GUIDING PRINCIPLES

to work together effectively on health and care research and ideas of how we might do that in practice

WORKING TOGETHER IN RESEARCH

NHS South Yorkshire Integrated Care Board

South Yorkshire's Community Foundation

DiverseCity Development Trust

FOREWORD

The Working Together in Research programme was funded through the ICS Research Engagement Network (REN) development programme of NHS England*. In South Yorkshire the programme was co-delivered by two voluntary sector organisations - these are DiverseCity Development Trust and South Yorkshire Community Foundation; with support from the NHS South Yorkshire Integrated Care Board.

These principles capture the key themes from the Working Together in Research programme, where communities and researchers shared ideas and experience of what it looks and feels like to work together effectively on health and care research.

In the process of developing these principles, we also co-developed other resources which are included in this booklet to stimulate ideas, knowledge sharing and collaborations on how to bring the principles to life. Hereinafter you can find:

- a set of recommendations and suggestions in the form of 'How might we..?' statements
- 3 Case Studies of collaborative approaches and models to research
- a 'Maturity Matrix': a toolkit to help one understand the increasing level of expected commitment as one climbs upwards in the journey of becoming more inclusive and participatory.

Our vision is that South Yorkshire is known for health and care research that centres health equity and inclusion.

Our ambition is for these principles to be at the heart of how all health and care research is undertaken in South Yorkshire.

We hope that partners across South Yorkshire will support these principles and bring them to life in their health and care research.

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*The views expressed in this publication are those of the author(s) and not necessarily those of NHS England or the Department of Health and Social Care.

Guiding Principle 1
Be community-centred

'Nothing about us without us'

Communities are at the heart of health and care research.
Communities' participation is crucial for successful research and therefore their needs, views and lives need to be at the heart of research. Voluntary, community, and faith groups know the communities they serve closely, which makes them key partners in research.

In recognition of this centrality of communities:

Involve communities in the design of research projects from the start and where possible choose research methodologies that enable participation (such as action research, art-based research, storytelling for data collection);

As well as starting with communities, ensure to come back and share outputs and lessons learnt, so that people can see what they have contributed to, and can share in the new knowledge that has been created thanks to their participation.

Guiding Principle 2
Be respectful and practice cultural humility

Communities are not homogenous but contain great diversity, even when they live in the same neighbourhood. Cultural and religious practices, historical and socio-economic factors all create rich diversity within communities.

Communities and researchers who strive to understand each other's contexts, personal and organisational structures are off to a good start of partnership working.

Recognise that research is a collaborative endeavour and that research with communities involves different types of equally important expertise: researchers have expertise in research methods and processes; community members have wisdom, knowledge, expertise, and experience about their communities.

Treat every person with respect and refrain from making assumptions: commit to learn about the groups and organisations each collaborator belongs to and their dynamics.

Self-reflect on the biases and assumptions each might bring into the collaboration. Where necessary, unlearn.

Guiding Principle 3
Recognise strengths and opportunities for mutual benefit

Community groups have many strengths. When building research partnerships, identify these and build on them.

Where possible, seek to match the needs of specific research studies to the expertise of community groups and strive to build partnerships of mutual benefit.

Recognise where there might be opportunities to build capacity by sharing knowledge, building expertise, and leaving a legacy beyond individual projects.

Guiding Principle 4
Build lasting partnerships

Genuine and sincere relationships are the cornerstone of mutually beneficial collaborations and equal partnerships.

Relationship-based research activity is more likely to endure through challenges, evolve over time, and last – and through these relationships, new opportunities for research can be collaboratively identified.

Open and honest conversations between community partners and research partners about each other's priorities, objectives and constraints will help build genuine and sustainable partnerships, and influence what and how research is undertaken.

Guiding Principle 5
Be aware of and anticipate the difference in each other's calendars

The concept of time varies significantly across cultures, both socially and organisationally.
Be aware of festivities and other events that are important to the communities involved in research (or that, such as religious celebrations), and work together to tailor plans to accommodate these.

Recognise that researchers are often working within constraints, but also that communities cannot always accommodate these.

