

Somerset Research Engagement Network (REN) Project 2023-24

Final Report & Recommendations





Disclaimer: This activity was funded through the ICS Research Engagement Network (REN) development programme. 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.



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Glossary, Abbreviations & Acronyms

REN/D Research Engagement Network/Development

ICB Integrated Care Board, which is known as 'NHS Somerset'

ICS Integrated Care System in Somerset, partners include NHS Somerset, Somerset Council & VCFE sector

VCFSE Voluntary, Community, Faith & Social Enterprise sector in Somerset

Community groups An umbrella term for organisations working locally, regionally or nationally for a defined community. Includes voluntary, community and social enterprise sectors.

Research Connector A term used by the Somerset REN project, for trusted community leaders who had conversations with individuals & groups that they support in localities across Somerset

CRN Clinical Research Network

NHS Somerset The Integrated Care Board in Somerset

NIHR National Institute for Health and Care Research

HDRC Health Determinants Research Collaboration



Introduction

“This was an important collaborative piece of work to help us understand how we might engage, involve and ultimately increase research participation for all the population we serve. The work has been a fantastic opportunity for the research infrastructure to understand the public perception of research and for non research organisations to learn more about the research opportunities that are available within their communities and health and care system. The work has allowed us to understand how we can work with the voluntary, community and social enterprise organisations who have established trust within the local communities to support future work. We have also created an opportunity to build on successful collaboration”.

**Pauline McGlone, Deputy Chief Operating Officer
NIHR Clinical Research Network South West Peninsula**



Overview of Somerset REN Project

Following a successful bid in October 2023, NHS Somerset secured funding from NHS England and the Department of Health and Social Care to deliver a Research Engagement Network (REN) Project across Somerset. The Somerset Research Engagement Network (REN) aimed to understand barriers to research participation among adults in Somerset not currently represented in research, explore the barriers people face that mean research participation in Somerset is low in areas where burden of disease is highest and to explore the significance of the barriers accessibility, language and trust.

The Somerset REN Project Oversight Group, comprised of key ICS partners, worked on an initial scoping phase followed by a community engagement phase. Scoping involved sharing our knowledge, experience and skills across the worlds of research, engagement and VCFSE sector. The group were able to share studies, analyse Public Health's Somerset data (e.g. key health inequalities data around Core20PLUS5) and to discuss experiences around health inequalities, public engagement and patient participation and involvement (PPI) in research. The Project Oversight Group used the lessons learned during the scoping phase to design community engagement activity, with the aim of hearing from VCFSE community groups about their knowledge, understanding and experiences of research. Based on Somerset health inequalities data, it was agreed that the focus would be to work with community groups in rural, urban and coastal settings who supported individuals with cancer, mental health or Dementia.

Spark Somerset, Somerset's VCFSE lead organisation, visited 3 'Talking Cafes' and established effective relationships with 7 community groups. Community-based organisation and group leaders, with their vital local knowledge, understanding and connections, were trained to be 'Research Connectors'. The 'Research Connectors' discussed with 10-15 members of each group or organisation key areas such as their knowledge and understanding of what health and social care research is, their awareness of past research in these health and care areas, and the reasons why they would or would not get involved in current or future research opportunities.

Overview (continued)

The organisations and groups that were identified and took part in the REN Project were:

- Dulverton Talking Café
- Williton Talking Café
- Minehead Talking Café
- Alzheimer's Society - Dementia Voice
- Nelson Trust
- Homestart
- Minehead Eye
- Watchet Dementia Alliance
- MIND (Bridgewater Group)
- Seed of Hope (West Somerset Group)

Engagement conversations started in February 2024 and were completed by early March 2024. The Somerset Integrated Care System commissioned Darmax Research to undertake the thematic analysis and report writing of the feedback gathered. Using this analysis, the Somerset REN Project Oversight Group produced a final report for NHS England which reflected on the learnings, challenges and achievements of the project.

The Somerset REN Project Oversight Group have developed key recommendations for the ICS, regarding effective community engagement around research, how to tackle the wide range barriers to participation and so to reduce inequalities in research participation. Increased diversity in research participation will in turn, help to develop and improve health and care services in Somerset and so supports the ICS's Strategy.

