

AI-MULTIPLY PPIE: Celebrating Communities and Collaboration



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Introduction: Welcome



Ceri Durham,
CEO Social Action for Health

It was with some trepidation back in 2021 that **Social Action for Health** agreed to become involved with the **AI-MULTIPLY** project. Whilst we were delighted to be invited to a project focusing on health inequalities and improving care for people living with multiple long-term health conditions (MLTCs), the concept of Artificial Intelligence (AI) was unknown.

We specialise in making academic and health research inclusive to our diverse community. However, we wondered if we could ever understand a complex topic like AI sufficiently to support and encourage genuine contribution and engagement at different levels of the project.

Roll on 5 years, and we have done it!

By using creative approaches to build community capacity over a sustained period, working closely with the PPIE group managed out of Newcastle (see page 4) and constantly learning alongside the whole project team, we have ensured that the lived experience and recommendations of communities most affected by MLTCs have remained a central and defining feature of **AI-MULTIPLY**.

The aim of this report is to capture some of our contributions and learnings, to spark excitement and commitment to research which can challenge health inequalities and leave communities stronger, and to celebrate all that has been achieved through **AI-MULTIPLY**. We hope you enjoy it.

AI-MULTIPLY Research

Mission statement

“Using the collective expertise of patients, clinicians, researchers, and artificial intelligence to improve care for people living with multiple health conditions and medicines.”

Living with MLTCs and taking many medicines (polypharmacy) is common and linked to poorer health outcomes, reduced quality of life, and higher healthcare costs. Yet how these conditions and medicines interact remains poorly understood.

This research uses AI to uncover these relationships to support better prevention, treatment, and decision-making, aligned with the NHS vision for future care.

Tower Hamlets

We ❤️ Tower Hamlets

People with the lowest incomes are **4x more likely to have MLTCs** than those with the highest incomes.

35% of Tower Hamlets residents

identify as Bangladeshi, the largest Bangladeshi population in England and Wales. 22.9% of all residents identified specifically as White British while 14.6% reported that their ethnicity fell into the “White Other” category (ONS 2021).

Most densely populated borough in England

(15,695 residents per square km compared to an average of 424 people per square km).*

3 times as likely for a likelihood of a diagnosis of diabetes

for Bangladeshis as for White residents by age 70.**

One in 10 residents has Type 2 diabetes

and there are high rates of early death from heart disease.**

Tower Hamlets is a young and diverse borough.

The average age is 30. (ONS 2024).

71% of children and 61% of older adults (those over 60) live in income deprived households.**

More deprived people in Tower Hamlets tend to live shorter lives than less deprived,

and this gap has widened in recent years*

Tower Hamlets is home to some of England’s richest and poorest residents

and this inequality is reflected in health outcomes. The gap is widening.*



* Tower Hamlets Local Authority JSNA, 2025

** English Indices of Deprivation Report 2025

*** Tower Hamlets Strategy for Long Term Condition Prevention, 2024

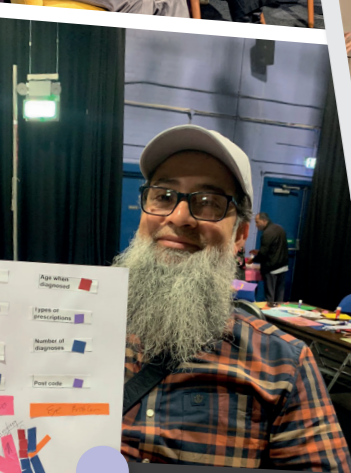
The Team



We are all artists...
Let's be Creative...



Artist Facilitator



Social Action for Health PPIE Group



 <p>Victoria Bartle PPIE Co-Lead and PPIE Representative</p>	 <p>Duncan Reynolds Research Associate at Queen Mary University of London</p>
 <p>Olivia Grant, OBE PPIE Co-Lead</p>	 <p>Lizzie Remfry PhD student at Queen Mary University of London</p>
 <p>Grainne Colligan Programmes Manager at SAfH</p>	 <p>Mike Barnes Project Co-Lead</p>
 <p>Ceri Durham PPIE Co-Lead and CEO at SAfH</p>	 <p>Nick Reynolds Project Co-Lead</p>

Other experts to involve

- Creative Methods Specialist
- Research Associate on Biostatistics
- Reader in Anthropology
- Professor of Computer and Data Science
- Professor of Pharmaceutical Public Health
- Artist
- Translators
- Project Manager
- Finance Officer
- GP
- PhD students
- Early Career Researchers
- PPIE Co-Lead and lay member co-applicant
- Epidemiologist



SAfH PPIE Womens group



Newcastle PPIE Members



Forum Theatre event

AI-MULTIPLY is funded by the NIHR Artificial Intelligence for Multiple Long-Term Conditions (AIM) Policy Research Programme (NIHR203982).