Have open and honest conversations about what is possible so that timeline pressures are not prioritised at the expense of respectful, long-term relationships.

Guiding Principle 6
Make research processes accessible, acceptable, and available

Meeting the needs and preferences of community collaborators with regards to financial, information and bureaucratic accessibility will encourage their participation in research activities.

Recognise the value that different partners bring to the table and compensate community collaborators for their time.

Adapt the style and format of communication; some recommendations include:

- for people with visual impairment
> use a screen reader, large text, or audio;
- for people with hearing impairment
> use signs, symbols, and infographics;
- for people with limited literacy
> use everyday words, summaries and easy-to-read documents, factor in costs for translation and interpreting services;

Lastly, prefer using person-first language to describe community members and participants; i.e. 'a person who uses a wheelchair' instead of 'a wheelchair user'.

Guiding Principle 7
Protect communities from harm

Being trauma-informed allows us to work with others whilst looking after our own and their wellbeing. The topics explored in research can be sensitive and emotionally charged and may recall past traumatic experiences that might not be immediately obvious for those with a different cultural context.

Be vigilant about the risk of harm for individuals and act with integrity and honesty at every stage of the research partnership.

Respect individuals' rights at all times, even where it involves having to challenge the expectations of funders or means having to turn down research opportunities.

‘HOW MIGHT WE..?’ STATEMENTS

Recommendations and suggestions of innovative ways for embedding the Guiding Principles in all of our research

no. 1

How might we…

Be community-centred in all of our research?

We regularly work with community groups to build research priorities and spot opportunities for community-generated and community-led research activities.

no. 2

How might we…

Be respectful and practice cultural humility?

We ensure researchers have regular training in cultural competency, both at the beginning and then throughout their research careers

We work in partnership to scale up existing cultural competency programmes that have demonstrated success, so that they reach more who could benefit from them: e.g. reverse mentoring and cultural competency training by the Ethnic Minority Research Inclusion (EMRI) Hub.

We create a route for feedback when things do not go well, so that we can learn and build stronger partnerships for the future.

no. 3

How might we…

Recognise strengths and opportunities for mutual benefit?

We review the range of existing training offers available for developing community research skills, and take a strategic approach to investing in these opportunities and ensuring they’re of high quality.

We develop accreditation models for community researchers and partners in community organisations who play a central role in delivering health and care research; e.g. honorary community professor roles.

no. 4

How might we…

Build lasting partnerships?

We develop mechanisms to systematically fund capacity within the VCSE for collaborative research partnerships, including activity outside of funded research projects like scoping and engagement to develop proposals and demonstrate community engagement. If the proposals are not successful, voluntary partners currently receive no compensation for the time they invest in this activity.

Models to explore might include (but not be limited to):

- Ringfencing % of funds of research funding applications to VCSE partnership work;
- A dedicated fund or a role within the voluntary and community sector that creates dedicated capacity for this activity.

We understand the range of research approaches that are being made to different community groups, and seeking to share research burden more equitably; and in doing so, increase inclusion and diversity in research activity.

no. 5

How might we...

Be aware of and anticipate the difference in each other's calendars?

We challenge where necessary research protocols that we know are not going to be feasible.

We are more strategic and less reactive in planning research studies and responding to funding calls, so that there is time for proper partnership work.

no. 6

How might we...

Make research processes accessible, acceptable, and available?

We share examples of great practice.

We create awareness of how community roles can be built into and funded within research studies.

We work with community organisations and research funders to build standards of research inclusion that give guidance on:

- Financial accessibility: what good practice look like in terms of compensation of research collaborators. We encourage considering a range of payment options, where possible, taking into account how payments can affect one's position with regards to benefits and financial support, including No Recourse to Public Funds status, and any obligations under HMRC. As for the rates, the NIHR Payment Guidance is a good starting point to develop a payment policy. Read more at: **https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392**
- Administrative accessibility: keeping the route to engaging in research as clear and as straightforward as possible, designed around the community;
- Information accessibility: what good practice looks like in terms of making the information about research inclusive of different needs.

We challenge where necessary research protocols that do not accommodate for inclusive and accessible engagement.