Project Background

NHS England, the government, and recent health care system legislation have indicated a strong commitment to growing research. Integrated Care Boards have a legal duty to facilitate and promote research, use evidence from research, and to involve people and communities in the development of health care provision (including research). **Our collective ambition is to increase the numbers of people participating in research and the diversity of people taking part will, once realised, ensure that research is more representative of our diverse populations and that communities are more actively involved in shaping the future of local health and care.**

The programme was funded jointly by NHS England and the Department of Health and Social Care (DHSC) and aimed to evaluate the feasibility of local approaches to support ICSs to:

- *Set up and/or grow their local research networks with local stakeholders (multi-organisational networks)*
- *Engage people in underserved communities in doing this*
- *Further develop a greater diversity of local participation in research by increasing opportunities and access to take part in research*
- *Integrate consideration of diverse participation in research within ICS governance and operations*
- *Generate evidence to demonstrate whether support for research networks across multiple organisations can be effective in increasing diversity in research.*

Successful applicants have trialled locally determined approaches to deliver these ambitions. The project team has been part of a sharing and learning network for the duration of the programme, building knowledge around what works. The learning will support subsequent guidance and development programmes for wider ICS involvement in potential further phases. The funding was available for each of the successful ICSs and their partners to deliver their programme of work by 31st March 2024.

Strong partnerships, including appropriate resourcing, were expected with the voluntary and community sector, and with local NIHR and other research partners.

Somerset REN Proposal

In October 2023, we submitted Somerset's REN proposal to NHS England, which outlined the following:

- Our ambition as an ICS to reducing health inequalities, and our commitment to involving those directly affected and impacted by health inequalities.
- Our experiences and challenges as Engagement at NHS Somerset in working with communities likely to be affected by health inequalities.
- Our aim to understand what is the role of trust within promoting health and care research participation in the context of health inequalities?
- This question will help clarify the extent of work the ICS must deliver to build mutually trusting relationships with people and communities in Somerset.
- The work here will lay the foundations for successful outcomes in its future ambitions for people in Somerset.

Somerset REN Project Aims

Aim 1: To improve understanding of engagement and research participation in Somerset, and the barriers to research participation

Aim 2: To create and develop relationships and trust with community groups and members

Aim 3: To promote awareness of engagement and research opportunities

Aim 3: To develop further relationships with VCFSE groups

Aim 4: To establish recommendations for ICS as well as future REN work

Aim 5: To create a Somerset Research Engagement Network

Aim 6: To enhance engagement structures





Membership of the Project Oversight Group



Timeline of Somerset's REN Project

- A. Mapping – Oct 2023
- B. Scoping – Nov - Dec 2023
- C. Focus – Jan – Feb 2024
- D. Engagement Activity – Mar 2024
- E. Summary of findings – Apr 2024
- F. Recommendations – May 2024



A. Mapping - Oct '23

Core20PLUS5 (adults) – an approach to reducing healthcare inequalities

- Core20PLUS5 is a national NHS England approach to inform action to reduce healthcare inequalities nationally and locally
- The approach defines a target population – the 'Core20PLUS' – and identifies '5' focus clinical areas requiring accelerated improvement.

Core20 - The most deprived 20% of the national population as identified by the national [Index of Multiple Deprivation \(IMD\)](#). The IMD has seven domains with indicators accounting for a wide range of social determinants of health.

PLUS - PLUS population groups should be identified at a local level.

5 - There are five clinical areas of focus which require accelerated improvement: 1) Maternity 2) Severe mental illness (SMI) 3) Chronic respiratory disease 4) Early cancer diagnoses 5) Hypertension

To read more: [NHS England » Core20PLUS5 \(adults\) – an approach to reducing healthcare inequalities](#)

The Project Oversight Group considered existing literature and evidence on health inequalities in Somerset

Engagement & research colleagues shared their experience regarding those who tended to take part, or not take part in our work.

