Research Engagement Network: Evaluation of Phase 1

March 2025

Lily Boag
Project Officer

healthwatch
Essex

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NHS Mid and South Essex ICB

REN Summative Report

Produced by

Healthwatch Essex

Project Officer

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1.0 Introduction

1.1 Healthwatch Essex

Healthwatch Essex is an independent charity which gathers and represents views about health and social care services in Essex. Our aim is to influence decision makers so that services are fit for purpose, effective and accessible, ultimately improving service user experience. We also provide an information and guidance service to help people access, understand, and navigate the health and social care system.

1.2 Acknowledgements

Healthwatch Essex would like to thank all those who took part in conversations that contributed to this report. We greatly appreciate the time all participants have taken to share their insights.

1.3 Disclaimer

Please note that this report relates to findings carried out on specific dates and times, representing the views of those who contributed to this report. This report summarises the themes, conversations and learnings gathered from the MSE ICB's Research Engagement Network, based on the experiences shared with Healthwatch Essex during this time.

1.4 Background

The Creation of a Research Engagement Network

In 2023, the NHS Mid and South Essex Integrated Care Board (MSE ICB) were successful in winning funding to facilitate a programme of activities as part of NHS England's Research Engagement Network Development scheme (REN), to improve the number of people from underserved communities to get involved in health and care research.

In the last 18 months the MSE ICB Engagement Team continued to develop the REN project, which supports researchers by providing an opportunity to reach the underserved communities in the mid and south areas of Essex, with the aim of improving participation and understandings of health and care research, by removing the barriers that hinder involvement.

The development of the programme has been led by Tina Starling (Senior Insight and Involvement Manager) and Emmanuel Umeh (REN Project Support Manager) at the MSE ICB.

Underrepresented Communities

The MSE ICB has been working with partner organisations in order to develop local research activities with underrepresented communities. The project has increased diversity in research by supporting those diverse local communities to get involved in research.

The MSE ICB identified several underrepresented communities through their common characteristics, which include:

- Lower inclusion in research than expected
- Higher healthcare burden unmatched by research for such groups
- Differences in how they engage with healthcare interventions compared to other communities

The community groups which shared these common characteristics were:

- Age extremes, including under 25s and over 65s
- Women of childbearing age
- Ethnically diverse groups, including faith groups and Gypsy and Roma travellers
- LGBTQ+ community groups
- Groups of people who suffer from health inequalities, including those with learning disabilities or a serious mental illness
- Neurodivergent individuals

Research Ready Communities

The MSE ICB have been keen to work with these underrepresented communities by taking an innovative approach to improve inclusion in research. The aim of the REN project has been to ensure health and social care research better reflects the needs and interests of all areas, groups and communities across Mid and South Essex. As a result, health and care services could then use this learning to better address health inequalities in the area.

The following programme aims and objectives were designed by the MSE ICB as part of the creation of their own Research Engagement Network.

Programme aims:

- Build trusting, mutually beneficial relationships with the community.
- Listen to and understand the community better.
- Work in partnership with community members and organisations to make research more inclusive and representative.

How to achieve these goals:

1. Partner with local organisations.
2. Work with partner organisations to find, train and fund community members as Community Champions.
3. Support Community Champions to listen to people in the community about their knowledge and views of health and social care research.
4. Co-design local activities that respond to what people have said, and help improve local inclusion in health and social care research.
5. Implement co-designed local activities together.
6. Continue long-term partnership to build inclusive research for the community.

Developing Partnerships

The first phase of the REN programme was designed to support and increase research readiness and engagement with communities at a local level. This has included the development of local partnerships between voluntary, community, faith, and social enterprise (VCFSE) organisations, the National Institute for Health Research (NIHR) and integrated care systems (ICS) to better enable diverse communities to get involved in research, and to embed this within ICS governance structures.

Healthwatch Essex was approached by the MSE ICB to support the programme by acting as a central coordinating body, overseeing the activities carried out by partner organisations involved in phase one of the REN project. Responsibilities also included allocating REN project funding to partner organisations as agreed by MSE ICB, facilitating communication and collaboration, and compiling progress reports on community engagement activities, outcomes, and challenges.

The second phase of the ICB's REN programme will aim to build on this success by continuing to focus on increasing opportunities and access to take part in research for communities, whilst also ensuring the sustainability of these approaches.

1.5 Report Aims

This report aims to provide an overview of the research and engagement activities carried out by partner organisations during phase one of the MSE REN programme. This includes reflecting on the experiences of participants who engaged in these activities and how effective these activities have been in contributing towards improving community engagement in healthcare research in Mid and South Essex. Examples of some of the activities which have been carried out by partner organisations include the use of new research and engagement approaches, community workshops, open discussions on experiences of accessing services, reflections on previous involvement in research projects, and sharing views on research.

Assessing the research and engagement activities of these partner organisations enables us to identify how future funding and resources can be best allocated to achieve the most effective outcomes and support the success of future phases of the REN programme. Through this shared understanding, the MSE REN programme can then be used as an evidence-based approach for improving community engagement in health and care research across Mid and South Essex.

By shaping our recommendations around the themes and key findings which have emerged during phase one of the MSE REN project, this report also aims to show how the programme can function as an effective model to improve the accessibility and inclusivity of healthcare research for diverse communities.

1.6 Glossary

The following glossary aims to define and summarise the various terminology, acronyms and data labels which are used in this report.

Terminology

Community Champions Individuals trained to listen to the community about their knowledge and views of health and care research.

Community Research Partners Local community organisations which have partnered with the NHS Mid and South Essex Integrated Care Board to improve inclusion in health and care research within their local community.

Research Engagement Network A network of organisations working to help local communities understand what health and care research is, how it can benefit people and how they can take part in local research projects.

Acronyms

BEM	Black and Ethnic Minority
CIC	Community Interest Company
ICB	Integrated Care Board
ICS	Integrated Care System
NEP	North Essex Partnership University NHS Foundation Trust
MSE ICB	Mid and South Essex NHS Integrated Care Board
REN	Research Engagement Network
SEND	Special Educational Need or Disability
SEPT	South Essex Partnership University NHS Foundation Trust
SNEE ICB	Suffolk and North East Essex NHS Integrated Care Board
VCFSE	Voluntary, Community, Faith and Social Enterprise Sector

Data Labels

For the creation of data and charts within this report, acronyms have been used to identify the following community research partner organisations.

