Guidance to work with **Community Researchers**

In the context of health and care services and research

Research for you and me

Research Engagement Network

Research Engagement Network

NHS England

DIVERSITY RESOURCE INTERNATIONAL

Sussex Health&Care Research Partnership

NIHR | Research Delivery Network

NIHR | Applied Research Collaboration Kent, Surrey and Sussex

SCRC Sussex Cancer Research Centre

Thank you to all the partners and funders who have joined the Sussex REN in the journey to improve participation in health and care research.

UNIVERSITY OF CHICHESTER

my University Hospitals Sussex

Brighton & Hove City Council

the clare project

switchboard
connecting you to LGBTQ+ support

west sussex county council

East Sussex County Council

Trust for Developing Communities

Crawley Community Action

sis sussexinterpretingservices

Voluntary Action Arun & Chichester

Acknowledgements

This guidance was co-produced by members of the Pan-Sussex Diversity in Research Engagement Network (Sussex REN).

The project was made possible through generous funding from the National Institute for Health and Care Research (NIHR) Regional Research Delivery Network (RRDN) and NHS England. We are also grateful for the support from the national REN Development programme, which funds Sussex REN.

We collaborated with community researchers to co-produce all the tools in this guidance document, along with the rest of the Sussex REN dissemination materials, which can be accessed here.

The input, designs, and feedback from community researchers and other research partners form the core strength that enriches these documents. We are truly grateful to have been part of this collaboration.

We asked Community Researchers to describe ***community research*** *in just one word. This is what they came up with...*

Authentic
Change
TEAMWORK
Rewarding
POWERFUL
EMPOWERING
diversity
Connecting
Essential

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Introduction

Background

We know that certain communities experience health inequalities, which the Kings Fund describes as:

> *"Avoidable, unfair and systematic differences in health between different groups of people"*

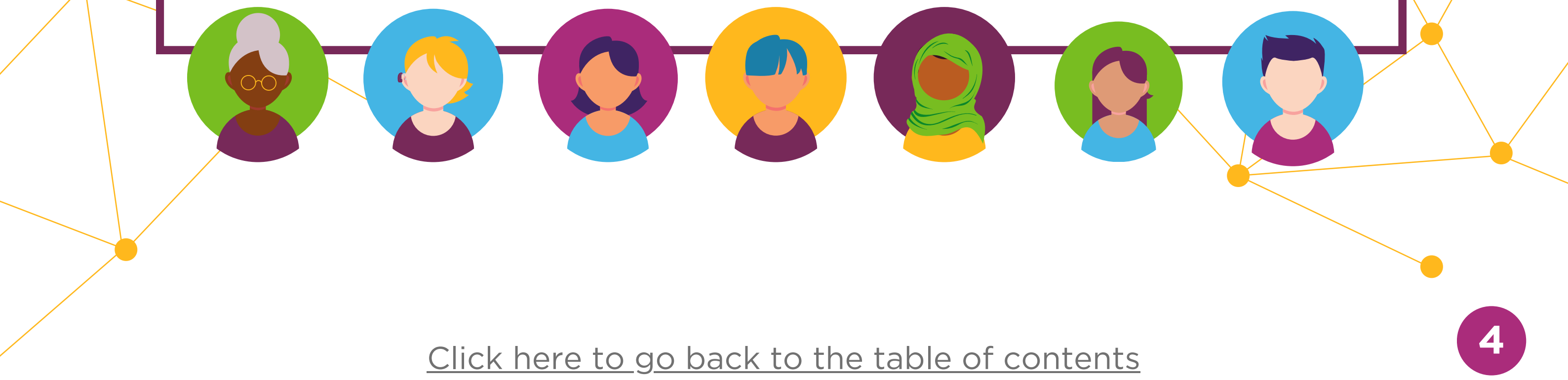
We also know that **those facing the most health inequalities are least likely to be involved in research** (NIHR Include Project 2020). This lack of inclusion operates on many levels, including identifying priorities for research, taking part in studies or leading research projects.

In response, Sussex Health & Care, local universities and the Voluntary, Community and Social Enterprise (VCSE) sector wished to work with traditionally disadvantaged communities to address this.