We develop strategic partnerships with groups such as the Ethnic Minority Research Inclusion (EMRI) Hub to support with translation.

no. 7

How might we...

Protect communities from harm?

We use our shared voice to challenge funders and research partners that prevent us from upholding these principles, and say no when we need to.

We develop trauma-informed skills within our community, health and research organisations.

CASE STUDY 1

Working in health and care at ‘the deep end’

The ‘Deep End’ is a primary care movement supporting GPs working at the deeper end of the social gradient of health. Started in Glasgow, the Deep End movement has spread worldwide inspired by the paradox of the Inverse Care Law: people who most need good health care are least likely to receive it.

In 2016 the Deep End Yorkshire and Humber Clinical Research Network (CRN) was established, bringing together 9 GP practices in some of the most deprived areas of Sheffield with diverse patient populations.

In 2021, the Deep End Research Alliance (DERA) was funded to work in collaboration with the Deep End CRN, focusing on how academic institutions and processes perpetuate inequality in research. This was funded by NIHR Yorkshire & Humber CRN, and the Sheffield Clinical Commissioning Group. DERA has grown and expanded to form partnerships with the Ethnic Minority Research Inclusion (EMRI) group and a number of community organisations.

Dr Kate Fryer and Dr Caroline Mitchell co-lead this work. Research Nurse, Johanna White, now an NIHR leadership fellow, works across the Deep End CRN and DERA.

Building capacity with the Deep End Patient and Public Involvement (PPI) group

The PPI group was established in 2017 with patients from the Deep End GP Practices to offer a patient’s perspective on research projects, whilst developing a wealth of knowledge in research as they take part in projects steering groups, events, training and conferences.

The PPI group have contributed to more than 20 research projects over the past 2 years.

General Practice at the Deep End
Yorkshire and the Humber

Participatory research on Prostate Cancer and the 1 in 4 Sheffield Prostate cancer Support Group

In the UK, 1 in 4 men of Black, African or Caribbean heritage are at risk of developing prostate cancer in their lifetime: that is twice the number of White men at risk (1 in 8). DERA established a collaboration with SACMHA, a charity working in the African-Caribbean community in Sheffield, to design and deliver a research project on prostate cancer, led by Dr Qizhi Huang.

The approach was participatory from the start: two community health workers were employed as Community Research Link Workers (CRLWs) to ensure culturally appropriate research and research team diversity. The CRLWs received relevant training and co-designed, organised, and co-facilitate workshops. They also took part in data analysis and dissemination, including presenting a research poster at the 2022 Black in Cancer Conference.

Following that, CRLW Sheila and research nurse Johanna joined forces to develop a piece of health promotion and awareness on prostate cancer. Sheila hit the barber shops used by members of Black African and Afro-Caribbean. Together, they set up the first cancer support group in the north of England, named 1 in 4 Sheffield Prostate cancer Support Group (1in4 SPSG).
To read more visit the website at:
https://www.1in4spsg.org/

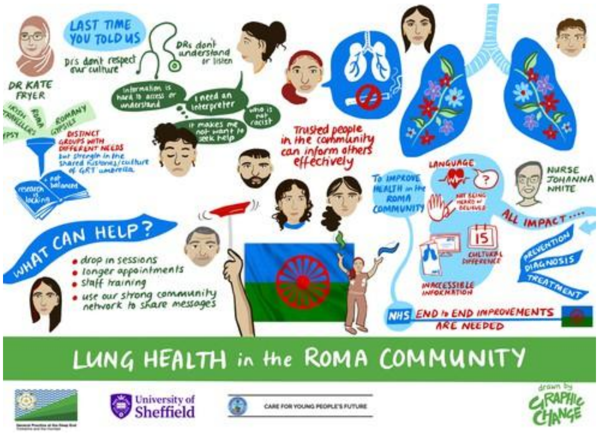
The CRLW model was then used by DERA in a number of other occasions, including the work on brain health and lung health priority setting (see next page).

Research Priority Setting with communities using the Community Researcher Link Worker (CRLW) Methodology

Awarded funding from Research England to explore research priorities directly with local communities, DERA employed and trained CRLWs to stimulate greater community involvement in health-based research.