Protected Characteristics - Health Equality Act 2010

- 1. Age:** Where this is referred to, it refers to people belonging to a particular age (e.g. 32 year olds) or range of ages (e.g. 18-30 year olds).
- 2. Disability:** A person has a disability if s/he has a physical or mental impairment which has a substantial and long-term adverse effect on that person's ability to carry out normal day-to-day activities.
- 3. Gender reassignment:** The process of transitioning from one gender to another.
- 4. Marriage/Civil partnership and same sex marriage:** Marriage is defined as a 'union between a man and a woman'. Same sex couples living together can also have their relationship legally recognised, either by civil partnership or through same sex marriage.
- 5. Pregnancy and maternity/paternity:** Pregnancy is the condition of being pregnant or expecting a baby. Maternity refers to the period after the birth, and is linked to maternity leave in the employment context. This refers to both women (maternity) and men (paternity). In the non-work context, protection against maternity discrimination is for 26 weeks after giving birth, and this includes treating a woman unfavourably because she is breastfeeding.
- 6. Race:** This refers to the protected characteristic of race. It refers to a group of people defined by their race, colour, and nationality (including citizenship) ethnic or national origins.
- 7. Religion or belief:** Religion has the meaning usually given to it but belief includes religious and philosophical beliefs including lack of belief, atheism for example. Generally a belief should affect your life choices or the way you live for it to be included in the definition.
- 8. Sex:** A man or a woman.
- 9. Sexual orientation:** Whether a person's sexual attraction is towards their own sex, the opposite sex or to both sexes.

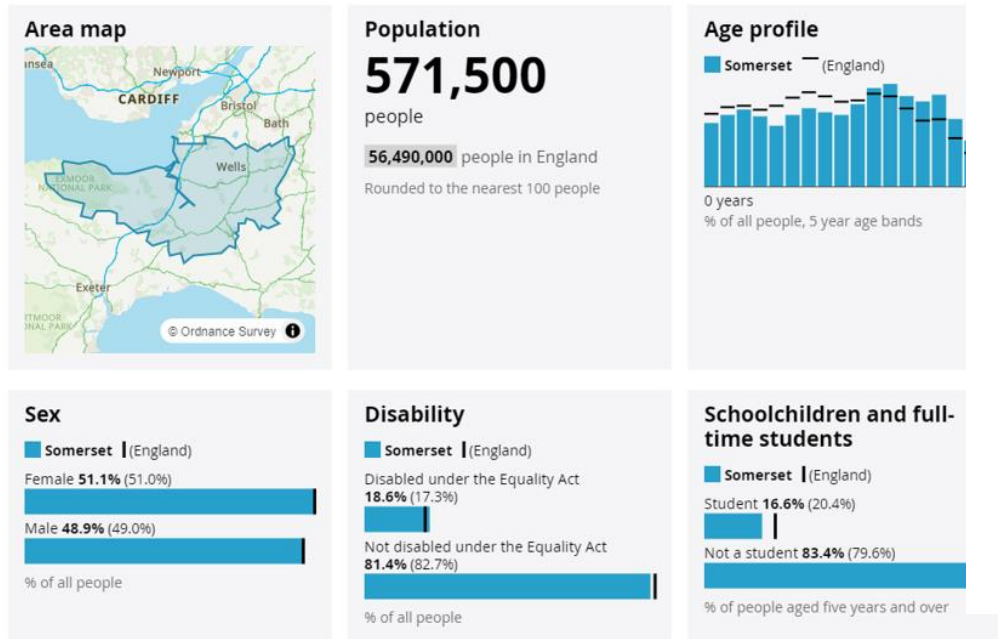


Mapping (continued)

