

AI-MULTIPLY PPIE: Sharing, Connecting, Shaping the Future

Our Mission: Using the collective expertise of patients, clinicians, researchers and artificial intelligence to improve the care of people who live with many health conditions and medicines



Contents



2. PPIE Goals and Ethos

5. Creating a Shared Mission for AI-MULTIPLY

6. PPIE Involvement in each Work Package

8. Social Action for Health

9. Our Involvement in AI-MULTIPLY

10. Our Publications

11. ECR Sessions

12. Forum Theatre

13. I Poems

14. Community Workshops

15. PPIE Evaluation

16. Conferences

18. Our PPIE Impact

19. Conclusion

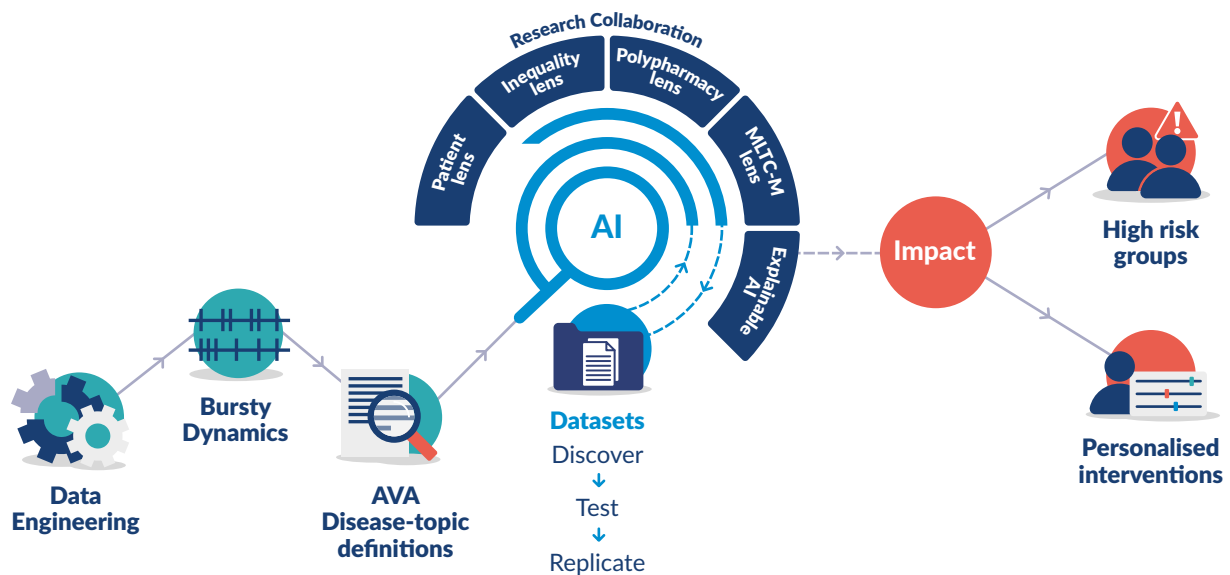
2 | AI-MULTIPLY

PPIE Goals and Ethos

Overarching aim of the project: understand how people with several long-term health conditions who take many medicines experience changes in their health over time, and how this links to inequalities and health outcomes.



AI-MULTIPLY Overview



Welcome letter from Olivia Grant OBE DL DCL, AI-MULTIPLY Co-Applicant and Co-PPIE Lead

When I was first asked to support Nick Reynolds, Mike Barnes and several other colleagues as they prepared, and then submitted, the first bid for NIHR funding for AI-MULTIPLY, I had to learn about this concept that was Patient and Public Involvement and Engagement (PPIE). I suspect that I can share my thanks, together with those of all my PPIE colleagues, with both Nick and Mike for inviting us all to join the learning curve that we have experienced over the past six years.

For me, as a PPIE novice, public involvement in AI-MULTIPLY was about two things:

1. really trying to understand how PPIE could fully support academic and medical staff as they sought to assist patients who have multiple long-term conditions; and
2. trying to think about, and learn about, AI, what AI is, what it might become, and, importantly, how it might empower patients to be better served and supported by our healthcare systems.

The bids for this project outlined that PPIE contributors were to be regarded as totally equal collaborators and fundamental to the research. It was agreed that we would have full membership of the management group, be able to invite medics and academics to PPIE meetings, rather than following the more traditional PPIE approach of awaiting invitations to meetings in which we had no direct input and were unsure how our discussions would affect the research. We also planned to support and train researchers in PPIE methods, evaluate our activities, and utilise "alternative" methods to engage with the wider public.