Equitable Engagement

From the outset, we were aware that meaningful engagement of people from our local communities into AI-MULTIPLY would require time, consideration and imagination.

After initial recruitment, we held our first PPIE meeting. This was designed to provide an overview of the research. Although we were working with our usual community facilitators and translators, we soon realised that the typical slide presentation and Q&A approach would not work for our group at this stage. People needed much more time to meet each other, share experiences of living with MLTCs and only then would they be in a position to understand the research, grow in confidence, and reach a place where they could contribute, pose questions and really feel part of the project.

This is when we started thinking about creative methodologies as an equitable, democratic and accessible way for diverse people to join in and have a voice. Thanks to the support of Lizzie Remfry, we were able to gain additional funding and develop our art workshop approach.

Building capacity in underserved communities:

Meaningful involvement throughout the research lifecycle has delivered benefits beyond the project itself. For example, 82% of Social Action for Health PPIE contributors were new to research, 73% do not speak day-to-day functional English, and 86% are from minoritised ethnic backgrounds.

Art Workshops

Working with an experienced artist and health facilitator, we ran a series of six workshops. Each week we used different materials and explored different topics which the group and team recognised as relevant to the research.



Community Art Exhibition

The success of the art workshops led to increased knowledge about research and confidence in the group who were excited to take the work out to the public domain as a community exhibition.

Academics, public members friends and family came to learn about the research and the artistic process used to elicit the lived experience and deep knowledge about the challenges faced by those living in complex situations alongside MLTC's and polypharmacy.

Animation

As members grew in confidence and understanding about the project and their role within it, a group of researchers approached with a request for a small group to work with them to co-design an accessible film about Large Language Models (LLM's).

Ultimately two films were made both in Bengali and in English, they are available by scanning the QR code.



SAFH team go to Glasgow



Attending Conferences

By the final year of the project, members of our group travelled with us and researchers to conferences in Birmingham and Glasgow. What started out in art workshops had led to this. We even won the People's Recognition Award for the LLM film work.

What I didn't expect was the new confidence I got. I've been to Birmingham, Glasgow, Queen Mary conferences, academic places I never thought I would be in. I didn't stand up and speak at first, I was shy but I still went. And later I put my hand up in a big lecture theatre. I wouldn't have done that before. I don't have any qualifications at all, but I've learned I can still understand and join in."

Lisa McFie, PPIE Contributor

Visual Minutes

We worked with 22 PPIE contributors from Tower Hamlets to develop research priorities for an AI research project focused on people living with multiple long-term conditions (MLTCs).



Practices of PPIE often exclude people due to their reliance on presentations, written materials and complex jargon (particularly when talking about AI).



Instead we ran arts-based workshops along with Bengali interpreters to support PPIE contributors new to research to get involved.



We found that arts-based approaches can make research playful and creating visual images helped centre lived experiential knowledge.