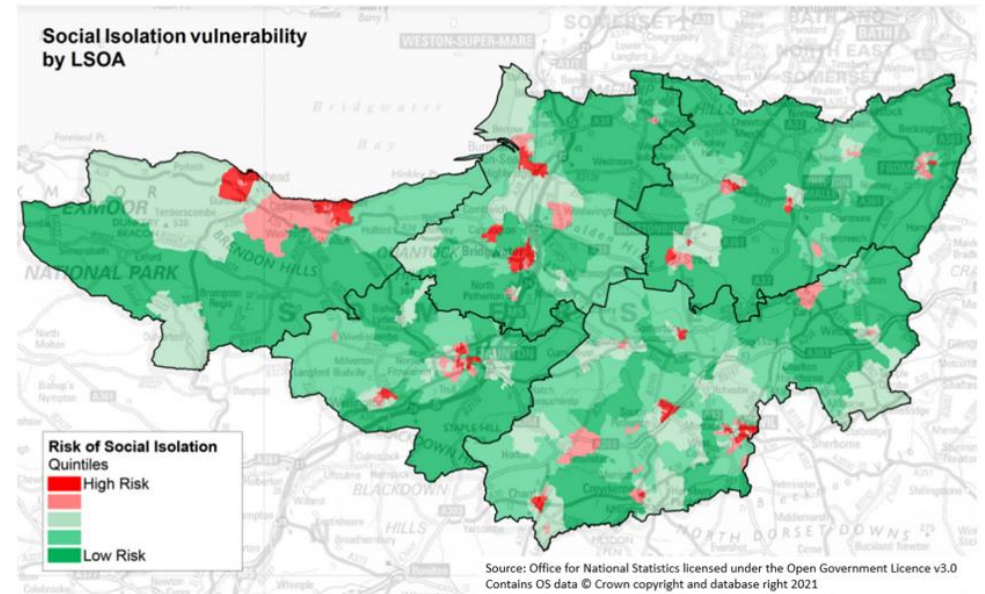
The Project Oversight Team also used all available data on Somerset's population to inform their thinking & planning. Below are just some examples of the Somerset data that Public Health were able to provide..

General Demographic Data for Somerset ICB (ONS, 2021)

Somerset



Risk of social isolation within Somerset (Somerset Intelligence, 2023)



B. Scoping

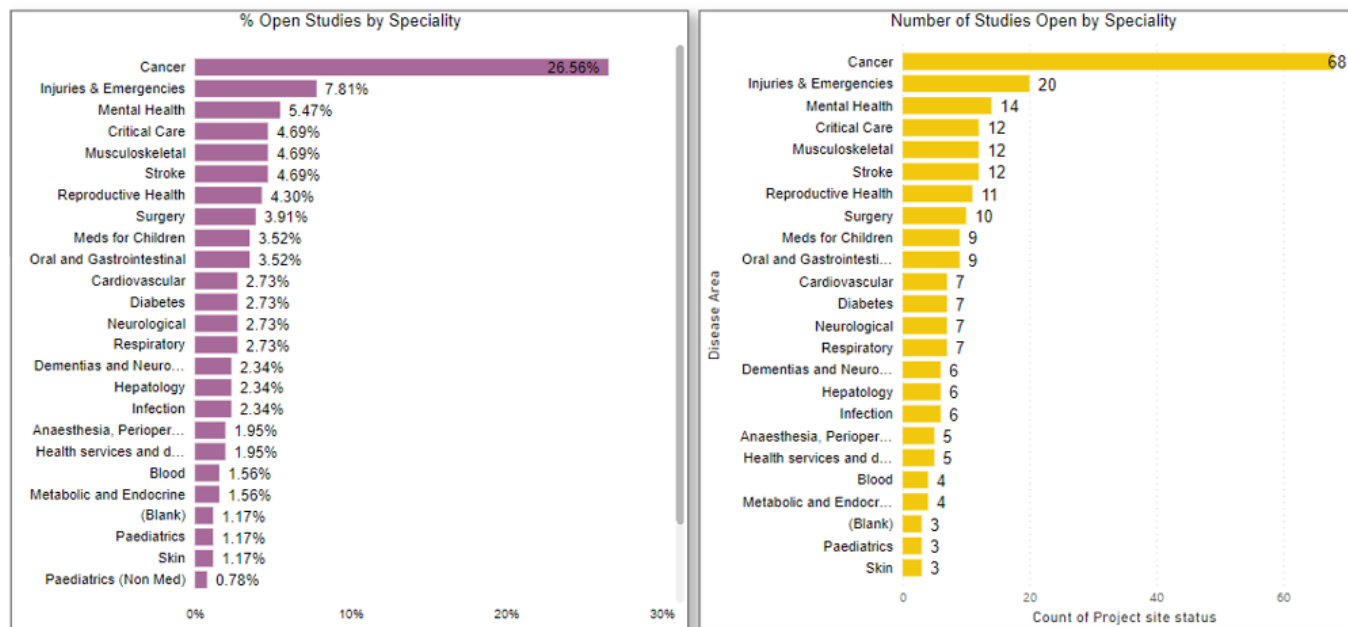
Scoping activity involved research colleagues from Somerset Foundation Trust, sharing with the Project Oversight Group information & data regarding:

- Types of health & social care in Somerset
- Research participation data from Somerset

Examples of current research in Somerset:

- Clinical trial of medicinal Product (CTIMP's)
- Clinical trial of medical devices
- Qualitative Research
- Questionnaires
- NIHR projects
- Researchers own projects

Studies open by specialty




C. Focus

The Project Oversight group used all learning from the mapping & scoping stages, plus an NHSE article which inspired the original proposal, to choose it's focus and plan for the Somerset REN project.