Building on pre-existing relationships, DERA established a collaboration with two community organisations, the Sheffield Chinese Community for brain health and Care for Young People's Futures, active in the Roma community, for lung health.

The CRLWs carried out priority setting exercises over two patient and public involvement meetings. The first meeting involved a lay introduction to the topic, and a discussion to draw out the concerns of the community members. A rapid literature review was then undertaken by the academic researchers. The main findings were presented in a lay format at a second meeting, with further discussion to establish where the community felt that more research was needed.



For more information on DERA's work, visit the website at **https://sites.google.com/sheffield.ac.uk/dera/home**

CASE STUDY 2

Developing new medical devices with members of the public

NIHR Devices for Dignity (D4D) MedTech Cooperative* is a national programme hosted by Sheffield Teaching Hospitals NHS Foundation Trust to catalyse MedTech innovation.

The mission of D4D is to develop technology solutions to unmet clinical needs for long-term health conditions that are typically associated with loss of dignity and independence, and poor patient outcomes.

In its Patient Carer and Public Involvement and Engagement Strategy, D4D has set out an objective to 'develop effective partnerships with individuals, patient/public groups, [...] charities [...] in order to co-develop research priorities, and to co-develop and delivery of projects'.

Lise Spronson, D4D Patient and Public Involvement (PPI) Lead, oversees the development of creative ways of engaging patients, carers and members of the public.

In 2020 this led to a partnership between D4D, the University of Sheffield and ISRAAC, the Somali Community Association, to work on the CognoSpeak™ project.

*As of April 1st, 2024, the programme has ceased to operate under its former name and has been replaced by NIHR Devices for Dignity HealthTech Research Centre (D4D HTRC). The newly established centre continues to be hosted within the Sheffield Teaching Hospital to develop innovative health technologies for people with long-term conditions.

NIHR | HealthTech Research Centre
Long term conditions

Working with the Somali community to reduce the bias of the AI: the CognoSpeak™ project

CognoSpeak™ uses Artificail Intelligence I and language analysis to detect early signs of dementia. CognoSpeak™ could allow individuals to undergo an at home, online memory assessment, thus reducing the strain on NHS memory clinics. However, there are concerns around the usability, acceptability and bias of AI. For instance, whether the system would be equally accurate for patients who speak English as a second language.

To drive the development of CognoSpeak™ and to investigate the uptake and responses of Ethnic Minority patients compared to White British patients, D4D has partnered with ISRAAC and members of the Somali Community.

Two Community Champions, Muse and Sahra, underwent research methodologies and governance training and effectively became Research Associates for the project. Together, they co-hosted a series of workshops to understand dementia and care needs of the Somali community and recruited a total of 46 participants to help test the AI and design the appearance of the 'digital doctor'.

Co-evaluating the impact of working together

D4D applied for additional funding from the University of Sheffield to carry out a piece of evaluative research with ISRAAC and members of the Somali Community who had previously taken part in the development of CognoSpeak™.

During the impact workshop 20 participants reflected on how they felt 2 years before, when they had no experience of taking part in research, and how they felt after the CognoSpeak™ project.

It emerged that the most valued element had been regular visits from clinicians and researchers to the centre. Therefore, the team co-designed and held three additional workshops; on brain health, heart health and diabetes where doctors shared information and answered questions from the community.

Beyond the improvements to CognoSpeak™'s accuracy in different demographic groups, this collaboration left a legacy of improved trust and participation in research within the Somali community. Right now, D4D and ISRAAC are working together on a film, a research poster and a paper.

For more information on NIHR Devices for Dignity/HealthTech Research Centre visit the website at **https://devicesfordignity.org.uk/**

CASE STUDY 3

Ethnicity and Unequal Ageing: storying life courses for intersectional inclusion in Sheffield and Rotherham

The Ethnicity and Unequal Ageing project, funded by the Economic and Social Research Council*, addresses the urgent need for evidence on how ethnic inequalities shape experiences of ageing over the life course in particular places.
The project explores the everyday lived experiences of older Black, Asian and Minoritised Ethnic and Refugee communities in Sheffield and Rotherham from an intersectional, life course perspective, considering multidimensional identities including gender, migratory history, race and ethnicity, and the importance of place.