The funding application was co-written by research, health, and care professionals in collaboration with VCSEs as equal partners. REN collaboration sessions are frequently held to plan activities such as these and to update the REN offer.

Our Sussex-based REN project began in October 2023 with the aim of exploring how communities, community researchers and health and care researchers can work together to tackle inequalities and improve research inclusion.

The project created a regional network of fifteen community researchers from marginalised backgrounds, including people from racially minoritised/global majority and migrant communities; lesbian, gay, bisexual, transgender, queer and intersex (LGBTQ+) communities; and disabled and neurodivergent individuals.



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The capacity of community researchers was built through development training and qualitative interviewing experience. The community researchers interviewed forty-two minoritised people from the above communities in geographical areas of deprivation, gaining in-depth knowledge of how to improve participation in health and care services and research.

Community research involves working with people who have lived experience of the subject being studied.

It brings unique insights and a deeper understanding, which in turn captures information that otherwise would not have been available.

> *"You'll get answers going through a community research route, which you just wouldn't get [otherwise]"*

REN Community Researcher

> *"If someone from the same background as them interviews them, [it] makes them open more, engage more and feel more confident"*

REN Community Researcher

> *"It gives the communities who are being researched an opportunity to feel that their voices are being fully heard. Those who are commissioned in the research also benefit from this approach, because it is very likely that the information that is obtained will be broader and more in-depth"*

Community Researcher Development Trainer

This document reflects the profound impact community researchers interviewing their peers had on the depth and quality of research, their learnings and future recommendations for Sussex and beyond.

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Benefits of community research for communities

Amplifies community voices

Empowering marginalised groups by prioritising their perspectives, ensuring their voices are heard and valued in decision-making processes.

Reduces the barriers to participation

Making research processes more accessible.

Makes the research more meaningful

And also more applicable to the real-life challenges communities have.

Develops new knowledge and skills

Within communities, creating empowerment and increasing community development.

Finds solutions to community challenges

By developing partnerships and creating evidence and expertise that is culturally appropriate.

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Benefits of community research for researchers

Improves data quality

Providing richer, more accurate and greater depth of findings.

Increases the relevance of the research

Addressing real-life issues and community priorities further increasing social impact.

Increases research impact

As it is more likely to inform policies, practice and interventions which will have actionable impact.

Increases accessibility

Building partnerships with unheard communities who experience the greatest inequalities.

Uncovers nuances

Often missed by traditional researchers.

Develops innovation

Co-designing research methods and providing different perspectives.

Builds trust

Among diverse marginalised communities.

Aligns with ethical best practices

Demonstrating a commitment to justice and equity and enhancing the societal relevance of the research.

Builds new skills

In participatory methods and cultural competence increasing professional growth.

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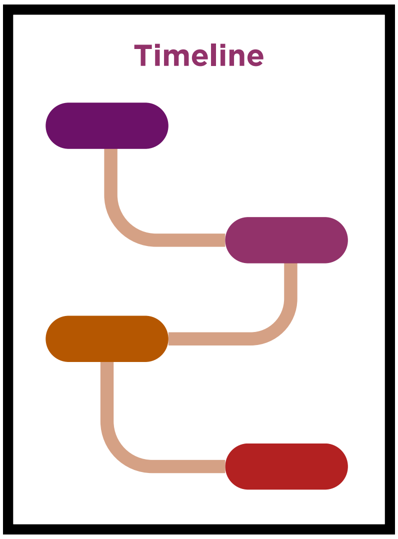
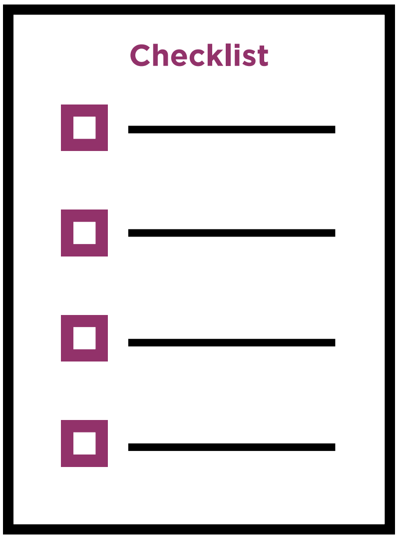
Tools

The tools which follow are a **timeline** and a **checklist** for community research. Our timeline starts at the point where funding is received; please be aware that costs and sufficient time need to be built into research projects when applying for funding.