The level of PPIE engagement envisaged in our bids to NIHR was questioned. There was scepticism that we could engage and retain 30 regular contributors from across the country (supported by the Newcastle team), alongside 25 based in London and supported by Social Action for Health (SAfH). This level of active engagement, and the depth of involvement in the study that we proposed, was regarded as unusual. I would therefore like to extend my thanks to NIHR for supporting us, and for believing that the aims of the PPIE within the initial application were deliverable.

Being joined by Victoria Bartle as PPIE co-lead was fundamental to delivering the PPIE as defined. Her insights, together with the hugely informed, imaginative and considered management support from Sue Mountain, Fiona Cammack and David Taylor, were integral to delivering this immense and exciting programme of PPIE. Their individual and shared experience has turned a proposal into a reality.

Having watched and participated in a myriad of activities since March 2020, I think all of us, as PPIE contributors, have learned a great deal and contributed significantly to the thinking and research of our academic colleagues. We believe that, together with our many PPIE colleagues, we have created a model and experience that others can use, share, modify and continue to develop, in order to better integrate PPIE into research.

Olivia Grant
OBE DL DCL, PPIE Co-Lead



AI-MULTIPLY PPIE Management Team



Olivia Grant
OBE DL DCL,
PPIE Co-Lead



Victoria Bartle
PPIE Co-Lead



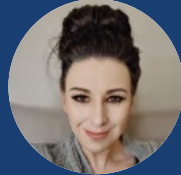
Sue Mountain
B.E.M, ECR Lead



David Taylor
PPIE Contributor



Alex Thompson
PPIE Evaluation Lead



Fiona Cammack
PPIE Contributor and
Creative Methods Lead



Duncan Reynolds
Research Associate at Queen
Mary University of London

Our aim for the PPIE

PPIE in this project has been both innovative and impactful with contributors involved in every aspect of the study design, delivery, and oversight. We have assembled a large and diverse PPIE group of people, living with multiple long-term conditions (MLTCs) and experiences of polypharmacy across the country. Members represent a wide range of socioeconomic, ethnic, age, gender, and lived experience backgrounds, including carers and those with multiple intersectionalities of inequity. Collectively, we bring extensive prior PPIE experience and a shared commitment to ensuring that public involvement in this project is inclusive, creative, and meaningful.

Recognising the public's mistrust surrounding artificial intelligence (AI) and data sharing, we were determined to create a collaborative approach that would help reduce these concerns. Our aim was to build trust not only in any AI tools developed through the project but also in the researchers' methods for analysing healthcare data.

To achieve this, PPIE was embedded across all areas of the project. We established a PPIE management group whose members sit as equal partners on the study management team, regularly presenting at team and steering group meetings. We take responsibility for our own reporting and have designed and delivered our own conference abstracts and papers to showcase our contributions and learning.

PPIE contributors have been actively involved in data engineering and whiteboard meetings, which is an unusual place to incorporate PPIE. The early career researchers (ECRs) on the project have all presented their work, whilst in progress, to the PPIE group and received constructive feedback. This process not only supports ECRs' professional development but also ensures that research activities are informed by lived experience perspectives.

Beyond formal meetings, we identified opportunities for broader involvement. We co-created a Forum Theatre piece to explore barriers and opportunities for PPIE in AI and big data projects. In addition, we designed and led community workshops to capture public perspectives on the AI tools being developed and the methods used to analyse severe mental illness (SMI) data. Our contributors are named co-authors on all project publications and have been directly involved in both qualitative and quantitative data analysis and synthesis across all work packages.

Through this work, we have made a significant contribution to AI-MULTIPLY.

Victoria Bartle
PPIE Co-Lead



Creating a shared mission for AI-MULTIPLY



During a whole team workshop led by Work Package 4 (WP4 – Social Science Investigation of Interdisciplinary Entanglements) in July 2023, it became clear that the broad scope of AI-MULTIPLY meant some team members felt a sense of disconnect between themselves and different parts of the project.

A PPIE contributor proposed that a mission statement could act as a unifying point. They drew on the example NASA in the 1960s, where everyone from top to bottom shared the common purpose of putting a man on the moon by the end of the decade. This suggestion was immediately taken up by Duncan Reynolds, Megan Clinch, and Deborah Swinglehurst of WP4 who began the process of collaboratively developing a statement.

The mission statement was built through an extensive co-production process. Early whiteboard sessions brought together WP leads and PPIE contributors to identify shared priorities. Drafts were circulated to the full team and anonymous surveys were then sent out to all team members to gather views on what should and should not be included. More dedicated workshops followed with both the London-based Social Action for Health PPIE group and the Newcastle PPIE group. From here, Duncan, Meg, and Deborah refined the mission statement in their own WP meetings, through informal conversations across the research team, and in email exchanges. In total, more than fifty people were involved in shaping and discussing the statement before final approval.