A cross-sector collaboration: when VCS organisations are Co-Investigators

Running between October 2022 and October 2025, the project is a collaboration between university-based researchers at the Universities of Sheffield, Birmingham and Liverpool, two VCS Co-Investigators, Co-Investigators at the Office for National Statistics, a range of policy and practice partners across South Yorkshire and a team of Community Researchers.

The VCS Co-Investigators are two grassroots community organisations: SADACCA, the Sheffield And District African Caribbean Community Association; and REMA, the Rotherham Ethnic Minority Alliance.

More information about the project can be found at **https://www.ethnicityandunequalageing.ac.uk**

Thinking beyond the research questions

Conscious of the unequal power relationships between universities and local communities, when developing the research proposal the emphasis was as much on the ways the research team wanted to work as it was on the actual research. Academic and VCS Co-Investigators designed a project that aims to foster a genuine cross-sector collaboration based on the principles of mutuality, reciprocity, inclusivity, equality, co-learning and a commitment to change.

VCS Co-Investigators' time commitment is fully costed and, in recognition of the precarity of the sector, the budget also includes resource for a bid writer to support REMA and SADACCA to secure future funding, leaving a legacy beyond this specific project.

Community Researchers

The entire project satellites around a a commitment to do research 'differently' and to start to bridge the gap between academia and communities, through mutual co-production and equitable knowledge exchange. To this end, the project employed a team of Community Researchers across Rotherham and Sheffield.

Community Researchers are employed by the University of Sheffield on a Post-doctoral Research Associate Grade on a series of casual contracts, which will run over the duration of the project. So far, they have been involved in training, designing and piloting of research instruments, project outreach, data collection (go-along & life-history interviews), data analysis, project dissemination, reflexive sessions and project meetings.

Each Community Researcher is paired with a university-based researcher in a co-mentoring scheme that includes 1:1 and group co-mentoring sessions. The university-based Research Associates work closely with the Community Researchers to help them navigate university systems and processes.

MATURITY MATRIX

The maturity model below builds on the research principles we have set out and starts to imagine what it would look like to go on a journey of increasing confidence and sophistication in bringing these principles to life.

GUIDING PRINCIPLE	LEVEL 1 BEGINNER	LEVEL 2 IMPROVER
1. Be community-centered	Researchers work with community partners to conduct research during the research scoping phase to inform study design as required by funders, typically with only a narrow sample of the community through a dedicated focus group. Research findings are shared with those involved in research when it is completed.	Research design is influenced at an early stage by potential participations in the research, through a collaborative process to identify research questions. As a result of this, community members might be recruited and trained as community researchers to co-lead data collection and analysis of findings.
2. Be respectful and practice cultural humility	There is bespoke one off training for researchers into cultural competency, with a particular focus on early career researchers.	There are embedded processes of continued and regular training, that is expected and completed for researchers throughout their career. Training is developed and delivered in partnership with community groups.
3. Recognize strengths and opportunities for mutual benefit	Partnerships between research organisations/ individuals are exclusively focused on the requirements of a particular research study such as recruitment needs.	Within a research study, researchers plan for and secure funding to conduct related capability building activities e.g. community researcher training.

GUIDING PRINCIPLE	LEVEL 1 BEGINNER	LEVEL 2 IMPROVER
4. Build lasting partnerships	Community collaborations are project specific, and there is limited to no understanding of the wider research collaborations community partners may be involved in. There is limited to no forward planning about the relationship beyond the duration of the individual research study/ project.	Research organisations are aware of the community partnerships in place within their own organisation, and they are mindful of distributing research burden and building both breadth and depth of partnerships to ensure partnership resilience. Following a research project, there is shared for reflection for how community organisations can take on learning generated through research activity.
5. Be aware of and anticipate the difference in each other's calendars	Research study schedules are driven by external factors, and whilst there is awareness of cultural festivities that may impact research, there is limited anticipation of these or adaptation to plans to ensure this isn't a barrier to community participation.	Mitigations are put in place to ensure that research studies accommodate cultural festivals
6. Make research processes accessible, acceptable, and available	Research communications are adapted and tailored to community needs on a case by case basis. Broad standards of accessibility are considered and planned for in research delivery, but these aren't tailored to the needs of specific groups.	Research studies anticipate barriers to participation that have been experienced before, and the resource required for translation and adaption of materials is accounted for in research planning.
7. Protect communities from harm	Core ethical requirements of research are understood and met.	Where there are concerns around the potentially sensitive nature of research topics, expert advice and community input is sought.