Alongside this guide, we have also created a document with useful links and information for **further reading** and a **glossary** of terms, which can be accessed through this link.

These tools are based on the learnings from the REN Phase 1 project and, importantly, they aim to establish a foundation for safe and productive community research, co-production and collaboration.

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Timeline

Pre-interviews and set-up

1 Funding accepted

Professionals involved in research to estimate how many respondents are needed

2 Needs for community research communicated

Work with VCSEs to discuss the demographics in the area relevant to the research needs and assign a number of interviews to each minority group per geographical location

3 Brief and marketing materials created

Professionals involved in research to compose materials in plain English considering different language skills and neurodiversity. Consider translation services if a particular language group is an important target.

4 Timeline Set-up

Professionals involved in research and VSCEs to create a workable timeline to review training, deliver interviews, analyse the findings and write the report. This should consider accessibility needs.

5 Community researchers appointed and engaged

VCSEs to deliver clear objectives and schedules to community researchers. At this point, check for additional needs of community researchers to provide better accessibility.

6 Research questions and marketing materials delivered

Community researchers to give feedback on all marketing materials. Enough time should be allocated to allow for changes.

7 Research training revisited

Schedule refresher training and facilitate role play interviews and any further guidance.

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Interviews, reporting and analysis

8

Confirm Interview participants

Provide and receive guidance on how to reach participants, confirm interviewees and schedule interviews.

9

Check-in and role play practice

Professionals involved in research and VCSEs to check on community researchers and provide further role play practice if needed.

10

Conduct interviews

Community researchers to conduct interviews.

11

Translate and transcribe

Transcribing software to be made accessible to community researchers and translating software to be made accessible to multilingual community researchers.

12

Analyse

Community researchers to refresh on analysis training and analyse findings.

13

Report writing

Complete individual community researchers' reporting and deliver to professionals involved in research or VCSEs.

Please note that this timeline doesn't need to be followed in a strict order and some elements can be actioned simultaneously.

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Checklist

The following checklist was developed by community researchers from the REN. It's important to note that community researchers interact with various collaborators depending on the research project.

For clarity, the checklist uses the term "research partner" to broadly include the following roles:

Funder

An organisation that provides the financial resources needed for the research project. While funders may offer briefs and guidelines, they typically do not participate actively in the research process.

VCSE organisation

Some projects require community researchers to work with VCSE organisations to gain access to local communities or other types of support. In these cases, the VCSE organisation may serve as a point of contact between them and the funders.

Mentor

A mentor can be a professional involved in research or part of an academic institution. They provide guidance to community researchers throughout the project. Mentors may work directly with the researcher or, in some cases, collaborate with a VCSE organisation to offer support.

Some items on the checklist may be included in both the "community researcher" and the "research partner" sections - this suggests that they should work on that specific item collaboratively.

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Pre-interviews and set-up

RESEARCH PARTNER

- ☐ Receive project brief from research lead
- ☐ Clear written objective(s) for CRs
- ☐ Timetabled check-in's/Q&A sessions
- ☐ Check additional accessibility needs for CRs
- ☐ Role play session(s)
- ☐ Bullet points/cheat sheet of subject matter
- ☐ Marketing materials for CRs appropriate to the target audience (e.g. print, digital, verbal, social media, etc.)
- ☐ Confirm room for timetabled interviews
- ☐ Timetabled check-ins with professional involved in research (lead)
- ☐ Organise Safeguarding Training for CRs
- ☐ Organise meeting to discuss finding interviewees
- ☐ Provide discussion on the demographics for the research
- ☐ Offer existing contacts as possible interviewees
- ☐ Provide guidelines on how best to communicate with each other (refresher for existing CRs)
- ☐ Refresher on open questions and how to guide interviewees
- ☐ Discuss best practices around expenses
- ☐ Is everyone clear on how to record sessions?
- ☐ Provide guidance on how to reach communities

