Research Engagement Network (REN) Phase 2 Programme Evaluation Report

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1.0 Abbreviations

CRN – Clinical Research Network

CV – Community Voices

NCF – Norfolk Community Foundation

NIHR – National Institute for Health and Care Research

REN – Research Engagement Network

REND – Research Engagement Network Development

SCF – Suffolk Community Foundation

TC – Trusted Communicator

VCSE – Voluntary Community and Social Enterprises

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2.0 Key Findings

- A variety of barriers, including communication challenges, time constraints, transportation issues, and trust concerns, hinder community participation in research. Employing strategies to overcome these barriers, such as increased transparency in communication and the provision of accessible resources, may improve research participation moving forwards.
- Trusted communicators played a vital role in facilitating engagement in research by using their existing relationships with the communities they support. Building a trusting and reciprocal relationship with community members was highlighted as a key factor in encouraging participation.
- Aligning research priorities to the needs and interests of local communities was seen as imperative to ensuring success. Topics such as mental health, cancer, and diabetes resonated strongly with the community members interacted with, emphasising the importance of addressing issues directly impacting them.
- Fostering collaboration among VCSE organisations, to promote resource and insight sharing, may facilitate a more comprehensive approach to community engagement in research.

3.0 Introduction

3.1 The evaluation

This report presents an evaluation of the second phase of the NHS Norfolk and Waveney ICS Research Engagement Network programme (REN 2). It describes the perceived impacts of the programme on local research engagement in Norfolk and Waveney.

3.2 Background

The Research Engagement Network Development (REND) programme's first phase, funded by NHS England, ran from December 2022 to March 2023. Its goal was to boost research engagement opportunities within diverse coastal communities in Great Yarmouth and Waveney. Building upon this, the second phase, REN 2, expanded the initiative to cover a broader area of Norfolk and Waveney in order to further community engagement and research participation. The process involved:

- Grant funding of trusted communicators in up to 20 local VCSE (Voluntary, Community and Social Enterprises) organisations who would receive a tailored Clinical Research Network (CRN) ‘Research Ready Communities’ package as well as Community Voices (CV) training in order to facilitate conversations with local communities.
- Delivery and recording of these conversations by the trusted communicators on the Insight Bank. They aimed to gather community insights on which health and social care topics should be researched, the barriers preventing research engagement, and the support needed to facilitate community engagement with research.

This report will focus primarily on presenting the results of the community engagement work performed by the trusted communicators with support from Norfolk Community Foundation (NCF) and Suffolk Community Foundation (SCF) who connected and supported appropriate VCSE organisations with the REN 2 programme.

4.0 Evaluation Methodology

4.1 Aim and objectives

Aim: To describe the perceived impacts of the REN 2 programme on local research engagement in Norfolk and Waveney.

Objectives:

1. To describe the trusted communicator entries into the Insight Bank.
2. To present the key themes identified from research-focused questions in the Community Voices conversations.
3. To describe the perceived value of the REN 2 programme for the trusted communicators and their organisations.

4.2 Data collection and analysis

The data that appears in this evaluation report includes the trusted communicator research conversations recorded on the Insight Bank (an online repository developed for recording of community insights), thematic analysis of focus groups with VCSE partners and trusted communicators, and narrative feedback from the core team involved in the implementation of REN 2.

4.2.1 Recorded conversations on the Insight Bank

Trusted communicators recorded key details from conversations with community members using a SmartSurvey form covering a series of prompts relating to engagement in health and care research. Additional data, including demographics, were also recorded with consent. These conversations took place over a three-month period, 11th January 2024 - 11th April 2024. This data was then prepared and analysed using Microsoft Excel.

4.2.2 Focus groups with VCSE partners

Five semi-structured focus group discussions took place with 16 partners in local VCSE organisations that had been involved in the delivery of REN 2. Conversations were conducted virtually using Microsoft Teams in March 2024. NCF and SCF issued partners an invitation to contact the Evidence and Evaluation Hub team if they wished to participate in one of these sessions. With informed consent from all participants, these sessions were recorded, transcribed, and analysed thematically using QSR NVivo. The key themes identified during this analysis are presented below.