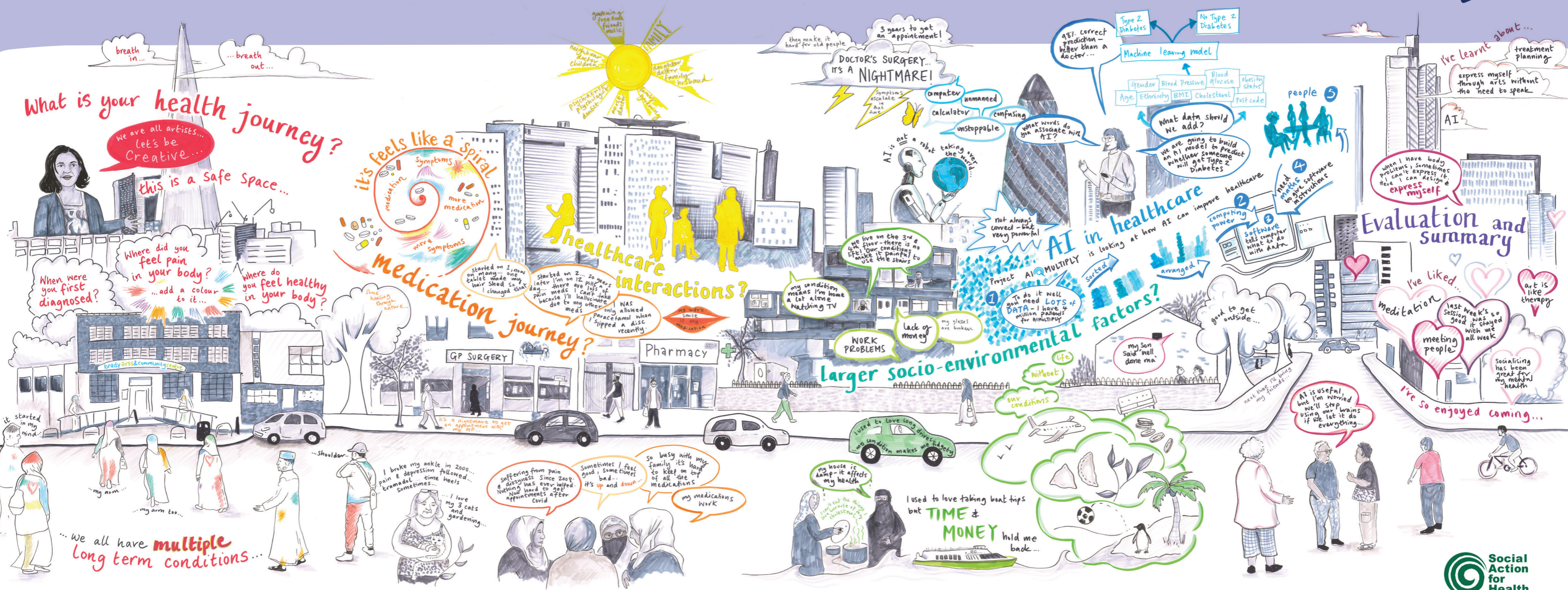


Contributors helped frame the research priorities by highlighting what data was important to them and their communities (housing quality data, availability of GP appointments, access to blue-green spaces, etc.).



Getting hands on time with a text-to-image AI generator was a useful way to develop critical AI literacy skills - PPIE contributors were quick to point out the lack of representation and bias in these systems!

Below: Visual minutes capturing the discussions and contributions from participants at Social Action for Health's art workshops.



Our PPIE Partners

Patient and Public Involvement and Engagement (PPIE) has been central to AI-MULTIPLY. It has been a pleasure to work with the wider PPIE team, coordinated by the PPIE Management Team based in Newcastle. They have assembled a large and diverse group either living with MLTCs and polypharmacy or caring for someone who does. They are from across the country, represent a wide range of socio-economic, ethnic, ages, gender and lived experience backgrounds. Collectively, they brought extensive PPIE experience and expertise to the project, ensuring that PPIE shaped the project at every stage including co-authoring papers, training Early Career Researchers in PPIE and presenting at research conferences.

Key PPIE achievements include:

International recognition:

PPIE-led abstracts were accepted at major conferences, including the Creative Methodologies Conference (Manchester), MLTC UKRI Conference (Birmingham), and the Participatory AI Conference (Paris), where AI-MULTIPLY was the only team to include PPIE contributors alongside researchers.

Innovative and creative methods:

Theatre:

A Forum Theatre production, co-created with Lawnmowers Theatre Company, explored barriers and opportunities for PPIE in AI research and is informing plans for a future Legislative Theatre project.

Skills and leadership development:

Early career researchers gained practical PPIE experience, while contributors were supported to co-author academic papers, extending impact beyond the project.

Community engagement:

Workshops on AI explainability have connected with communities affected by kidney disease, diabetes and severe mental illness, helping ensure research reflects lived experience.

"I Poems don't just analyse what participants say – they let us hear how they speak themselves into being."