PPIE contributors played a central role in shaping the mission statement. One of the main ways this initially happened was that contributors challenged an early draft for sounding too corporate and taking issue with the term “life-course” for describing their lives. This was an interesting point of difference as “life course” had been the preferred phrase from researchers but was quickly pushed back on by PPIE contributors for not adequately reflecting their day-to-day experiences of living with multiple long-term conditions and instead reducing this to academic jargon. Further changes were also made based on PPIE feedback on the ordering of disciplines, the call for clearer emphasis on impact, and encouraged language that reflected a sense of collective endeavour. These directly informed successive revisions which (we hope!) helped to ensure the mission statement spoke to patients, researchers, and clinicians alike.

The final mission statement was agreed at a hybrid meeting that brought together, for the first time, the London and Newcastle PPIE groups in a shared discussion. This meeting became an important bridging moment between the two groups and marked a shared commitment to the project’s direction.

Through this collaborative process, the mission statement was agreed as:

“Using the collective expertise of patients, clinicians, researchers and artificial intelligence to improve the care of people who live with many health conditions and medicines.”

Since then, the mission statement has provided a public anchor for AI-MULTIPLY and is used across the project website, publications, presentations, and outreach materials.



Figure 1: The hybrid meeting between Social Action for Health and the Newcastle PPIE group.

“I like that the statement starts with ‘us’ and encompasses all of the areas we hope to include. I agree that some mention of impact needs to be included.”

JW

From the first planning online meeting

PPIE Involvement in Each Work Package



Work Package 1 & Work Package 2

Work Package 1: Data collation, wrangling and engineering

- Collating and structuring the data into usable formats for the researchers to analyse.

Work Package 2: Machine Learning and AI pipeline development

- Using Machine Learning and AI Algorithms (Bursty Dynamics, AVA, ATM, polypharmacy workbench) to identify risks in MLTCs and polypharmacy, symptom/condition clusters and possible diagnosis timelines.

Researchers	PPIE Involvement	Impact on People & Project
Nick Reynolds & Mike Barnes	Discussed WP overview in PPIE meetings	<ul style="list-style-type: none"> • Contributors understood project data; researchers gained insight into public views on data use and project goals.
	ECR Sessions: Twice-monthly Q&A with PPIE group	<ul style="list-style-type: none"> • ECRs built PPIE and communication skills; contributors deepened project understanding.
	Data Engineering Meetings: Regular PPIE attendance	<ul style="list-style-type: none"> • Reminded researchers they are working with people, not just data.
Early Career Researchers (ECRs)	Meetings on data sources and analysis	<ul style="list-style-type: none"> • Contributors learned about datasets and challenges; researchers got feedback on data validity and gaps.
Paolo Missier	Presented at Sept 24 PPIE meeting, discussed WP overview questions	<ul style="list-style-type: none"> • Contributors shared views on data use; researchers gained public perspectives and ideas for future work.



Work Package 3

Towards interpretation and clinical decision making:

- Qualitative interviews with people living with MLTCs.
- Mental Health and Inflammation sub themes and Epidemiology.

Researchers	PPIE Involvement	Impact on People & Project
Barbara Hanratty & Alex Thompson	Workshops on topic guide, coding, and themes	<ul style="list-style-type: none"> • Contributors learnt thematic analysis; researchers gained alternative views of the analysis.
Hamish McAllistair-Williams & Soraia Guerra Sousa	Discussions on mental health trial emulations	<ul style="list-style-type: none"> • Contributors learnt about MH data; supported deprescribing trial idea.
Akrivia Health	Co-delivered session on Cumbria, Northumberland, Tyne and Wear mental Health trust (CNTW) data use	<ul style="list-style-type: none"> • Built links with AI-MULTIPLY offered opportunities to our PPIE group; feedback shared with researchers.
Dexter Canoy	Delivered session on epidemiology and synthetic data	<ul style="list-style-type: none"> • Contributors learnt about data use in AI-MULTIPLY; researcher developed PPIE skills.
Whiteboard Discussions	PPIE attended all WP3 planning sessions	<ul style="list-style-type: none"> • Contributors stayed informed; researchers benefited from PPIE input in decision-making.



Work Package 4

Interdisciplinary entanglements: emergence of ideas, consensus and technologies in scientific practice.

- Looking at how the collaborative work together, using ethnographic and qualitative approaches to understand how the work is done, the value that the people involved place on the work, and what is accomplished.