COMMUNITY RESEARCHER (CR)

- ☐ Do I have the brief?
- ☐ Do I understand the objectives?
- ☐ Do the questions make sense?
- ☐ Do I need to put the questions in a more digestible/easily understandable language?
- ☐ Mutually agreed check-in's with the research partner
- ☐ Do I understand the subject matter?
- ☐ Do I understand what will happen to the research?
- ☐ Do I understand my timelines for interviewing, analysis and write-up?
- ☐ Discussion about where to find interviewees
- ☐ Do I have marketing materials appropriate to the target audience (e.g. print, digital, verbal, social media, etc.)?
- ☐ Do I need to take safeguarding training?
- ☐ Do I have an introductory script for the interviews?
- ☐ Work to find interviewees
- ☐ Confirm interviewees and set up appointments
- ☐ Inform the research partner of the planned schedule
- ☐ Do I have a clear strategy for asking questions?
- ☐ Do I have clear travel information to get to the interview's venue?
- ☐ Review and discuss guidance on how to reach communities

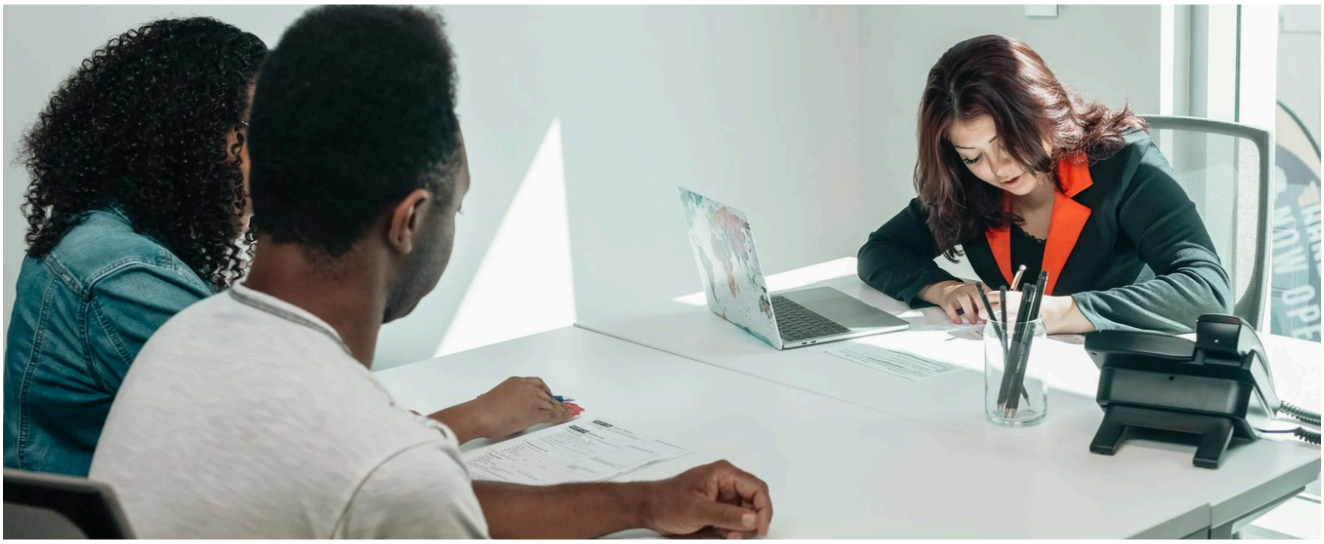
Interview stage

RESEARCH PARTNER

- ☐ Rooms or meeting link (if online) for timetabled interviews and refreshments (if arranged in person)
- ☐ Accessibility needs considered and planned for, including reimbursement of travel to and from the venue
- ☐ Role play/practice interview session scheduled
- ☐ Timetabled check-in's/Q&A sessions
- ☐ Have you checked additional needs for CRs?
- ☐ Bullet points/cheat sheet of subject matter
- ☐ Marketing materials provided
- ☐ Post interview check-in/supervision available
- ☐ Provide consent forms