B3	B3 - Bumps, Birth and Belonging and Black Working Mothers Network
ECVYS	Essex Council for Voluntary Youth Services
EPUT	Essex Partnership University NHS Foundation Trust
ERF	Essex Recovery Foundation
FIF	Families InFocus
HT	Hamelin Trust
MM	Motivated-Minds
MEWA	Multicultural Essex Women's Association
MyOTAS	My Own Times and Space
O5BM	Over 50s Black Men Forum CIC
SAFE	Supporting Asperger Families in Essex
SC	Southend Carers
SDACS	Seventh-Day Adventist Community Services
SHIELDS	Supporting Helping and Informing Everyone with Learning Disabilities in Southend.
SP	Signpost
SYMCA	Southend YMCA
TBM	Thurrock and Brentwood Mind
TL	Thinklusive
TLS	Thurrock Lifestyle Solutions CIC

2.0 Community Research Partners

The MSE ICB has partnered with 20 local community organisations to improve inclusion in health and social care research in the region.

Table Overview: Community Research Partners

B3 - Bumps, Birth and Belonging CIC	B3 - Bumps, Birth and Belonging CIC was created in direct response to the black maternal health crisis in the UK. The team believe in informing people about their rights, consent and self-advocacy to confidently make the decisions that are right for them, during pregnancy and in parenthood.
Black Working Mothers Network	Black Working Mothers Network is a platform to connect women of black heritage to speak about all things to do with motherhood and work, provide coaching and guidance on their employment rights, build their confidence and raise awareness around the challenges black women face in the workplace.
Essex Council for Voluntary Youth Services (ECVYS)	ECVYS are an independent charity with a passionate and strong voice for the voluntary youth sector in Essex. It aims to support, network and resource the voluntary youth sector whilst building links and possibilities with statutory services that wish to engage with the sector.
Essex Partnership University NHS Foundation Trust (EPUT)	EPUT was formed by the merger of North Essex Partnership University NHS Foundation Trust (NEP) and South Essex Partnership University NHS Foundation Trust (SEPT). It provides various community health, mental health and learning disability services across Luton and Bedfordshire, Essex and Suffolk.

Essex Recovery Foundation (ERF)	Essex Recovery Foundation is a charity with a growing recovery community who aim to use their voices to influence how services function and change perceptions of drug and alcohol addiction and recovery.
Families InFocus (FIF)	Families InFocus provide confidential, independent, practical and emotional support to families in Essex with a child or young person with any Special Educational Need or Disability.
Hamelin Trust (HT)	Hamelin Trust is a leading Essex based charity for supporting people with learning disabilities and their families. It provides short break services, a resource centre and outreach services within the community and individual's homes.
Motivated-Minds (MM)	Motivated-Minds designs and facilitates sustainable mental health and wellbeing solutions. With a preventative focus and an aim to reduce stigma, it offers services across schools, workplaces and in the community for those suffering from mental ill health.
Multicultural Essex Women Association (MEWA)	Multicultural Essex Women Association, was first established under the name of 'Multicultural Southend' with the aim of supporting disadvantaged women and those from ethnic minority communities. Its mission is to help empower individuals and provide them with opportunities to engage in community activities.
My Own Time and Space (MyOTAS)	My Own Time and Space aims to improve the lives of Neurodivergent (Autism, ADHD, Dyspraxia, Dyslexia, Sensory Processing Disorder, etc.) children and young people and their families by providing small group, inclusive activities tailored to their particular needs.

Over 50s Black Men Forum CIC (O5BM)	The Over 50s Black Men Forum envision a future where every black man over the age of 50 can enjoy optimal physical health, mental resilience, and a strong sense of community. The forum aims to help reduce health, economic and social inequalities as well as create a space where the over 50s black men community can thrive.
Supporting Asperger Families in Essex (SAFE)	SAFE is a parent support group that raises autism awareness and provides essential support to autistic individuals and their families in Essex. It offers a supportive platform where individuals can share and learn essential information on practical topics, helping them navigate life's challenges and access necessary resources.
Seventh-Day Adventist Community Services (SDACS)	Seventh Day Adventist Community Services is a department of the church which aims to meet the needs of its local community. It includes several ministry groups for men, women, youth, children, capabilities (formally disabilities), health and family life.
Signpost (SP)	Signpost is a person-centred charity dedicated to helping individuals overcome challenges to securing meaningful employment. It offers support in various forms, such as employability assistance, training, or simply providing a listening ear.
SHIELDS	SHIELDS stands for supporting, helping and informing everyone with learning disabilities in Southend. It’s formed by a council who ensure people with a learning disability have a voice about the services they receive.

Southend Carers (SC)	Southend Carers announced its closure, effective on July 30, 2024. Previously, the team provided services to unpaid carers in the local community, aiming to offer assistance, hope and a sense of community.
Southend YMCA (SYMCA)	Southend YMCA is a charity and housing provider that works with children, young people, families and the wider community to provide education, accommodation and activities.
Thinklusive (TL)	Thinklusive works with health and social care organisations locally, regionally and nationally. It specialises in creating communications that are accessible to all using print, audio, video and digital solutions.
Thurrock and Brentwood Mind (TBM)	Thurrock and Brentwood Mind provides services for those experiencing emotional and mental distress. Offering advice and support to empower anyone experiencing a mental health problem, the team also campaign to improve services, raise awareness and promote understanding.
Thurrock Lifestyle Solutions CIC (TLS)	Thurrock Lifestyle Solutions CIC was founded on the concept of 'community solutions'. Having disabled people as its experts by experience, Thurrock Lifestyle Solutions have developed several models of supporting people to live lifestyles of choice in their own communities.