Learning from previous research projects is reflected on and embedded into future plans.

GUIDING PRINCIPLE	**LEVEL 3 MATURE**
1. Be community-centered	Research is co-created with communities throughout the research cycle, from research question, through to design, delivery method and knowledge sharing so that it is all tailored by community insight. Community organisations may be co-investigators on the research project as a result of this collaborative work. Researchers work with a diverse group of partners to ensure diverse representation of community perspectives, and confidently recognise, acknowledge, and incorporate difference of perspective and experience. Community partners acknowledge the constraints in their own reach and plans are put in place to ensure that there are opportunities to participate in research for those that might otherwise be left behind.
2. Be respectful and practice cultural humility	Researchers and community members collaborate through reverse-mentoring schemes to build a shared understanding of each other's contexts. Academic and clinical researchers create opportunities for community groups to understand the wider research landscape that individual research projects/ collaborations operate within so there is shared understanding.
3. Recognize strengths and opportunities for mutual benefit	Within a long-term collaborative partnership, community groups and researchers co-identify opportunities for sharing knowledge and plan for and fund reciprocal capability building activities.
4. Build lasting partnerships	Across the South Yorkshire system, there is a shared understanding of partner research activity, and an active process of distributing research burden between partners to ensure wide access to research for communities, and sustainability for individual research partners. There are confident and challenging conversations about the quality of partnerships and active management of research partnerships to ensure they continue to thrive (e.g. problems raised proactively, resolutions put in place). Partners plan together about how to use the outcome of their shared research to influence policy change.

GUIDING PRINCIPLE	LEVEL 3 MATURE
5. Be aware of and anticipate the difference in each other's calendars	Partners proactively plan together the schedule of research activity to ensure to maximise engagement and to balance each other's competing priorities, so that there is pragmatic and ambitious delivery plan
6. Make research processes accessible, acceptable, and available	At the outset of a research study, collaborations with community groups help identify what engagement communication will be needed and how best for this to be delivered, in order to break down barriers as much as is feasible. Limitations in processes are identified, explored and explained - and learning is taken forward for future research. Systemic barriers to making research processes inclusive are raised with funding organisations. Community partners and research organisations have inclusion requirements that are used to guide what research they will and won't collaborate on.
7. Protect communities from harm	Research agendas are shaped with funding bodies based on community perspectives and working in partnership to inform protocols to ensure research inclusivity. Community and research partners are trained in trauma-informed practice, and there are processes in place to support regular learning and improvement, as well as identifying risks and resolving problems when they arise.

ACKNOWLEDGMENTS

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ACT
African Voice Platform
Autistic Spectrum
Deep End Clinical Research Network
Deep End Research Alliance
Diabetes UK Sheffield
Ethnic Minority Research Inclusion Hub
Family Voice Sheffield
Firvale Community Hub
ISRAAC Somali Community Association
MAAN Somali Mental Health
Motion Exercise
NIHR CRN Yorkshire and Humber
NIHR Devices 4 Dignity HealthTech Research Centre
Rotherham, Doncaster and South Humber NHS FT
S62 Community Together Rotherham
SACMHA Health and Social Care
Sheffield Hallam University
Sheffield Health and Social Care NHS FT
Sheffield Mencap and Gateway
South West Yorkshire Partnership NHS FT
Spectrum Rainbow Community
University of Sheffield
VCSE Alliance

If this booklet has stimulated your thinking and you have suggestions and ideas that would support, sustain and expand this work, you can contact the Project Team at the following addresses:

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