4.2.3 Core team reflections

The core team established to oversee the delivery of the REN 2 programme included representatives from the VCSE sector, NIHR infrastructure, ICB, and NHS R&D. Narrative analysis is presented from meeting notes, individual and group recorded sessions, and written feedback.

5.0 Findings

5.1 Recorded conversations on the Insight Bank

Over the three-month reporting period (11th January 2024 - 11th April 2024) a total of 436 REN 2 specified conversations with community members were recorded on the Insight Bank by Trusted Communicators. REN 2 conversations were recorded by 16 of the organisations approached to participate.

Trusted communicators made note of the locations of conversations held with community members. Table 1 presents a breakdown of the conversations by Place within Norfolk and Waveney, not all conversations were assigned a postcode. The most common sites for conversations to take place were within a local community centre (112, 32.0%), a VCSE organisation's own offices (74, 21.1%), advocacy group meetings (40, 11.4%), and in a community member's home (37, 10.6%). There was a large variety of other locations in which conversations took place in fewer numbers, including but not limited to allotments, cafes, car rides, shops, libraries, public transport, and walks.

Place	Number of conversations recorded
Gt. Yarmouth and Waveney	83
North Norfolk	45
Norwich	160
South Norfolk	129
West Norfolk	11
Unknown/ not reported	8

Table 1: Number of conversations hosted within each Norfolk and Waveney locality.

Trusted communicators also recorded the number of times they had spoken to a community member before engaging in the REN 2 focused conversation. Having had zero previous conversations was reported 160 times (45.7%), once before (37, 10.6%), two or three times (34, 9.7%), four or five times (17, 4.8%), and six or more times (102, 29.1%).

Local community members expressed interest in a wide variety of health topics they considered important to themselves, their families, and friends and would like to see prioritised in research moving forwards. More than 35 health and social care issues were cited during the recorded conversations but the most common included mental health issues (33.7% of total conversations, 147), cancer (15.4%, 67), blood pressure (9.4%, 41), diabetes (9.2%, 40), dementia (8.0%, 35), heart disease (7.3%, 32), sight loss (7.3%, 32), and obesity (7.1%, 31). It should be noted that some VCSE organisations involved in the REN 2 programme focused on helping community members with a specific condition and, as such, certain conditions may be overrepresented in the findings. Most commonly, community members wanted to see research into health and social issues that had directly impacted them or those close to them:

"Mostly talked about mental health and the daily struggle. Cancer was also a topic the client felt should be researched further."

"Arthritis, Mental health, research the effect of closing of services, hospitals and lack of GPs and dentist on wider society."

"Dementia is important to this lady as her husband has dementia. Also spoke about mental health as she has a son with mental health issues who receives virtually no help and long waiting lists."

The conversations recorded on the Insight Bank suggested that one significant barrier to community engagement with research is communication. Numerous references were made to the challenges faced in obtaining accurate, accessible, and reliable information regarding research by local communities. Difficulties arose from materials being available only in English or containing complex scientific jargon, making them hard to comprehend:

“People are not fully aware where to go, what to do, or don’t understand due to English language barriers or jargon.”

“Other people also might need translating [into their first language]. Jargon, medical language puts her off or totally.”

“Not interested. Language barrier and accessibility would be a problem.”

Similarly, the availability of transparent information from a trusted source that clearly outlined the research's objectives, its potential benefits for individuals and their communities, and the provision of feedback following the publishing findings, was seen as encouraging participation in research:

“Clear information about what's going to happen, easy to understand. Debrief, after if wanted, feedback on results. Recognises that people in their work ask, what's the point of this research? Why are you asking these questions. Let people who take part know what the findings are and that it's not just a tick box exercise. To know who is funding [the research project] and what are their aims and motive.”

“Would like feedback to know that taking part in the research had been useful.”

Another barrier highlighted was the lack of available time to take part in research due to existing commitments, or a lack of interest as participation is perceived to require a lot of time from individuals:

“Commented that their time is limited with taking care of the children and running a home.”