3.0 Community Champions

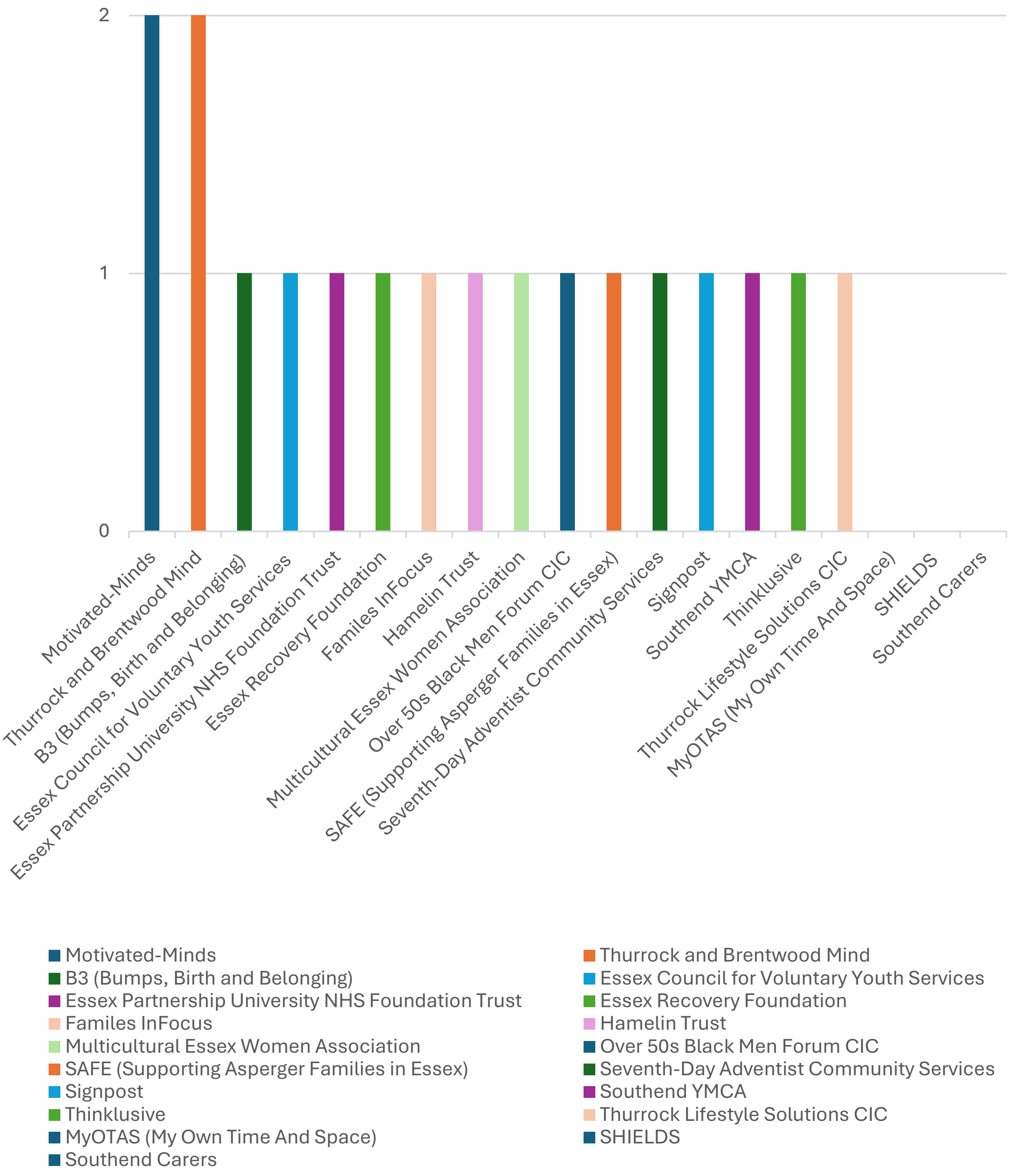
A total of 18 community champions were recorded to have been recruited by partner organisations during phase one of the MSE REN programme. Each champion has been trained to assist with research and engagement activities within their community organisation and encourage others to share their knowledge and views of health and social care research. The table below shows how many community champions have been allocated within each organisation.

Table Overview: Community Champions

Name of Organisation	Number of Champions
B3 - Bumps, Birth and Belonging and BWM	**1**
Essex Council for Voluntary Youth Services	**1**
Essex Partnership University NHS Foundation Trust	**1**
Essex Recovery Foundation	**1**
Familes InFocus	**1**
Hamelin Trust	**1**
Motivated-Minds	**2**
Multicultural Essex Women Association	**1**
MyOTAS (My Own Time And Space)	**0**
Over 50s Black Men Forum CIC	**1**
SAFE (Supporting Asperger Families in Essex)	**1**
Seventh-Day Adventist Community Services	**1**
SHIELDS	**0**
Signpost	**1**
Southend Carers	**0**
Southend YMCA	**1**
Thinklusive	**1**
Thurrock and Brentwood Mind	**2**
Thurrock Lifestyle Solutions CIC	**1**
Total	**18**

Data Visualisation: Community Champions

The bar graph below shows how many community champions have been allocated within each partner organisation to support their research and engagement activities.



4.0 MSE ICB Activities

During phase one of the REN programme, the MSE ICB have organised several activities and key dates, including training sessions and shared learning events.

REN Project Community Champion Training (June 25th 2024)

Community champion training took place in Basildon during June 2024. This was led by the MSE ICB, facilitated by Healthwatch Southend, supported by Motivated Minds, with REN promotional materials provided by Braintree District Council.

REN Project Learning Event (November 28th 2024)

The REN Learning Event involved more than 30 attendees comprising of community champions, primary care network researchers, university researchers and non-executive members from the ICB. Community champions presented the outcomes they have achieved since joining the REN project, showcasing the power of collaboration between the REN community and the research sector. All community champions were awarded a certificate to recognise their contributions. Overall, the event highlighted the progress of the REN project and the learning experiences gained.

The event was opened with an introduction by Tom Abell, Chief Executive Officer of the MSE ICB and a presentation from Dr. James Hickling, Deputy Medical Director at the MSE ICB. Researchers shared their collaborations with REN champions and provided insights into future research opportunities. Dr. Sophia Morris, System Clinical Lead for Health Inequalities, discussed the impact of health inequalities on marginalised groups and shared opportunities to further support community champions.

Inclusive Research Sharing Best Practice (December 10th 2024)

An event exploring inclusive research and sharing best practices was organised by Suffolk and North East Essex (SNEE) in partnership with the MSE ICB at ARU. Around 30 attendees were invited to the workshop to identify, explore and consider the best way to learn from each other and share best practice.

