made and for a two-way flow of information to grow, and improve access to intelligence for researchers, planners and decision makers.

The story so far

Early in 2022 the NIHR provided a small amount of funding for each region to start the conversation about how best to connect communities with researchers and decisions about services. The focus for our project was to establish connections between key regional stakeholder; the new HNY Health and Care Partnership, the NIHR, researchers and the VCSE sector, as the first step to building relationships with our communities. The [Forum](#) and the [PPI Voices Yorkshire and Humber](#) team has started conversations with NIHR public contributors, researchers and the VCSE Leads within the HNY Health and Care Partnership. Together we have drafted this Community Engagement Framework to serve the needs of communities, researchers, service planners and those deciding on funding investment.

HNY's challenges

In HNY the Health and Care Partnership and research sector has 2 key challenges:

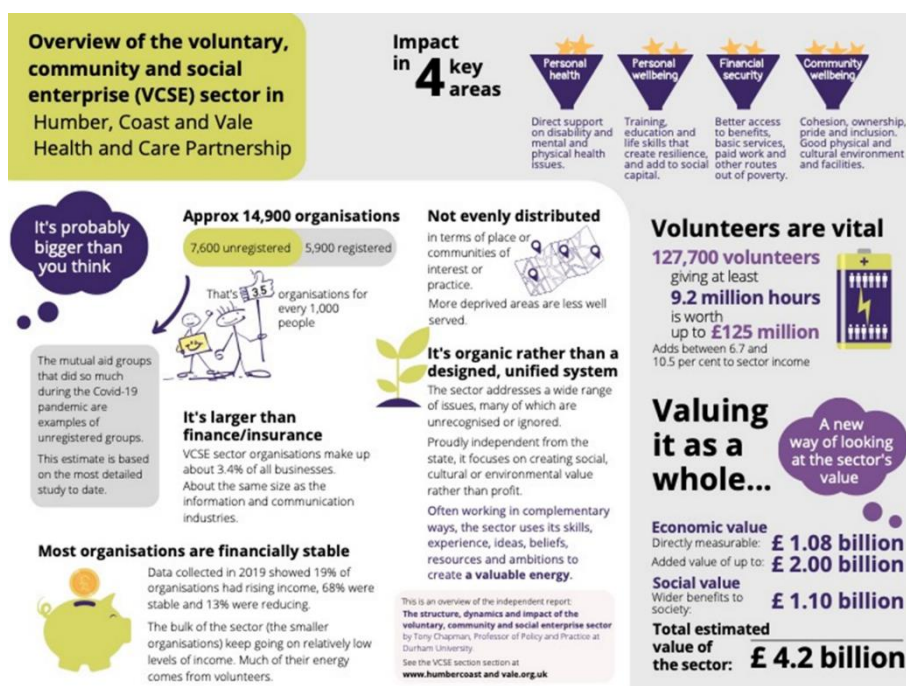
1. How to reach communities to talk, how to work with them to identify local health and care priorities and how they determine their own needs?
2. How to join up these conversations with
 - a) decision making about services within the HNY Health and Care Partnership
 - b) the research community and the NIHR so that research includes more diverse engagement and involvement in both current research opportunities and to generate new research questions.

Our Solution: A Framework for Engagement

This HNY Community Engagement Framework capitalises on the understanding of the existing VCSE sector in HNY outlined in Figure 2. This substantial network of organisations and people is the foundation for ongoing engagement and connection between HNY communities, H&SC services, researchers and the NIHR. Sustained trusted relationships form the foundation for increased equality, diversity and inclusion in research and services. We propose that this Framework connects health and social care researchers, services and the NIHR with this existing diverse VCSE network across HNY.

⁸ <https://humberandnorthyorkshire.org.uk/> previously known and the Humber Coast and Vale Health and Care Partnership (HCV)

Figure 2. VCSE in Humber and North Yorkshire



Principles

In our conversations with NIHR public contributors, researchers and VCSE Leads we agreed that we should adopt the principles of coproduction to guide our ways of working throughout the Framework. Such principles, based on a regionally produced example of a coproduction framework⁹ to guide community engagement include:

1. Share power amongst all partners e.g. by having joint Chairs (public and professional)
2. Embrace a wide range of perspectives and skills to ensure these are represented in the project
3. Respect and value the 'lived experience' and how different forms of knowledge can be expressed and transmitted
4. Ensure there are benefits¹⁰ for all parties involved in the Coproduction activities e.g. places where people are involved in decisions and influence systems are more likely to have high-performing public services
5. Go to communities. Do not expect communities to come to you
6. Work flexibly
7. Avoid jargon and ensure communities have access to the right information at the right time
8. Build relationships with communities for the long-term and not for the short-term and should generate trust through openness, respect, integrity, authenticity and honesty about what can happen to ensure expectations are clearly articulated and not raised unrealistically
9. Resource coproduction activities with communities adequately
10. Create a feedback loop to prevent extraction of information – ensure communities are well informed as to what happens to information they offer – the information belongs to them so promote interactive approaches

⁹ [ActEarly Coproduction Strategy](#) and augmented through our conversations

¹⁰ [Systematic scoping review of indicators of community wellbeing in the UK](#)

11. Think ethically ensure communities fully understand the process, give consent and understand rights to withdraw and be anonymously represented

What might the Framework look like?