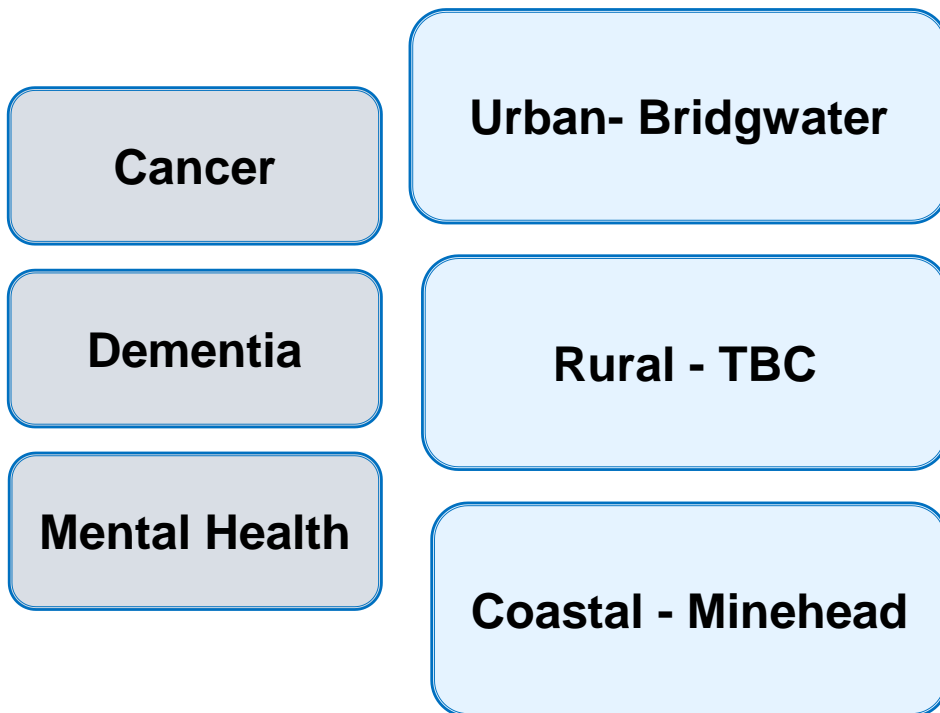
Inspiring NHSE article

'Trust'



[NHS Accelerated Access Collaborative » Increasing diversity in research participation: A good practice guide for engaging with underrepresented groups \(england.nhs.uk\)](https://www.england.nhs.uk/accelerated-access-collaborative/increasing-diversity-in-research-participation-a-good-practice-guide-for-engaging-with-underrepresented-groups/)

Spark to scope VCFSE groups



Community VCFSE **Research Champions** to have conversations with people & communities around research

Sustainable outcomes

- Outcome 1:** Improved understanding of research participation diversity in Somerset
- Outcome 2:** Better understanding of barriers and enablers for individual and VCFSE research participation
- Outcome 3:** Better understanding of the long-term strategies needed to increase diversity of research participation
- Outcome 4:** Improved relationships for ICS partnership working and opportunities
- Outcome 5:** Strengthened relationships between ICS partners and research infrastructure
- Outcome 6:** Developed a greater awareness of research within the Somerset health and care system
- Outcome 7:** Improved community awareness of research campaigns and opportunities
- Outcome 8:** Influenced wider work programmes approach to partnership design and delivery
- Outcome 9:** Influenced ICS research set of recommendations

D. Engagement Activity

Below is a summary of the Somerset REN engagement phase activity:

Planning

- ✓ Targeted community mapping across deprived rural and coastal areas
- ✓ Consideration of research engagement activities and approaches previously undertaken by others, such as PenARC and CRN SWP
- ✓ Design of our key questions around research and research participation
- ✓ Development of the 'Research Connectors' role
- ✓ Development of a training package for training conversations between Spark Somerset & Research Connectors
- ✓ Planning of practical logistics of engagement activity
- ✓ Talking to community groups and community leaders and inviting them to become 'Research Connectors'

Data Collection

- ✓ Spark Somerset attended 3 'Talking Cafes' and 7 Research Connectors hosted individual and group conversations about research
- ✓ Data sharing agreements established, to enable Spark Somerset to work with VCFSE organisations, for all findings to be shared with the ICB and between the ICB and Darmax for analysis
- ✓ Financial agreements established between ICB & Spark Somerset to enable the dissemination of funding to community groups

Analysis, Reporting and Dissemination

- ✓ Findings analysis completed by an external agency, Darmax, who produced a findings report with themes, trends and key findings
- ✓ Developing multiple resources to share the findings of the REN project as widely as possible

E. Summary of findings

For more details around each of these findings, please see Appendix ?

Understanding of Research

- A majority of participants indicated that they didn't know **what health and care research is**, or **what it involves**.
- Participants were aware that research was linked to service provision and that it **could involve collecting data, information, opinions and experiences**.

Experiences of Research Participation

Experience of participation

- Most participants had **never taken part** in health and care research.
- Those who had taken part in research, did so as it was a specific project **related to a health condition and lived experience**.



E. Summary of findings (cont)

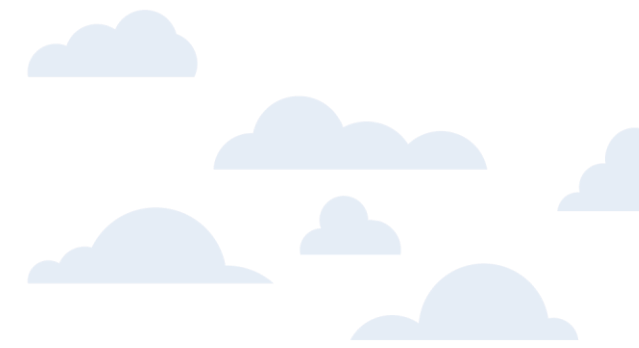
Motivators and Barriers to Research participation

Motivators for participation

- To improve healthcare, specific services and/or treatments for health conditions,
- Personal interest, incentives, potential health benefits for themselves, or because they had been invited by a trusted medical professional.

Barriers to Participation

- **Lack of awareness** of, and **communication** around, opportunities
- **Time, travel difficulties, rurality, cost implications**, or being asked **too many questions**.
- Involvement in research would not lead to service improvement, nor would they know what happened with the results
- Research participation **would not help them directly** or provide short-term benefits



Summary of findings

Awareness of research activities

- **Significant lack of awareness** on any health and care research **opportunities** locally
- **No awareness** of the National Institute's Health and Care Research '**Be Part of Research**' initiative for public involvement in studies.
- Only awareness and knowledge of research was from participants direct personal medical experiences

Raising awareness of research opportunities

- Need to **connect and collaborate** with existing and trusted community networks, organisations, groups and trusted contacts such as **village agents, community centres, pharmacists, charities** and **schools** to spread awareness and facilitate view-seeking and feedback exercises
- Participants recommended **promotion of research** in accessible, everyday locations like **GP surgeries, libraries, community groups and supermarkets**
- The **face-to-face presence from researchers** to explain what involvement means and the impact people could have, would encourage participation
- In addition to this, **online methods** such as **social media** or **emails**, as well as **noticeboards, mailouts** and **articles in local magazines** could be utilised



Summary of findings (continued)

Lack of diversity and representation in research

- **Cynicism** around research **aims** and **outcomes** – does research led to meaningful improvements or was just a box-ticking exercise?
- Participants **not feeling that their lived experience is important** to research
- Research is **unfamiliar** to people and therefore the environment is **uncomfortable**
- An older and less ethnically diverse local population
- **Lack of digital connectivity** in **rural parts** of the county
- A **class divide** in the county may influence people's ability to participate
- **Language** used within research engagement activities is **not appropriate** and may put people off from taking part
- **Time, illness** and knowing how the information provided to researchers will be used