“With research, face to face is hard with kids and time off work. So it would be hard to schedule the date where people could join. […] People are put off because of the time or place of the research.”

“Feels has limited time available. Might be encouraged if was local and not time consuming.”

The accessibility of research participation locations, along with the scarcity of public transportation in rural areas, was also identified as a significant barrier. Many individuals expressed concerns about having to travel long distances or incur personal expenses to participate in research:

“For some people the problem would be the transport links as some people can’t use public transport.”

“Making research local to people so easy to access. Rural areas without transport links mean it would cost to get a taxi to go to a place for research.”

“Having to travel to take part would put them off as they don't drive and their public transport links are poor.”

Another barrier cited as preventing engagement with research was the issue of trust. Several respondents have felt let down and underserved by the NHS in the past and were therefore reluctant to engage in any form or research. Similarly, concerns about who would have access to any personal data they provided and broader issues surrounding confidentiality were also frequently cited:

“What puts people off is distrust of who has and is using their information.”

"[Community member’s] trust in the NHS has been eroded in the last 6 years"

“He would be more up for it if it was done by independent agency. He thinks that NHS won’t release honest or trustful results (or manipulate them if the results are not as they wanted).”

“Trusting the organisation running the research. Concerns around confidentiality and what their personal information would be used for. Would trust a GP asking them to get involved in research.”

“Particular concern about confidentiality, would need to be very confident that any information was not identifiable in research.”

Some strategies in which the impacts of these perceived barriers could be lessened to promote more participation in research were highlighted. These suggested strategies often revolved around encouraging greater reciprocity in the relationship between researchers and participants. Individuals emphasised the importance of receiving compensation for their time and having their travel expenses reimbursed when participating in research:

“Payment or some sort of recompense for their time. To be made to feel they are helping their community or society as a whole somehow.”

“People might be put off if it is going to take a long time and she thought offering something like a voucher might encourage people to get involved.”

“They would be encouraged to take part if they had transport.”

“People feeling valued for their time and input, […] people need realistic times as to how long research will take and need to know their expenses at the very least will be covered.”

Another significant factor influencing people's decision to participate in research was the perceived relevance of a programme to themselves and their communities. The sense that a research project could address a tangible health or social care issue impacting individuals, coupled with the belief that their input would be valuable, was seen as influential in encouraging engagement:

“They would get involved if the subject seemed relevant and more importantly to her if they could see the results having a positive impact on the health service she and her family access. Thinks that many people wouldn't see the point of getting involved as they can't see the impact.”

“However she also said that she would only want to get involved if it was a subject that was relevant to her/her family/friends and she feels that this would be the case for most people.”

“They would be encouraged to take part in research if it was relevant to them and if they could see the outcomes as the research develops.”

5.2 Focus groups with VCSE partners

The focus group discussions identified the following key themes: trusted communicators facilitating meaningful community engagement, current REN 2 impacts and proposed sustainability increasing actions, and the impact of existing attitudes towards the NHS on research engagement.

Trusted communicators facilitating meaningful community engagement

Partners highlighted a crucial aspect of the REN 2 programme as their capacity to use established relationships with individuals supported by their organisations. This enabled them to introduce and discuss topics like health research without the resistance many researchers engaging with community members for the first time may encounter. Also, the existing relationships between VCSE organisations and the communities they serve was perceived to involve reciprocity, which promoted a greater willingness among community members to share their experiences and opinions with the trusted communicators:

“They've [VCSE organisations with trusted communicators] been working with those clients for a long time. Those clients understand them what they're about. Why they're doing stuff and what they're providing to them. So there's a level of trust. There's also probably a level of wanting to give back so they will do things for us that maybe they wouldn't do for anybody else because we've asked them so.” (TC2)

Due to the nature of the existing relationship between VCSE organisations and community members, trusted communicators referenced instances where conversations extended beyond REN 2’s research focus. While this occasionally made data collection more difficult for trusted communicators by deviating from the original topic, it also allowed community members to take a more holistic view of their personal lives and health issues. This broader perspective enabled them to recognise the issues important to them personally and, therefore, where they would like to see health and social care research targeted moving forwards:

“It's all about support for us. We're used to people telling us every detail of their life. We're used to asking sort of very probing questions. So I think the actual project itself and talking to people about all this kind of stuff about, because people like, once you start talking about health, they want to tell you all about that health. You kind of got to get through that first before you start talking about, well, the research and what you're doing.” (TC1)

Current REN 2 impacts and proposed sustainability increasing actions

Trusted communicators frequently referenced REN 2 as an opportunity to provide historically underserved communities with a voice in research. REN 2 was seen as a means to convey community members’ opinions meaningfully to researchers, highlighting their health and social care priorities:

“I think it was, it was a really good opportunity to be able to let people know that they really do have a voice.” (TC12)

Suggestions to enhance the impact and sustainability of the REN 2 programme and research engagement within communities were also provided by the trusted communicators. Many of the responses reflected recommendations from recorded conversations in the Insight Bank, such as compensation for time and travel expenses, ensuring resources were accessible, and aligning research with the needs of individuals and groups. However, further suggestions pertained to VCSE organisations themselves, including simplifying conversation structure and reporting mechanisms, securing consistent funding for longer term involvement in research, and adopting targeted approaches to research topics for VCSE organisations e.g., utilising an organisation that works primarily with women to recruit for menopause research:

“If you'd have said to me I want you to do research on the menopause, I'd have had millions of people talking to me and I'd have enjoyed it so much. And you can get so much out of that. But this […] is just a bit too generalised, I think as well.” (TC9)

Trusted communicators noted that the studies available for community members at the time of hosting research conversations were largely irrelevant to the communities they served. This could result in community members being discouraged, as those eager to engage in research were directed towards studies that were not suitable for them. In some instances, this led to trusted communicators from certain organisations feeling unable to signpost to the currently available studies:

“*We couldn't signpost to any of the studies because none of the studies had any accessible information with them. So we had kind of agreed that, yeah, we'd agreed that up front, that it […] wasn't appropriate*.” (TC13)

Impact of existing attitudes towards the NHS on research engagement

A recurring theme in the focus group sessions was the perception among community members engaging with VCSE organisations that they had been let down by the NHS in the past. This perception of negative prior experiences was suggested to contribute to apathy or reluctance among community members to engage with research opportunities when presented to them:

“They can't break the link between the appalling ways they've been treated in the NHS and the fact that the NHS was talking about research so they couldn't break that link, no matter how much I tried and I and I used the translator and I turned it and I said, look what they've done in the past. You know, if you've got a replacement hip that's down to NHS, but they're too angry about the fact that the NHS is so dire and they know people have died.” (TC13)

Some community members expressed the viewpoint that addressing existing issues they are experiencing when trying to access health and social care should take precedence over the pursuit of new research activities:

“I was quite surprised how angry everybody was about the NHS in our sessions, got loads of people who said they would definitely never take part because if the NHS could take their blood for research, why would they not take their blood when they were sick?” (TC14)

Many community members also expressed to trusted communicators their reservations about engaging with research, citing concerns about why the NHS was collecting their data, who would have access to it, and the methods employed in the research process:

“But in one group of quite a few people just fear they assumed that medical research meant something that would be, you know, prodded, poked hurt. So the answer from a few people was I would never do that because it would be scary.” (TC8)

5.3 Core team reflections

REN 2 expanded the scope of research-focused discussions initiated during REND by expanding its geographical coverage. This phase of the programme encompassed a wider array VCSE organisations, which in turn, facilitated increased engagement with the diverse communities situated in Norfolk and Waveney.

The core team reflected on the persistence of certain barriers that continued from the first phase of REND. Primarily, the difficulties revolved around the issue of short-term funding allocated to partner organisations for hosting conversations. While this approach enabled rapid accumulation of insights within a brief period, it limited the sustainability of any research engagement work without the partner organisations potentially needing to provide funding for additional works themselves.