East of England REN Regional Event (March 18th 2025)

A regional event sponsored by NHS England was organised by the MSE ICB which was designed to bring together REN teams within the region to share knowledge, insights, collaborations, engagements, and findings through their REN networks. This event provided an opportunity for research partners to connect, learn from one another, and further strengthen the REN community.

5.0 Quarterly Progress Reports

Each community organisation was asked to submit a progress report during each quarterly period to summarise their ongoing research and engagement activities throughout phase one of the MSE REN programme.

The submission deadlines for the quarterly project progress reports included: March 28, May 31, August 2, October 4 and December 20 in 2024.

Table Overview: Quarterly Progress Report Questions

Partner organisations were asked to answer the following questions when submitting their quarterly progress reports.

Activities	Please tell us about your engagement with community groups in the last month. How many community groups have you engaged with? How many of these discussions were with groups? How many of these discussions were one-to-one?
Summary of community engagement activities	Please tell us about the activities conducted during this period. (Maximum 200 words)
Participation level	Please tell us about your participation, community responses, and overall impact of activities. (Maximum 200 words)
Achievements, success stories or positive outcome.	Please tell us what has gone well. (Maximum 200 words)
Challenges encountered and how the challenges were addressed.	Please tell us about any challenges you have faced, any issues that have arisen, and any potential risks to completing this project and how they were addressed. (Maximum 200 words)

Evaluation of effectiveness of community engagement effort.	Please tell us about your evaluation on the engagement. (Maximum 200 words)
Tell us what you discovered during your community engagement event.	Please tell us about what you discovered during the engagement. (Maximum 500 words)
What are the barriers community members raise for not engaging in research?	Please tell us about any barriers which have impacted research engagement. (Maximum 500 words).
Collaboration with Community Champion(s)	Please tell us in detail the support you provided to your community champion(s). (Maximum 200 words)
Feedback received from community champions and actions taken to enhance performance.	Please tell us about the feedback and actions taken. (Maximum 200 words)
Coordination efforts with community champions to ensure alignment of activities.	Please tell us about your coordination. (Maximum 200 words)
Next Step: Planned activities.	Please tell us about your planned activities for the next reporting period. (Maximum 200 words)
Objectives and goals to be achieved in the upcoming weeks.	Please tell us about what you tend to achieve in the coming weeks. (Maximum 200 words)

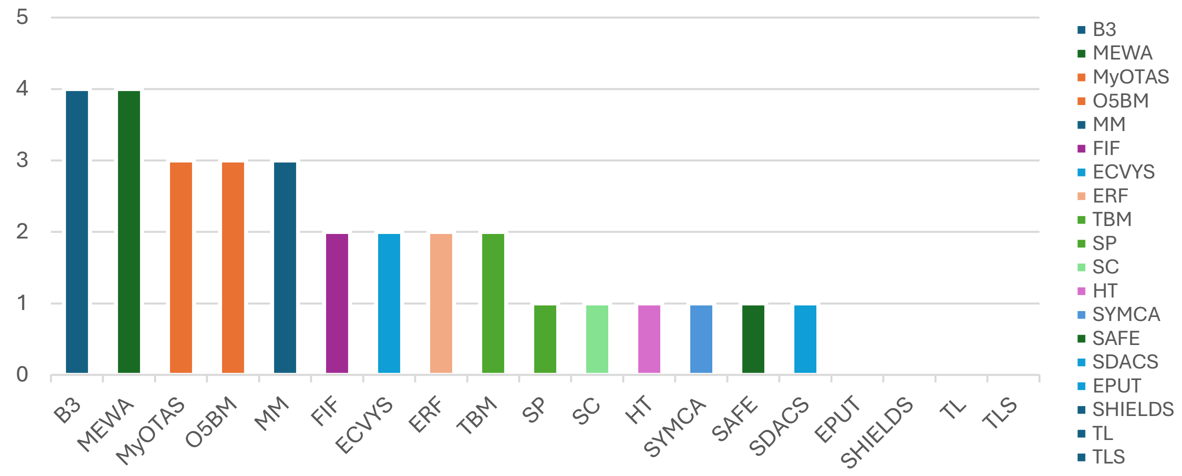
Table Overview: Quarterly Progress Report Records

The table below shows which partner organisations submitted a progress report in each quarter (marked with an 'x') and the total reports submitted per quarter.

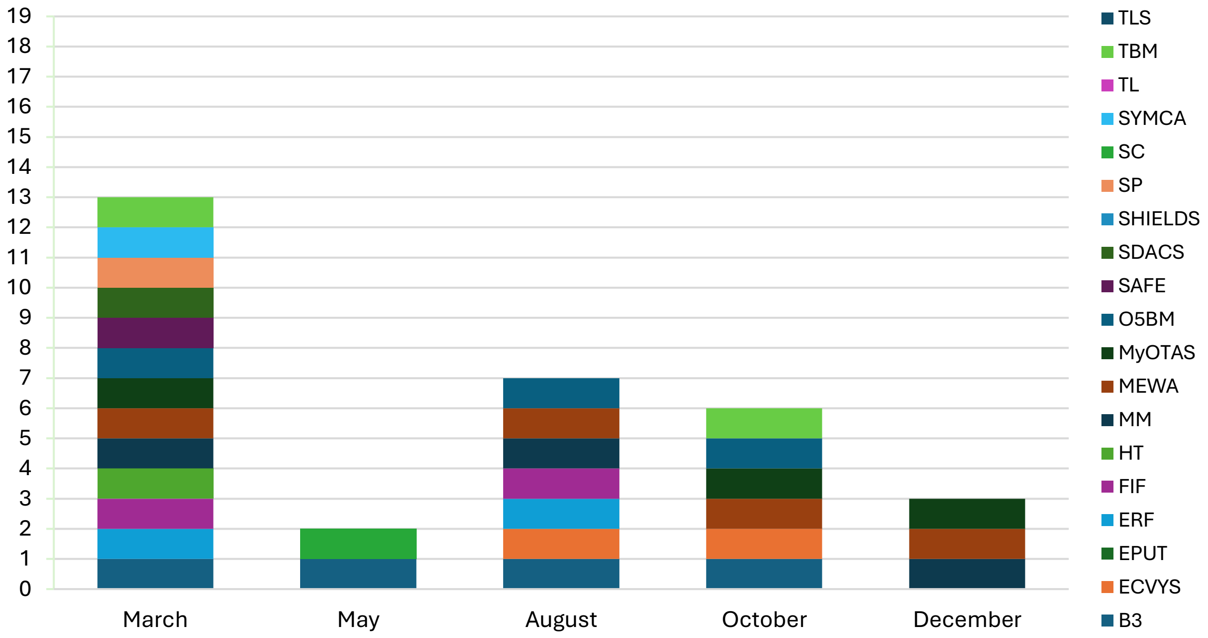
Name of Organisation	Mar	May	Aug	Oct	Dec
B3 – Bumps Birth and Belonging and BWM	x	x	x	x	
Essex Council for Voluntary Youth Services			x	x	
Essex Partnership University NHS Foundation Trust					
Essex Recovery Foundation	x		x		
Familes InFocus	x		x		
Hamelin Trust	x				
Motivated-Minds	x		x		x
Multicultural Essex Women Association	x		x	x	x
MyOTAS (My Own Time And Space)	x			x	x
Over 50s Black Men Forum CIC	x		x	x	
SAFE (Supporting Asperger Families in Essex)	X				
Seventh-Day Adventist Community Services	X				
SHIELDS					
Signpost	X				
Southend Carers		X			
Southend YMCA	X				
Thinklusive					
Thurrock and Brentwood Mind	x			x	
Thurrock Lifestyle Solutions CIC					
Total reports	13	2	7	6	3