Summary of findings (continued)

Connecting researchers with individuals, groups and communities

- Participants had a range of suggestions for how researchers could better engage with local communities, such as:
 - Communication via **trusted channels** (e.g. health professionals, village agents and health connectors)
 - Researchers **visiting existing community groups** and **networks** to share opportunities and to listen to communities' voices and opinions
 - Engagement events and research activities should be held in **local, accessible community spaces**, enabling individuals, families and carers to participate
 - Engagement should involve **small groups** to enable people to feel that they can have a voice
 - **Clear information** should be provided about intended research **outcomes** and **impacts**, so people can **understand how their contribution is used**
 - Researchers should **give ownership to people** to allow them to fully contribute in a co-produced approach
 - A **variety of promotion methods and materials**, in addition to financial support to facilitate participation (e.g. vouchers, travel expenses)
 - Feedback forms need to be **simple to understand** and not take too long to complete

Summary of findings (continued)

Participation in research development and design

Desire to participate

- Participants generally wanted to be involved as public voices in shaping health research, and are often motivated if the subject is particularly relevant (e.g. personal or family experience of a health condition)

Facilitating participation

- Researchers should **clearly outline expectations** regarding **level of commitment** required and **intended outcomes**
- Utilising **group settings**
- Connection, and facilitation of sessions, via **trusted, local community networks, groups** and **individuals** within **accessible community spaces**
- **Incentives** to account for time commitments, in addition to offering flexible times to **accommodate** for **work** and **caring responsibilities**

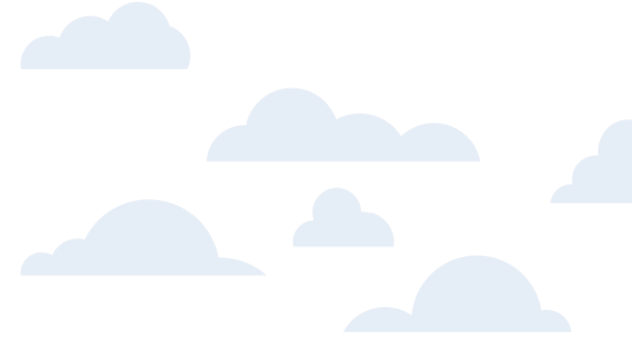
Barriers to participation

- A **fear of criticising services** may **hinder** people's ability to access health and care services in the future
- **Time**



F. Recommendations

1. Develop peoples' knowledge and understanding of what health & care research is
2. Raise awareness of research and research opportunities through a wide range of communications
3. Researchers should travel to local communities, meet people face-to-face and connect with individuals, groups, trusted leaders and networks
4. Build effective, long-term relationships with local, trusted community leaders to work collaboratively on engagement and research projects
5. Plan engagement around research in accessible, local community spaces



Recommendations (Continued)

6. Ensure that all view seeking and feedback activities are accessible for all
7. Recognise and value peoples' time, expenses and feedback through monetary or other payments
8. Invite people to partake in co-production of a project but understand the barriers and challenges people may face
9. Ensure that participants are aware of the projects' aims, intended outcomes and why their contribution matters
10. Commit to sharing how peoples' contributions were used and had an impact



Outcomes

- ✓ Outcome 1: Improved understanding of research participation diversity in Somerset
- ✓ Outcome 2: Better understanding of barriers and enablers for individual and VCFSE research participation
- ✓ Outcome 3: Better understanding of the long-term strategies needed to increase diversity of research participation
- ✓ Outcome 4: Improved relationships for ICS partnership working and opportunities
- ✓ Outcome 5: Strengthened relationships between ICS partners and research infrastructure
- ✓ Outcome 6: Developed a greater awareness of research within the Somerset health and care system
- ✓ Outcome 7: Improved community awareness of research campaigns and opportunities
- ✓ Outcome 8: Influenced wider work programmes approach to partnership design and delivery
- ✓ Outcome 9: Influenced ICS research priority setting through a set of recommendations



Next Steps/Sustainability

The following are activities that will be undertaken in 2024-25, to continue conversations around research, research opportunities & how to ensure diversity of research participation in Somerset.