“When the winds of change blow, some people build walls and other build windmills”

– Chinese proverb

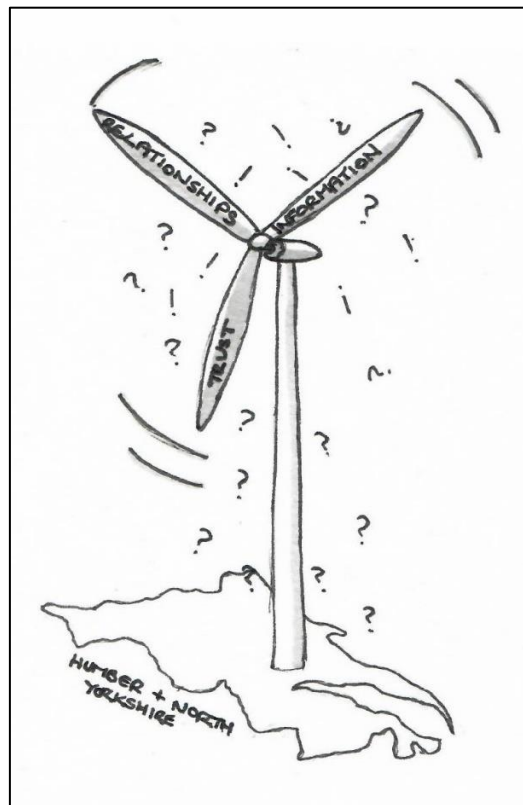


Image by Christine Smith

We think of our Community Engagement Framework like a wind turbine.

- The HNY VCSE network (**the tower**) is grounded in the HNY health and social care landscape (see Fig. 1).
- Challenges, ideas and research questions (?) come from communities, researchers and health and social care services.
- The HNY Community Engagement Hub (**the nacelle or generator**) engages with, makes links, builds trust and relationships and shares information (**blades**) with and between communities, researchers and services. This hub also drives activities such as priority setting exercises, communication and capacity building and ‘matching’ for participation and involvement in research. The results of this activity are solutions, research projects and service improvements (!) which evolve the HNY landscape, driving change and increasing impact.

The Community Engagement Hub will **connect communities** with the Health and Care Partnership and researchers from both within and outside HNY. Its role will be to:

- Act as a regional first point of contact for national and regional NIHR, and researchers the HCP as needed
- Map existing regional assets and share intelligence between partners
- To broaden and augment the reach of existing networks without duplicating effort, and to build and sustain new trusted relationships with communities on behalf of the whole system, linking with charities and community champions
- Connect researchers and the Health Care Partnership with each other and communities:
 - To work with communities to understand local health and care priorities and to capture and generate ideas and research priorities and questions, using existing networks where possible
 - To share information with communities about opportunities for involvement and participation in research and decision making about services
- Develop communications and work with creative partners to co-create and share research opportunities and outputs
- Build regional capacity for involvement and participation in research within communities.

Although at present the governance of this Framework and exact routes to engagement are still unclear, we propose that the powerhouse of this Hub will be an information hub, underpinned by pre-existing community assets within the system and a team of Community Engagement officers. These officers will make connections and build relationships with other pre-existing engagement teams and underserved communities, via the VCSE network and its embedded engagement teams, on behalf of the HNY Health and Care Partnership and research partners in the region. They will bring together local insights to shape research priorities and actions, share findings and gather feedback to add to intelligence to shape research questions and service improvements. They will play a pivotal role within a co-production approach. They may be hosted by university or VCSE partners. It is important to acknowledge that many such roles already exist within the VCSE and research sector, such as within the NIHR Local Clinical Research Network. It is important that this Framework maximises the benefit of linking with such roles whilst avoiding duplication.

Next Steps

This first version of the Framework represents the beginning of a regional conversation, both within HNY and with the wider Yorkshire region and we recognise there are many gaps in our current stakeholder map. Through our recent discussions we have identified the following vital steps to develop it further.

6. Continue to identify missing stakeholders and increase awareness of the Framework within the region including within the three regional Universities and more widely within the HNY Health and Care Partnership, the VCSE sector and the YH NIHR infrastructure via the YH Voices network.
7. Map assets within the region
8. Map NIHR and HNY HCP priorities and synergies.
9. Agree the governance and hosting of the Framework and Community Engagement Hub¹¹.
10. Identify resources for the staffing and activities of the CE Hub. Some of these resources already exist but may need to be linked in with the Framework or reconfigured. Still, new resources will need to be identified and ringfenced.
11. Develop a process map

¹¹ Possibly as part of the six ICS place-based partnerships

12. Identify opportunities and test the Framework.

For more information

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We'd like to thank everyone who has contributed to this draft framework; the public contributors and colleagues from the academic, VCSE and NHS and social care sectors. We are very much looking forward to expanding this list of partners as we go forward to further evolve and implement this in the region.