Data Visualisation: Quarterly Progress Report Record

The first chart below shows how many reports were submitted by each organisation during phase one of the MSE REN programme. The second chart shows which organisations submitted reports in each quarter.



- In March, 13 out of 19 organisations (68%) submitted a report.
- In May 2024, 2 out of 19 organisations (11%) submitted a report.
- In August 2024, 7 out of 19 organisations (42%) submitted a report.
- In October 2024, 6 out of 19 organisations (37%) submitted a report.
- In December 2024, 3 out of 19 organisations (20%) submitted a report.



6.0 Key Findings

Key findings have been gathered from the quarterly progress reports which were submitted by community organisations during phase one of the MSE REN project.

Quarterly Progress Reports

Below is a list of the community research partners which submitted the highest number of quarterly progress reports during phase one of the MSE REN project.

Highest Report Submissions
• B3 – Bumps Birth and Belonging and Black Working Mothers Network • Multicultural Essex Women's Association • MyOTAS • Over 50s Black Men Forum • Motivated-Minds • Families InFocus • Essex Council of Voluntary Youth Services • Essex Recovery Foundation • Thurrock and Brentwood Mind

Community Research Funding

Below is a list of the community research partners which received the highest and lowest amount of funding during phase one of the MSE REN project.

Highest Funding	**Lowest Funding**
• Motivated-Minds • Thurrock and Brentwood Mind • B3 – Bumps, Birth and Belonging and Black Working Mothers Network • Essex Partnership University NHS Foundation Trust (EPUT) • Families InFocus • Hamelin Trust • Southend YMCA • Thinklusive • Thurrock Lifestyle Solutions	• Essex Council for Voluntary Youth Services • Multicultural Essex Women Association • Over 50s Black Men Forum • SAFE (Supporting Asperger Families in Essex) • Seventh-Day Adventist Community Services • Signpost • Southend Carers

Summary of Community Engagement and Participation

The following information has been estimated using details from the quarterly progress reports submitted during phase one of the MSE REN project.

Community Research Partner Organisations	**Participation Levels**	**Engaged Communities**
B3 – Bumps, Birth and Belonging & Black Working Mothers Network	2 community groups 22 participants	Afro-Caribbean women and men
Essex Council of Voluntary Youth Services	10 community groups 160 participants	Youth groups (including faith, SEN, LGBTQ+, BAME and young carers)
Essex Recovery Foundation	1 community group	Drug and alcohol addiction recovery service users
Families InFocus	3 community groups 5 one-to-ones	SEND parents and carers
Hamelin Trust	3 community groups 3 one-to-ones	Parents of individuals with learning disabilities or neurodiversity
Motivated-Minds	23 community groups 432 group participants 6 one-to-ones	Mental health service users LGBTQ+ adults
Multicultural Essex Women Association	13 community groups 23 one-to-ones 24 sessions	Muslim women South Asian community (including Bangladeshi, Pakistani, African, Egyptian, Eastern European, Sri Lankan)
MyOTAS	16 community groups 181 group participants 153 survey responses 12 one-to-ones	SEND parents and carers
Over 50s Black Men Forum	1 community group 45 group participants 10 one-to-ones	50+ Black men
SAFE	7 community groups 120 group participants	Autistic adults and children Parents of autistic individuals
Seventh-Day Adventist Community Services	15 community groups 70 group participants 22 one-to-ones	South African, Zimbabwean, Zambian, Malawian, Kenyan, Ghanian, Caribbean, Indian, Mauritian, Filipino, Angola, British, Portuguese, Ugandan and Gambian nationalities
Signpost	8 community groups 48 group participants	Refugees Youth clubs Disabled community
Southend Carers	40 survey participants	Adult unpaid carers
Southend YMCA	1 community group 6 group participants	Parents and carers Young homeless community
Thurrock and Brentwood Mind	10 community groups 34 group participants 46 one-to-ones	Mental health service users Parents of young children

Summary of Engagement Methods and Research Interests

The following information has been estimated using details from the quarterly progress reports submitted during phase one of the MSE REN project.