Activity	Details
<p>Spark Somerset – VCFSE Research Event May 2024</p>	<p>On 14th May, Spark Somerset arranged a Research Event bringing together representatives from over 65 groups and organisations from across Somerset, for example, individuals from the VCFSE sector, from statutory, health & social care organisations and academics.</p>
<p>Somerset’s Big Conversation May-September 2024</p>	<p>The aim is to embed research conversations as part of a key workstream, alongside other health & care projects, that will be taken around the county as part of NHS Somerset’s roadshow, with the aim of talking to and hearing from diverse people & communities.</p>
<p>VCFSE Participation Fund</p>	<p>A VCFSE ‘Participation Pot’ of money to enable VCFSE organisations to be awarded bids, to carry out research engagement activities with local people. We aim to build on the original REN project relationships with VCFSE groups, use the strength of trusted community relationships to engage with and hear from those who we have historically found challenging to reach.</p>
<p>ICS Research Strategy</p>	<p>NHS Somerset have now appointed a research & innovation lead and there is work currently underway to develop a Research Strategy for the ICS. There will be close working together as part of a regional-wide research and innovation strategy. We will ensure that we are linked into this.</p>

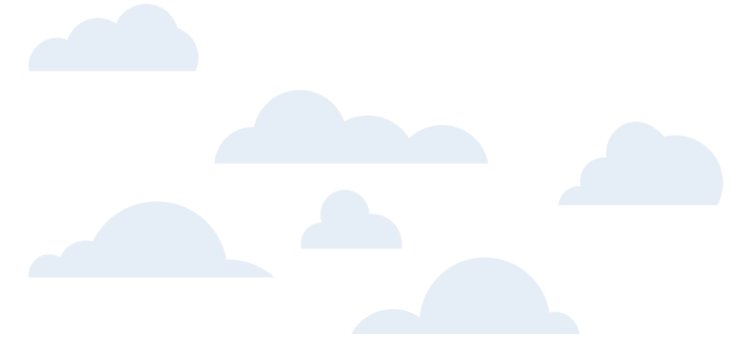
Somerset REN Project Oversight Group

- **Kat Tottle** – Engagement & Insight Lead Officer, NHS Somerset – Somerset REN Project Co-ordinator
- **Jack Brazier** – Public Health – Somerset REN Project Co-Ordinator Support
- **Laura Alexander** – Engagement Team – NHS Somerset - Former Engagement Lead & initial Somerset REN Project Co-Ordinator
- **Charlotte Callen** - NHS Somerset
- **Sara Bonfanti** – Head of Communications & Engagement – NHS Somerset
- **Katie Mooney** – Community Connector Coordinator, Spark Somerset, VCFSE Lead
- **Cindy Furse** – VCFSE/Public Sector Partnerships Lead, Spark Somerset, VCFSE Lead
- **Dr Oliver Clabburn** – Research Manager, Spark Somerset, VCFSE Lead
- **Katherine Nolan** – Chief Executive, Spark Somerset, VCFSE Lead
- **Dr Pauline McGlone** – Deputy Chief Operating Officer NIHR
- **Andrea Mostyn- Jones** – Trust Lead Research Nurse, Somerset Foundation Trust
- **Karen Tanner** – Research Manager, Somerset Foundation Trust
- **Eelke Zoestbergen** – Quality Lead for Learning Disabilities, NHS Somerset
- **Lee Reed** – Quality Lead for Learning Disabilities, NHS Somerset
- **Kate Boddy** – Research Fellow, NIHR PenARC
- **Elly French** – Training & Workforce Manager, NIHR SW Peninsula
- **Sophie Henderson** – Communications & Engagement Manager, NIHR PenARC



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- MIND (Bridgewater Group)
- Seed of Hope (West Somerset Group)
- Jonathan Hibbert, Director – Darmax Research



Appendices

1. Engagement activity resources: Somerset REN Research Connectors Guide Parts 1 & 2
2. Engagement activity resources: Somerset REN Research Connectors' Engagement Activity Proforma
3. Engagement activity resources: Our Somerset photo filming audio consent form
4. Engagement activity resources: Somerset REN Patient Information and Consent Form
5. Engagement activity resources: Somerset REN Spark Mid-Point Reviews
5. Somerset REN Project - Testimonials