Fiona Cammack, PPIE Contributor and Creative Methods Lead

*I'm involved in fitness and prehab.
I'm due to have a major operation.
I got involved as a teenager.
I had two loves or passions of mine as a young person.
I took the music path for my job.
I have problems with my hips.
I had both my hips replaced.
I also have a lower back problem.
I've had really serious*

"I Poems":

The group developed forms of poetry which use the exact words of research participants to add depth and emotional resonance to what might remain hidden.



Reflections and Research Outputs

It has not always been plain sailing – especially working with a large team on a complicated topic like AI. We share here some of our reflections and learnings which we hope can be useful for others in future projects.

Reflections

1.

Not everyone is used to talking about and recognising health inequity. We all have to be vigilant at recognising disproportionate impacts and be better at explaining the lived reality of what that means.

2.

Relationship building is key. Plan (and budget for) in-person meetings with time to get to know everyone at a human level.

3.

Recognise that everyone might be involved for different reasons. Find your common goal to enable you to think about the longer-term.

4.

Meaningfully involving people with lived-experience, requires recognition and accommodation of that experience; eg: translation, travel adjustments, overnight stays.

5.

Build in time for PPIE members to share lived experiences with each other, and have support in place.

6.

Choose your battles! Be kind, respectful and keep listening to each other.

Key research outputs from this project can be found in the accompanying Impacts and Outputs brochure.



Building a Polypharmacy Workbench
Rafael Henkin, QMUL

Mental Health Matters: Antidepressants, Multimorbidity, and Long-Term Health
Soraia Sousa, Newcastle University

Finding Hidden Health Pathways: Using Probabilistic Models to Understand Lifelong Care Patterns
Kieran Richards, Edinburgh University

Social Science Investigation of interdisciplinary AI-in-healthcare work
Duncan Reynolds & Megan Clinch, QMUL

Bursty Dynamics in Health: Can the Timing of Our Health Events Tell Us Something Important?
Alisha Angdembe, QMUL

Trial emulation using Real-World Data to Bridge the Evidence Gap
James Wason, Newcastle

Beyond Labels: Using Self-Supervised Learning to Predict Hospital Readmission
Rebeen Hamad, Newcastle University



Developing People and Partnerships

The length of funding through AI-MULTIPLY, has enabled us to sustain and develop our involvement and that of our community. A particular highlight has been the capacity building of our organisation, PPIE members and academic partners, leaving all our communities stronger.



... I am grateful that AI-MULTIPLY enabled me to take my first step in PPIE."

Liyuan Zhu, PhD Student

"If you think about the impact that PPIE has had for ~5% of the project budget, I think it's amazing."

Nick Reynolds, Co-Principal Investigator

"I never thought I would be talking about AI"

Lisa

"The overarching goal is to move beyond tokenistic involvement, positioning public contributors as equal partners in research that is relevant, ethical and capable of improving lives."

Victoria Bartle, PPIE Co-Lead



"I have really enjoyed myself. Especially, because we had one translator for our table of four ladies. She translated to us in a way we understood and beyond. I couldn't do this session at all without her support."

SAfH Art Workshop Participant



"There has been up and downs working with so many people with differing knowledge and expertise but together we've ended up with a fantastic model of how to engage a wide and diverse cross-section of the public in health research from educating researchers and contributing to academic papers, to meaningfully engaging and hearing from marginalised communities who experience the most health inequalities and who's knowledge is not commonly heard or seen."

Grainne Colligan, SAfH Programmes Manager

Taking part in the LLM project was a really enjoyable and helpful experience. It helped me understand more about what it is and gave me the confidence to explain it to others.

Sulima Alom, PPIE Contributor



Working with SAFH showed me just how valuable diverse public perspectives are. It changed how I think about research by showing me that everyday experiences and concerns can meaningfully shape even highly technical work like AI."

Duncan Reynolds, Research Associate at Queen Mary University London

"Social Action for Health and their public participants have brought such a unique perspective to our research. Serving, both as a sounding board to understand what really matters to patients and public, and also as a reminder that health issues can be as diverse as the communities we work with in East London. Simply put, it shows us that one size cannot fit all when health is concerned."

Mike Barnes, Co-Principal Investigator



During my PhD it was a joy to work with Social Action for Health on all things public and patient involvement and engagement (PPIE) and this paper is from the first project we collaborated on!"