Community Research Partner Organisations	Engagement Methods	Research Interests
B3 – Bumps, Birth and Belonging & Black Working Mothers Network	Focus group Surveys Interviews Group discussion	Maternity care and mental health Perinatal and post-natal mental health Healthcare disparities Culturally competent care High blood pressure, diabetes, and heart health Cancers within the black community, prostate cancer, testicular cancer, Hodgkin's lymphoma Allergy awareness within the Black community Skin conditions on Afro-Caribbean skin Maternity care and experiences Breastfeeding and weaning Emergency C-sections performed on black women Babies skincare and nutrition
Essex Council of Voluntary Youth Services	Survey Group activities Group discussion	Young people’s mental health Young people vaping and smoking Young people’s sexual health Drugs and substance addiction in young people Young people’s experiences of knife crime Young people’s experiences of cancer Young people’s experiences of chronic illness Skincare conditions and practices
Essex Recovery Foundation	Focus group Group discussions Outreach events	(No research interests identified in progress reports)
Families InFocus	Outreach events Group discussions	(No research interests identified in progress reports)
Hamelin Trust	Interviews Focus group	(No research interests identified in progress reports)
Motivated-Minds	1:1 discussions Group discussions Outreach events Group activities	(No research interests identified in progress reports)
Multicultural Essex Women Association	Group discussions Organisational events Collaborative events 1:1 discussions Outreach events	Improving health outcomes for ethnic minority groups Sexual health and menopause Diabetes Breast cancer Cardiovascular disease

	Focus group Research participation Expert talks Workshops Presentations Physical activity sessions (boxing, football, cycling, cricket, walking, running)	High blood pressure Difficulties accessing GPs Genetic research
MyOTAS	Survey Focus group Group discussions 1:1 discussions Exhibition Outreach events Charity night Training sessions	(No research interests identified in progress reports)
Over 50s Black Men Forum	Health seminar Survey 1:1 discussions Group discussions Expert talks Focus Group	Lack of ethnic diversity in health research roles 'Data Literacy Education Program'
SAFE	Group discussions Focus group	(No research interests identified in progress reports)
Seventh-Day Adventist Community Services	Group sessions 1:1 discussions Survey	(No research interests identified in progress reports)
Signpost	Survey Group Discussions	(No research interests identified in progress reports)
Southend Carers	Organisational events Group discussions Survey	Autism and neurodiversity Immune system research Research to support future carers
Southend YMCA	Focus group	Maternity and mental health Returning to work after maternity leave Childcare and childminder costs
Thurrock and Brentwood Mind	Group activities Group discussions Survey Outreach events 1:1 discussions Organisational events Collaborative events	(No research interests identified in progress reports)

Summary of MSE REN Achievements

Projects and Research Activities

Focus Groups & Interviews: Focus groups and one-to-one interviews were conducted with various community groups to gather insights on healthcare experiences, understandings of research and barriers to research participation.

Surveys: Surveys were distributed to various community groups, including Afro-Caribbean women, youth groups, SEND parents, and carers, to understand their views and concerns around healthcare research and any participation barriers.

Community Champion Outreach: Trained community champions engaged with various groups to promote healthcare research and gather feedback on how to increase participation, especially in underrepresented communities.

Workshops & Webinars: Workshops, webinars and group discussions were held to openly discuss healthcare research and explore participation in research.

Community Events: Events like coffee mornings, physical activity and fitness, creative sessions, and social gatherings were used to inform communities about healthcare research and encourage participation, including outreach in places like churches, mosques, community centres and youth clubs.

Digital & Social Media Outreach: Research opportunities were promoted in-person, through newsletters, social media, leaflets and information cards.

Collaborative Partnerships: Local organisations, including NHS and third-sector groups, were also engaged with to improve research access and promote participation, especially in ethnic minority and marginalised communities.

Discussion Topics

Cultural Barriers and Trust: Participants expressed concerns about cultural barriers in healthcare, mistrust towards professionals, and the need for research topics relevant to their communities. Transparency in healthcare and the desire to contribute to research that reflects their experiences were emphasised.

Barriers to NHS Research Participation: Barriers to participation in NHS research were discussed and included time constraints, lack of awareness, and mistrust.

Understanding of Health Research: Some participants lacked an understanding of health research and how to get involved. Time constraints and concerns over potential negative consequences were common barriers.

Community Engagement and Feedback: Engagement efforts varied, with some communities showing high participation and others more hesitant. Discussions revealed a need for more accessible and culturally sensitive research methods.

Cultural Sensitivity and Language Barriers: The use of comfortable languages and understanding cultural sensitivities helped increase engagement, especially in faith-based communities. Participants appreciated being included in research.

Tech and Data Concerns: Participants showed interest in using apps for research but raised concerns over data privacy, ownership, and potential misuse.

Survey Feedback: The surveys collected valuable feedback, with participants expressing a desire for research that directly impacts their communities.

Focus Group Insights: Focus groups helped shape future research directions, revealing that participants were open to involvement if methods were convenient and relationships with researchers were positive.

Building Trust and Engagement: Trust-building was key to successful engagement, with low-pressure environments and clarity on research goals.

Diverse Community Engagement: The diversity of engagement methods, including social media, surveys and discussions, led to increased participation, although some participants felt opportunities were not engaging or relevant.

Identified Research Barriers

Accessibility Barriers:

- Difficulty accessing local support.
- Limited availability of some groups, especially during the summer holidays.
- Limited transportation options preventing participation.
- Technological difficulties, particularly with digital platforms.

Knowledge and Awareness Issues:

- Limited awareness about common health issues within the community.
- Lack of awareness of ongoing and upcoming research opportunities.
- Uncertainty about how participants are selected for research.
- Not feeling as though opportunities to take part in research are provided.

Misunderstanding and Confusion:

- Participants did not fully understand the goals of health and care research.
- Confusion between research, clinical trials, and treatment options.
- Complexity of research methods and poorly structured research questions.

Feedback and Communication:

- Concerns about not receiving feedback after participating in research.
- A need for clearer communication materials (e.g., flyers, project outlines).
- Lack of context for questions leading to confusion and disengagement.
- A need for clearer communication about research goals and outcomes.

Trust and Mistrust:

- General mistrust in the healthcare and research systems.
- Concerns about researcher bias, especially around specific ethnic groups.
- Suspicion regarding the research source and participants' best interest.
- Fear of misuse of personal data and concerns about data ownership.

Cultural Sensitivity and Inclusion:

- Lack of culturally appropriate engagement with specific ethnic groups.
- Underrepresentation of ethnic groups in healthcare research roles.
- Family roles, particularly in more conservative households, restricting mobility (especially for women).
- Traditional family roles and economic disadvantages, such as low income and unemployment, further hindering participation.

