Lincolnshire COUNTY COUNCIL

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Strengthening Community-Led Research in Health & Social Care

Recommendations to Support Policy and Practice

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Introduction

Community-led research places people with lived experience at the heart of exploring health and social care issues. It creates opportunities for communities to identify what matters most to them, share their knowledge, and generate insights that are rooted in everyday experiences.

Through the Lincolnshire Research Engagement Network (REN), eleven community-led research projects worked alongside seldom-heard groups to explore a wide range of health and wellbeing challenges. These research projects did more than generate findings - they built connections, created meaningful opportunities for participation, and brought forward perspectives that are too often overlooked in research, policy, and decision-making.

This booklet shares learning from these experiences, highlighting the potential of community-led research to shape more responsive services and systems. It also reflects on the changes needed to embed community-led research more effectively - from early-stage support for communities to develop ideas, through to the systems and relationships required to ensure community knowledge informs and influences policy, practice, and wider decision-making.

"It was really interesting to take ownership of the research... it was solely ours."



What the research tells us

Community-led research is not simply a different way of collecting data - it represents a distinct way of understanding knowledge, relationships, and change.

Seven interconnected insights emerged:

1

Purpose-driven and values-led

Participation is motivated by a commitment to improving systems, addressing inequalities, and responding to community priorities - not simply generating evidence.

2

Relationships as the foundation

Trust, conversation, and sustained engagement are central to generating meaningful insight. Relational approaches often produce richer understanding than standardised methods.

3

Capability is built through participation

Research skills, confidence, and critical reflection develop through experience, supported by mentoring and peer learning. This process often begins before projects are funded, as communities need time and support to shape ideas and navigate what research involves.

4

Impact is multi-layered

Community-led research strengthens individuals, informs organisations, and has clear potential to influence wider systems - though this potential is not always realised.

"Communities... who have that lived experience... can have conversations that none of us could dream of having."

5

Structural constraints persist

Short-term funding, complex governance processes, and misalignment with policy systems can limit both reach and impact. There are also challenges in reaching beyond established networks to engage communities who are less connected to existing structures.

6

Enabling conditions matter

Flexible funding, protected time, responsive mentoring, and effective coordination are critical to success. Flexibility works best when combined with light-touch structure to support groups who may be new to research.

7

Whose knowledge counts?

Lived experience generates unique and valuable insight, yet is not always afforded equal legitimacy within formal decision-making structures. There is also a risk that community-led approaches are absorbed into existing systems without shifting underlying power dynamics.



"It revealed what isn't being researched... what needs to be researched... stories that weren't being told."

Recommendations: Strengthening the foundations



Sustain investment in community-led research

Long-term, flexible funding models are essential to support locally driven inquiry and maintain community ownership. Trust-based approaches enable more meaningful and responsive research.

Strengthen pathways to policy & practice

Stronger, more explicit mechanisms are needed to connect community-generated evidence with commissioners, policymakers, and system leaders. Without these connections, valuable insight risks remaining underutilised.

Invest in dissemination & knowledge exchange

Community-led research requires infrastructure to support visibility, dialogue, and influence - including networks, events, and platforms that reach beyond individual organisations. Investment in peer learning and accessible dissemination ensures findings reach those who can act on them.

Build research capability & confidence

Supporting learning through practice, alongside accessible training, pre-application support, and peer learning, enables sustained engagement and strengthens long-term capacity within communities and organisations.

"I feel a sense of responsibility to do justice to the individuals who are part of this."

Recommendations: Creating the conditions for impact



Strengthen mentoring & coordination

Mentoring plays a critical role in enabling participation and ensuring research quality. Equally important is effective programme coordination to support community organisations, manage system requirements, and create the conditions for success. Future programmes should provide clear frameworks while preserving flexibility and responsiveness.

Review governance & ethics processes

Existing ethics and governance structures are often misaligned with the pace and nature of community-led research. More proportionate and adaptable approaches are needed to support, rather than constrain, participation.

This includes ensuring funding flows, processes and timelines are aligned with how community organisations work in practice.



Recognise lived experience as legitimate evidence

Community knowledge should be embedded within decision-making processes as a valid and essential form of evidence, complementing traditional research approaches.

Support continuity & sustainability

Build in opportunities for projects to continue, evolve or connect to further funding, ensuring that community capacity and momentum are not lost.

The Central Challenge

The 'Missing Middle': from Knowledge to Action

A consistent finding across all projects is the existence of **a gap between the production of community-generated knowledge and its translation into system-level change**.

While community-led research is highly effective in generating insight, there are limited mechanisms to ensure that this insight informs policy, commissioning, or practice.



Understanding the gap:

This **"missing middle"** reflects the intersection of:

- the strong impact potential of community-generated evidence
- structural and institutional barriers
- limited infrastructure for dissemination and engagement

"It's a shame the project ended and there was no clear what next."



Participants frequently described uncertainty about what happens after research is completed, alongside concerns that valuable insights "don't quite go anywhere".

This gap also extends beyond dissemination to continuity. In many cases, there are limited pathways for sustaining or building on research once projects end, despite the momentum and capacity that has been created.

Why it matters:

Without effective pathways into decision-making systems:

- community knowledge remains underutilised
- opportunities for system learning are lost
- inequalities in whose knowledge counts are reinforced

"There's no obvious route to disseminating that information outside of my organisation."



"It revealed what isn't being researched... what needs to be researched... stories that weren't being told."

What is needed:

Addressing the ‘missing middle’ requires:

- stronger relationships between communities and decision-makers
- clearer routes for evidence to influence policy and commissioning
- sustained investment beyond individual projects, including pathways for continuation and growth
- shared responsibility for translating insight into action



"I wish we'd been more proactive in finding a way to make it run after one year."

Conclusion
From Insight to Influence

Community-led research generates insight that is grounded, credible, and deeply connected to lived experience. It builds confidence, strengthens relationships, and reveals issues that may otherwise remain unseen.

However, the central challenge is not the generation of evidence- it is ensuring that this evidence is recognised, mobilised, and acted upon.

Addressing the “missing middle” represents a critical opportunity: to move from isolated pockets of insight towards a more connected system in which community knowledge meaningfully shapes policy, practice, and service design

Realising this potential will require investment not only in research activity, but in the infrastructures, relationships and power-sharing arrangements that enable community-generated evidence to influence change.

Our research findings provide a practical framework to help policymakers, practitioners and partners work collectively to strengthen community-led research in health and social care.

Realising this potential will require investment not only in research activity, but in the infrastructures, relationships and power-sharing arrangements that enable community-generated evidence to influence change - from initial idea development through to sustained system impact.

“We’re not just going to sit on this… their voices are going somewhere.”



Further Information

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Photo Credits

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