Lizzie Remfry, PhD Student

I never heard what AI was until this session. Please do more sessions like this. Please provide translator too!"

SAfH Art Workshop Participant

In the art workshops we learned about the kinds of things Generative AI could produce. This was the first time most people tried any kind of AI tool.

diabetic in Tower hamlets in the style of shaha buddin

Generate



Inequalities Scorecard

AI has great potential to improve healthcare, but when it is trained on data that reflect only a narrow segment of society, it risks reinforcing existing health inequalities. In healthcare, this problem is acute: AI can only learn from what is represented in the data, and many datasets under-represent groups defined by ethnicity, deprivation, gender, geography, or combinations of these factors.

As part of our role to ensure a focus on health inequalities throughout **AI-MULTIPLY**, the PPIE groups have worked with the team from QMUL to start the development of an Intersectional Inequalities Scorecard to help address this challenge. Using the insights and recommendations of lived-experience of living with MLTCs, The scorecard provides a simple, practical framework that researchers can use at two critical stages of AI development.

1.

It enables teams to assess datasets before AI training, identifying which population groups are well represented, where gaps exist, and what limitations or mitigation strategies should be considered.

2.

Second, it supports the development of inequality-aware AI models by guiding systematic evaluation of model performance across different communities and intersectional subgroups, rather than relying on average performance alone.

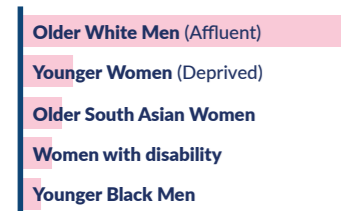
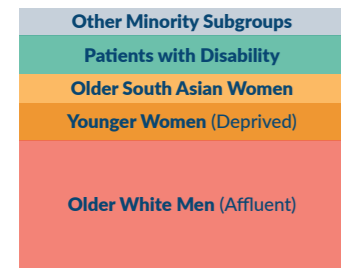
The scorecard encourages equity to be designed into healthcare AI from the outset, rather than added retrospectively. It is shaped by the lived experience of patient and public contributors within the **AI-MULTIPLY** programme, whose insights helped identify blind spots and set priorities that might otherwise be overlooked.

The result is a scalable, transparent tool that strengthens trust, supports fairer model development, and helps ensure healthcare AI benefits the full population it is intended to serve.

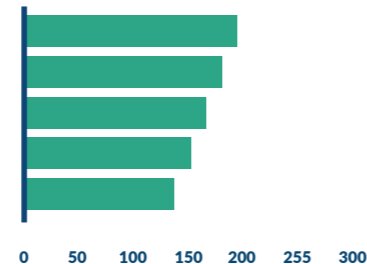
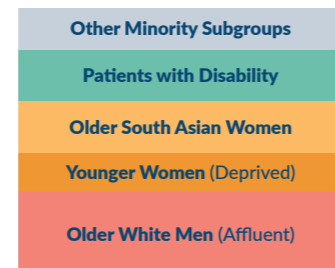
How can we address AI bias?

We built a scorecard to make AI more equitable and inclusive.

Before Adjustment



After Adjustment



Equality: Evaluate and adjust training data



Equity: Apply weights to training data

Conclusion

Call-to-action

As ever when a project of this nature finishes, attention turns to the next steps. Some of us will move on to new projects, others will be writing up academic findings, others will be continuing to find better ways to manage their MLTCs. Whatever those steps are for you, we implore everyone to remain vigilant about health equity and continue working towards reducing preventable health inequalities in whatever way you can.

In the current UK social context where health inequalities are widening, AI is being used increasingly, and racial, religious and community tensions are being stirred up, it is more important than ever to move forward with intention. Don't assume that AI won't have inequalities built in. Think about who is missing, why, and what can YOU do to change it?

To find out more about Social Action for Health, please get in touch.



Coming together is a beginning, staying together is progress, and working together is success."

Henry Ford, Founder of Ford Motor Company

Thank you to the whole AI-MULTIPLY team.

It has been a pleasure working with you.



Further Information

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Facebook: [@SAfHUK](https://www.facebook.com/SAfHUK)

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The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

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Design by **Altogether**



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