Incentives and Motivation:

- Participants noted that clear incentives, such as gift vouchers or financial compensation, could increase engagement.

Mental Health Sensitivity:

- Some participants were not in the right mental space to engage in research, particularly around sensitive mental health topics.
- Fear of triggering negative emotions when discussing mental health.

Generational and Socioeconomic Factors:

- Family roles, particularly in conservative households, restricting mobility (especially for women).
- Economic disadvantages, including low income and unemployment, hindering participation.

Historical Concerns:

- Negative past experiences with healthcare or research leading to low engagement.

7.0 Recommendations

The following recommendations have been gathered during the evaluation of phase one of the MSE REN project to assist with the development of future phases.

Recommendations for Community Research Partners

Below is a list of the community research partners who have had the highest participation levels, engaged with the most community groups, used the most research methods, gathered the most research interests and recruited the most research participants throughout the year. This has been estimated using details from the quarterly progress reports submitted during phase one of the MSE REN project. Based on these results, the community research partners below would be the best organisations to invest in for future phases of the MSE REN programme.

Performance Evaluation of Community Research Partners

Highest Participation Levels	• Essex Council of Voluntary Youth Services • Multicultural Essex Women's Association • Motivated-Minds • MyOTAS • Seventh-Day Adventist Community Services • Thurrock and Brentwood Mind
Most Community Groups Engaged	• Essex Council of Voluntary Youth Services • Multicultural Essex Women Association • Seventh-Day Adventist Community Services
Most Engagement Methods Used	• B3 – Bumps, Birth and Belonging & Black Working Mothers Network • Motivated-Minds • Multicultural Essex Women Association • MyOTAS • Over 50s Black Men Forum • Thurrock and Brentwood Mind
Most Research Interests	• B3 – Bumps, Birth and Belonging & Black Working Mothers Network • Essex Council of Voluntary Youth Services • Multicultural Essex Women Association
Recruited Research Participants	• Multicultural Essex Women Association

Recommendations for Successful Engagement

Based on the achievements of the community research partners above, below is a list of some recommendations for how the MSE ICB and community organisations could achieve the best research engagement results.

Information and promotional materials: The MSE ICB should consider creating more REN information and materials which are inclusive and accessible for all. For instance, providing information in different languages. Sourcing translation services to support community research partners to overcome language barriers could also support wider inclusivity, accessibility and research interest.

Project examples and community champions: Some organisations requested more clarity around the role responsibilities of community champions and any success stories which could be shared to inspire and motivate individuals.

Research and community collaboration: Community research partners should consider co-operating with the MSE ICB or other healthcare research organisations to host events, activities, information sessions, expert talks, focus groups and promote current research initiatives. This could provide opportunities for recruiting research participants and promoting community research interests.

Use a range of engagement methods: Community research partners should consider using a range of engagement methods to provide greater choice and enable individuals to decide how they would like to participate in discussions and research initiatives. This could encourage wider participation and involvement.

Engage with diverse community groups: Community research partners should be encouraged to engage with a diverse range of community groups to ensure they are gathering information and responses which reflect the experiences of all members of the local community, including those from different backgrounds.

Diversify communication channels: The MSE ICB and community research partners should consider using a wide range of communication channels, which are inclusive and accessible for all, to increase the visibility of projects and research participation opportunities. Facilitating educational sessions around the meaning of research and teaching participants digital skills to make information and research participation more inclusive and accessible should be considered.

Encourage communication and partnership between organisations: More communication and integrated partnership working between organisations should be encouraged to strengthen the voice of the REN network and improve outreach efforts and engagement initiatives.

Recommendations for Quarterly Progress Reports

Over the year, the submission of quarterly progress reports dropped from 68% in March to 20% in December. The report submissions show higher engagement levels at the beginning and lower engagement levels towards the end of phase one of the MSE REN project. This could be due to organisations experiencing busier time periods at the beginning of the financial year and at the end of the calendar year. However, this might also indicate that the progress report questions may be too rigorous and time-consuming for organisations to regularly complete.

Simplify and streamline reporting process:

- Reduce the complexity by focusing on key performance indicators (KPIs) and relevant progress data that can be easily provided by organisations without requiring extensive time or resources.
- Consider using tick-box or multiple choice questions around activities carried out, engagement methods used, community groups that have been engaged with, participation levels reached and research barriers faced to allow data metrics to be more easily analysed and evaluated.
- Provide options for different report formats (e.g., surveys, templates, or online tools) to make submission easier for under-resourced organisations.
- Where possible, pre-fill sections with data from previous reports or automatically pull data from other sources where applicable.

Offer flexibility in deadlines:

- Recognise that the end of the financial year and the holiday period can be particularly busy for organisations. Offer flexibility in deadlines or allow rolling submissions for reports. This could help organisations submit reports without feeling the pressure of a fixed deadline.

Consider incentivising timely reporting:

- Offer incentives for organisations that consistently submit reports on time, such as recognition or certificates. Acknowledge the importance of their contribution and encourage regular reporting.

Provide support and reminders:

- Regularly remind organisations about upcoming reporting deadlines. These reminders can be sent via email, text, or a designated platform.
- Offer a helpdesk or point of contact for organisations to seek clarification or assistance with the reporting process.

Engage organisations in early stages:

- Hold a workshop or meeting at the beginning of each reporting cycle to review expectations, clarify any ambiguities, and explain the importance of timely and accurate reports.
- During these sessions, emphasise the value of progress reports for both the organisations themselves and the funders, demonstrating how reporting can also benefit them by showcasing their impact.

Highlight the impact of timely reports:

- Regularly communicate how timely report submissions lead to positive outcomes, such as securing future funding, receiving feedback, and fostering stronger collaboration with other organisations.

Recommendations for Overcoming Research Barriers

Various research barriers were identified as factors which prevented people from participating in health and care research during engagement and discussions between community research partners, community champions and the public.

Accessibility Barriers

Difficulty accessing local support:

- Partner with community organisations to provide support and resources.
- Offer virtual consultations and support networks to increase accessibility.

Limited availability of groups:

- Offer flexible scheduling for research activities, including weekends or after-hours sessions.
- Provide options for asynchronous participation (e.g., online surveys).