Researchers	PPIE Involvement	Impact on People & Project
Deborah Swinglehurst, Duncan Reynolds & Megan Clinch	Co-developed project mission statement	<ul style="list-style-type: none"> • Contributors shaped the mission statement, researchers built PPIE and hybrid facilitation skills; mission statement now used in all comms.
	Workshops on research roles and collaboration	<ul style="list-style-type: none"> • Contributors saw WP4 activities, understood their role, and contributed to evaluation data.



Work Package 5

Health and social care outcomes, translation into practice:

- Trial emulations of questions raised by the other work packages.

Researchers	PPIE Involvement	Impact on People & Project
James Wason & Adam Todd	Trial emulation training & co-design	<ul style="list-style-type: none"> • Contributors learnt about trial emulations; co-created a deprescribing study question now part of a funding bid.
	PPIE input into study design	<ul style="list-style-type: none"> • Researchers gained co-production and communication skills; contributors involved in shaping the study.
	Attendance at WP5 whiteboard sessions	<ul style="list-style-type: none"> • Contributors stayed informed; researchers benefited from PPIE input in decision-making.

Inequalities

Researchers	PPIE Involvement	Impact on People & Project
Vanessa Apea	Discussion on inequalities scorecard	<ul style="list-style-type: none"> • Contributors learnt about plans for future research tools; suggested new domains like health literacy, Severe Mental Illness, and social prescribing for inclusion
Vanessa Apea, Mike Barnes & SAfH	Review prototype scorecard and how it can be applied to design inclusive studies and reduce bias in AI	<ul style="list-style-type: none"> • Contributors identified intersectional inequalities that need to be considered in the development of AI models.

Social Action for Health



Social Action for Health (SAfH) is an East London community-based health charity providing services and support to people most affected by health inequalities. Their mission is to champion the case for wider structural and societal change whilst addressing the priorities of their community.

A key part of their work is ensuring participation in health research of minoritised ethnic communities and those living in complex social situations to ensure inclusive health research and outcomes that benefit all.

Researchers/Leads



Ceri Durham
PPIE Co-Lead and CEO, SAfH



Grainne Colligan
Programmes Manager, SAfH



Lizzie Remfry
PhD student at Queen Mary University of London

PPIE Involvement	Impact on People & Project
Art-based workshops were completed with the SAfH team, exploring lived experiences of MLTCs and polypharmacy alongside social factors which contribute to health	<ul style="list-style-type: none"> • Art exhibition created and hosted to showcase work. • Real life perspectives from the art works fed into the inequalities scorecard and the Forum theatre production. • Relationships built between communities and researchers. • Highlighted the value of creative methods in developing AI tools and encouraged inclusive dialogue between the research team and public contributors.
SAfH team contributed to the project's Mission Statement development	<ul style="list-style-type: none"> • Researchers gained experience of working with translators and people with a broad range of PPIE experience. • Diversity of voices and experience was added to the project Mission Statement. • Contributors learnt about the project as a whole and their role within it.
SAfH recruited and supported a diverse group of participants for the qualitative work package interviews	<ul style="list-style-type: none"> • Ensured that diversity of lived experience was represented in the qualitative work package.
SAfH team delivered focus groups with ECRs	<ul style="list-style-type: none"> • Researchers gained insight into outcomes important to members of the public in regards to prescribing patterns. • Researchers developed skills in delivering PPIE sessions involving translators.
SAfH management attended Forum Theatre workshops	<ul style="list-style-type: none"> • The theatre piece was influenced by findings from the art work and other PPIE activities carried out by SAfH. Improving diversity of input and representation within the piece.
SAfH team contributed to a Forum session of the theatre production	<ul style="list-style-type: none"> • Researchers gained additional insight into PPIE barriers and facilitators to be used in the recommendations for improving PPIE within AI and big data research. • Contributors gained an understanding of Theatre of the Oppressed and it's use in research.
3 AI explainer animated videos in English and Bengali were co-produced with SAfH PPIE group and Lizzie (PhD researcher at QMUL)	<ul style="list-style-type: none"> • Contributors improved their understanding of large language models and what they can bring to patient healthcare. • Researchers gained co-production experience. • Videos are available as tools to be used in future research to aid public understanding and involvement in AI development.