Facilitators to the successes of REN 2 included an expanded training programme, featuring face to face sessions where possible, as well as continued support for VCSE partners recording conversations. Additionally, while still relatively short-term, REN 2 was resourced over a longer period than REND. This allowed for a more thorough planning process and resulted in a greater number of conversations taking place.

It was also observed that interactions between VCSE organisations due to REN 2 related activities has resulted in the sharing of resources and insights between partner organisations. Notably, this increased collaboration occurred among community organisations which served vastly different communities and had limited interaction in the past. The following case study demonstrates resource development by, and sharing between, VCSE organisations involved in REN 2.

Case study: Opening Doors*

Opening Doors is a user led organisation run by people with learning disabilities. It is run for people with learning disabilities and or autism to have their say and be more confident to speak up to make their own decisions and live the life they want to have. On joining REN, Opening Doors used their established model for gathering insights and hearing and understanding people's views from their communities, a different approach to other VCSEs in REN.

The experts by lived experience worked alongside advisers without learning disabilities to understand the questions the local REN team had developed – 'translating' them into concepts and phrasing and choosing words that people with learning disabilities would be able to understand. The experts by lived experience designed and tested the co-produced easy read documents and used them as printed books and A3 worksheets to have individual and group conversations. Participants chose then used individual 'character' stampers to record anonymously their opinions and ideas. The experts by lived experienced who designed the easy read tools then delivered the workshops across Norfolk with support of people they trust. The conversations were supported in their local advocacy groups including one in a locked secure setting. Finally, they co-produced an easy read booklet summarising all the recorded conversations and feedback (with a hard copy) to all the Advocacy Groups.

The Opening Doors approach was inclusive and flexible, adapting to different needs – e.g. people in a secure unit, people with dementia and learning disability and with autism, people who prefer a different format for recording conversations in line with the 2016 Accessible Information Standard. The material they produced provided invaluable insight into the accessibility of research and research participation for people with learning disabilities. The resources Opening Doors have developed have been shared with all REN VCSEs locally and they have said they are an invaluable resource for starting conversations within their own communities.

*Many thanks to Opening Doors for developing this case study with the evaluation team.

6.0 Implications and considerations

A structured approach that effectively incorporates the engagement work carried out during REND and REN 2 is pivotal in achieving the primary objective of the REN programme, increasing community participation in research. The following factors could therefore prove influential when considering any future community research engagement work:

Taking a community centred approach. The successes of research initiatives rely heavily on the engagement of communities at a local level. By aligning research initiatives more closely with community priorities, researchers may be able to ensure greater participation from historically underserved groups.

Alleviating barriers to participation. Identifying and addressing barriers to participation is essential for ensuring continued engagement in research. Communication issues, time constraints, transportation, and trust all emerged as significant barriers during the evaluation period. Strategies to overcome these barriers may include the provision of accessible information, compensating participants for their time and travel expenses, and offering more flexibility when looking at how individuals may participate.

Developing a sustainable approach. Ensuring consistent research engagement requires long-term planning, reliable funding, and ongoing support for VCSE partners. VCSE organisations may be reluctant to facilitate the relationship between researchers and community members due to the additional workload diverting resources from their original community supporting role.

7.0 Conclusion

The three-month evaluation period for REN 2 (11th January 2024 – 11th April 2024) highlighted the programme successes in engaging meaningfully in research-oriented conversations with a diverse range of community members across Norfolk and Waveney. Trusted communicators played a crucial role in facilitating an open dialogue to identify the wide range of health topics of interest to local communities, emphasising the importance of aligning research activities to local community priorities. Despite barriers, REN 2 demonstrated effectiveness in promoting community engagement and resource sharing amongst previously disparate VCSE organisations.

Moving forward, addressing communication barriers, enhancing the accessibility or resources, and improving trust are key steps in promoting increased community participation in research initiatives. Employing strategies such as providing transparent information in multiple languages, compensating participants for their time and travel expenses, and tailoring research initiatives to address community priorities may help to alleviate the effects of these barriers.