Limited transportation options:

- Offer transportation subsidies or provide transportation services to and from research locations.
- Consider virtual participation to reduce the need for physical attendance.

Technological difficulties:

- Provide training for on how to use digital platforms and offer tech support.
- Use multiple formats for participation (e.g., phone calls, paper surveys) to accommodate those with limited digital skills.

Knowledge and Awareness Issues

Limited awareness around common community health issues:

- Engage in community outreach efforts to educate people about common health issues (e.g., workshops, informational brochures).
- Use social media and local events to spread awareness.

Lack of awareness of research opportunities:

- Use targeted communication strategies, such as community bulletin boards, newsletters, and social media to share research opportunities.
- Create a centralised online platform or app where individuals can easily access information about research initiatives.

Uncertainty about how participants are selected for research:

- Provide clear, transparent information on the research recruitment process and criteria for selection.
- Use community champions or trusted figures to relay information on research opportunities and selection processes.

Lack of opportunity to participate in research:

- Implement proactive recruitment strategies, including outreach to underserved communities.
- Ensure that recruitment efforts reach a diverse range of individuals and encourage participation through inclusive channels.

Misunderstanding and Confusion

Not understanding the goals of health and care research:

- Simplify research goals and processes in easy-to-understand language.
- Provide informational sessions or videos to explain research goals.

Confusion between research, clinical trials, and treatment options:

- Offer educational sessions to distinguish the differences between health and care research, clinical trials, and medical treatments.
- Use visuals or analogies to help simplify complex concepts.

Complex research methods:

- Provide multiple options and alternatives for research participation by taking into account cultural sensitivities and personal comfort levels.
- Offer thorough explanations of why specific methods are used for research.

Confusion around research questions:

- Restructure survey questions to ensure clarity and open-ended responses.
- Pilot questions with a group of participants to identify any clarity issues.

Feedback and Communication

Not receiving feedback after research participation:

- Ensure participants are informed about the results of the research, either through follow-up reports, newsletters, or meetings.
- Create clear feedback loops where participants can track the progress and impact of the research they contributed to.

Clearer communication materials:

- Design simple, accessible, and engaging communication materials (flyers, videos, infographics) to explain research goals, benefits, and outcomes.
- Tailor materials to suit literacy and cultural preferences of the community.

Lack of context for questions leading to confusion and disengagement

- Provide context before a survey to explain why the questions are being asked and their relevance and use examples to clarify complex questions.

Trust and Mistrust

General mistrust in the healthcare and research systems

- Engage with community leaders and trusted figures to increase credibility.
- Ensure transparency in the research process, including data handling, analysis, and outcomes.

Concerns about researcher bias, especially around specific ethnic groups

- Promote diversity within the research team and involve community members in the design and implementation of research.
- Address and openly discuss biases to reassure participants of the impartiality of the research process.

Suspicion regarding the research source

- Provide clear, transparent information about the research source, its purpose, and the benefits to the community.
- Foster trust through consistent communication, regular updates, and open forums for questions.

Cultural Sensitivity and Inclusion

Lack of culturally appropriate engagement with specific ethnic groups

- Adapt engagement methods to respect cultural values and preferences.
- Engage cultural brokers or community liaisons to bridge the gap between researchers and communities.

Underrepresentation of specific ethnic groups in research roles

- Promote the recruitment of ethnic minorities for roles in data analysis, research design, and leadership positions.
- Promote mentorship and career development opportunities for underrepresented groups in the research field.

Family roles, particularly in conservative households, restricting mobility

- Offer gender-sensitive accommodations, such as women-only sessions or childcare support during research participation.
- Provide flexible schedules or virtual participation options to cater to those with family responsibilities.

Incentives and Motivation

Offer clear incentives or compensation to increase engagement

- Offer incentives such as gift cards, free health screenings, or monetary compensation to encourage participation.
- Ensure that incentives are culturally appropriate and align with the community’s values.

Mental Health Sensitivity

Mental capacity to engage in research

- Allow participants to opt out of sensitive topics or offer an alternative form of participation that doesn’t touch on mental health.
- Provide mental health support and resources for participants before, during, and after participation.

Fear of triggering negative emotions

- Offer resources for emotional support, such as counselling or helplines, before, during, and after participation.
- Ensure that participants are comfortable with the sensitive topics discussed and make participation voluntary.

Generational and Socioeconomic Factors

Economic disadvantages, including low income and unemployment

- Provide financial support for participants, such as reimbursements for travel costs or childcare.
- Offer low-barrier participation options that don't require financial resources, like online surveys or home visits.

Family roles, particularly in conservative households, restricting mobility

- Provide family-friendly participation options, such as flexible times or child care during events.
- Foster community involvement in support roles to reduce the burden on individual participants.

Historical Concerns

Negative past experiences with healthcare or research

- Acknowledge and address past issues openly and transparently.
- Create initiatives that demonstrate commitment to improving the research process and benefiting the community.

8.0 Conclusion

In conclusion, the evaluation of phase one of the MSE REN project has provided valuable insights and actionable recommendations for enhancing community engagement and research participation in future phases. The performance of the community research partners has highlighted the importance of investing in community organisations to better understand the healthcare views and experiences of different communities, and their research needs and interests.

By building stronger communication and partnerships between organisations, addressing mistrust in research, highlighting relevant opportunities for participation, and understanding how research barriers can impact different communities, the MSE ICB can foster a fully inclusive research network and ensure those from underserved or minority backgrounds have equal opportunities to participate. This will contribute to ensuring that the voices of all community groups are heard and valued. These recommendations, when implemented, will not only enhance the effectiveness of the MSE REN programme but also ensure that it remains a valuable resource for engaging with and supporting diverse and underrepresented communities in health and care research.

Committed to quality

We are committed to the quality of our information. Every three years we perform an in depth audit so that we can be certain of this.

healthwatch
Essex

Healthwatch Essex
49 High Street
Earls Colne
Colchester
Essex
CO6 2PB

www.healthwatchessex.co.uk
0300 500 1895
enquiries@healthwatchessex.co.uk
@HWEssex
/healthwatchessex
@HWEssex
/healthwatch-essex
@hiddenvoiceshwe