COMMUNITY RESEARCHER

- ☐ Setup interviews in a safe space in person or online
- ☐ Check accessibility needs
- ☐ Do the questions make sense?
- ☐ Am I clear on the objectives?
- ☐ Am I prepared?
- ☐ Do I understand the subject matter?
- ☐ Do I have my introductory script ready?
- ☐ Do I have marketing materials at hand (if needed)?
- ☐ Remember to set a time goal for the interview at the start
- ☐ Do I need to debrief after each interview?
- ☐ Get consent forms signed
- ☐ Explain at the session that audio will be recorded, anonomised and kept confidential
- ☐ Practice sessions



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Transcript stage

RESEARCH PARTNER

- ☐ Provide transcribing technology/knowledge
- ☐ Set clear timelines for transcripts (bearing in mind neurodivergence and translation needs*)
- ☐ Timetabled check-in's/Q&A sessions
- ☐ Have you checked additional needs for CRs in this process?
- ☐ Are CRs clear on how to provide transcripts?
- ☐ Provide template for report with ideas on how to format it
- ☐ Check-in session scheduled
- ☐ CR invoicing arranged

COMMUNITY RESEARCHER

- ☐ Do I know how to transfer my audio to text?
- ☐ Do I have access to transcribing technology?
- ☐ Do I know where to get access to technology?
- ☐ Do I need extra time?
- ☐ Mutually agreed check-ins with research partner
- ☐ Do I understand the subject matter?
- ☐ Do I understand the goals and objectives?
- ☐ Have I included quotes and know the location of them on the transcript?
- ☐ Have I invoiced the research partner for my time?

*The language used during the research process should be easy to understand for everyone regardless of their education level or familiarity with English.

It's essential to provide translation services for individuals who would benefit from it to ensure the process remains accessible for all despite potential language barriers.

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Analysis and reporting stage

RESEARCH PARTNER

☐ Hold space for reviewing analysis process
☐ Scheduled meeting with professional involved in research (lead)
☐ Timetabled check-ins/Q&A sessions
☐ Do CRs have all they need including any additional support?
☐ Accessibility needs asked
☐ Schedule extra support for those who need it
☐ Practice session
☐ Provide Bullet points/cheat sheet on how to analyse findings

COMMUNITY RESEARCHER

☐ Do I have the brief?
☐ Do I understand the objectives and ways to analyse the information from the transcription?
☐ Mutually agreed check-in's with the research partner
☐ Do I understand the subject matter?
☐ Do I understand what will happen to the research?
☐ Do I understand my timelines for analysis and write-up?
☐ Do I have all the materials needed to write my report?

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Final thoughts

These guidelines were developed by members of the Pan-Sussex Diversity in Research Engagement Network (REN) to help individuals understand the unique value of community research, how different it can be from traditional research, and how to establish a clear and accessible process for conducting it.

The document was informed by early experiences and feedback from collaborating on previous REN projects. Other resources on community research were also used and are included in the further reading document available on through this link.

We encourage individuals to view these guidelines as a flexible resource that can be adapted to fit their specific needs. The checklist and timeline provided are not exhaustive and can be tailored to suit individual projects. Our vision was to produce simple and brief guidance for health and care researchers and community researchers to support them in working together more efficiently.

Community research creates opportunities to engage directly with the individuals at the heart of the research in a way that they trust and through which they can feel represented.

The REN acts as a central hub for anyone interested in community research:

- VCSE Organisations, researchers (academic, clinical, etc.), and funders can reach out to REN to identify suitable community researchers who can support their research needs and projects.
- Community researchers can contact REN to connect with VCSEs seeking their expertise for upcoming or ongoing projects.
- Individuals aspiring to become community researchers can reach out to REN to connect with training providers or VCSEs offering training or onboarding opportunities.

For more information about REN or to contact the team, please refer to the following details:

Email: sussexren@bsms.ac.uk
Website: www.bsms.ac.uk/research/support-and-governance/shcrp/ren.aspx

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