Our Involvement in AI-MULTIPLY



As a PPIE group, we have held:



Meetings with the researchers:

Overview of WP 1
3 meetings



ECR sessions
25 sessions



Akrivia data session
1 session



AI training for PPIE contributors
3 sessions



Community workshops
2 workshops



Trial emulation question development
4 sessions



I Poem training and creation
2 sessions, 1 in person and 1 online



Delivery of Forum Theatre production
Performed in person and recorded. Recording was shown to wider PPIE group and SAfH group. "Forum" sessions delivered 3 times



Overview of WP 2
4 meetings



Workshops for Lawnmowers collaboration – story and character ideas
3 workshops



Full group PPIE meetings
2 in person and 2 online



Qualitative data analysis workshops
2 workshops



Mission statement co-production meetings
2 meetings



Forum Theatre development and rehearsal weeks
2 weeks Forum theatre project creation



End of Project and next steps meetings
4 meetings, 1 for each work package, (WP 1&2 combined)



We have attended:

Data engineering meetings
PPIE representatives attended weekly from March 2024



Conferences to present about the PPIE
7 conferences – AIM consortium, Turing Institute x2, Participatory AI, UKRI MLTC, Creative Methods and Innovation Observatory



Project management meetings
Monthly throughout project



Whiteboard discussion sessions
7 meetings discussing WP 3 and WP 5 activities



We have been involved in the study reporting:

Research Steering Group reports
Written the PPIE sections (4 years)



NIHR annual reporting
Written the PPIE sections (4 years)



Research Fish annual reporting
Written the PPIE sections (3 years)



Risk register and milestone achievements
Updated sections re PPIE (3 years)



CAG amendment
PPIE management group members wrote a supporting statement; this was followed up with 3 sessions with our PPIE group and the Northumbria Uni PPIE module class re the data use and public opinion to strengthen the proposal



We have presented on the PPIE at every Full Team and Steering Group meetings:

AI-MULTIPLY Full Team and Steering Group meetings
Quarterly meetings: 15–30 min presentations about the PPIE activities within the project



Our Publications



The PPIE group has been involved in the conceptualisation, writing, editing and revising following submissions to journals of the majority of papers from the project.

All PPIE contributors were asked to identify areas of interest, previous experience and preferences for paper involvement. A guidance document was created for the contributors and the researchers to support with the process of co-authorship.

PPIE contributors were carefully selected to work with the researchers on the wide variety of papers with previous skills and experiences considered to ensure the best fit and working relationships.

Contributors and researchers were supported by the PPIE management team to ensure effective collaborative working.



Peer-reviewed papers

- Reynolds DJ, Mountain S, Bartle V, Remfry E, Barnes MR, Reynolds NJ, Thompson A. *Targeting everyday decision makers in research: ECR and PPIE collaboration in an AI-in-healthcare project*

[Click here to view the publication](#)

- Thompson A, Bartle V, Remfry E, Reynolds DJ, Barnes MR, Reynolds NJ, Hanratty B. *Public and Patient Involvement in Artificial Intelligence and Big Data Healthcare Research: An Exploration of Issues and Challenges Within the AI-MULTIPLY Project*

[Click here to view the publication](#)

- Remfry, E., Reynolds, D.J., Morgado de Queiroz, S., Social Action for Health, Mathur, R., Barnes, M.r., Thomson, A., AI-MULTIPLY PPIE Group and the AI-MULTIPLY Consortium. *Using arts-based methods to involve people living in Tower Hamlets with multiple long-term conditions in the development of artificial intelligence tools in healthcare research*

[Click here to view the publication](#)



Figure 2: AI-MULTIPLY researchers, PPIE contributors and SAfH at our showcase event 'Patient Journeys in Health – Bringing AI Along for the ride'.

ECR Sessions



The Early Career (ECR) sessions have been one of the most popular, successful and replicable parts of the PPIE in AI-MULTIPLY.

They were devised following a conversation about how to get the public contributors included in the decision making when the AI models were being created.

An additional and equally important goal of the sessions was to support the ECRs to develop PPIE skills, which are an integral part of research that is often overlooked in their training.



Figure 3: At AI-MULTIPLY showcase event, Sue Mountain, B.E.M, sharing insights and speaking about her experience of leading ECR sessions which are also reported in a published ECR paper 'Targeting everyday decision makers in research'. Sue is a member of the PPIE management group.



Structure

- Fortnightly drop in (for our PPIE group) meetings scheduled with each ECR booking into a slot.
- An experienced facilitator was identified from the PPIE management group to chair the meetings, support the ECRs with preparation and provide feedback following the sessions. They also collated the feedback forms and provided updates and recommendations to the PPIE management group when challenges were identified.



Challenges

- **ECR preconceptions and personal barriers** – we had to do a pre meeting with them to explain the purpose, process and the point of the sessions. Some were very nervous and had several meetings or email discussions with the facilitator about their presentations and the groups expectations.
- **Facilitation** – because of the high level of interest, attendance exceeded 15 contributors per session. This scale made it difficult for everyone to participate fully or raise questions, and both the facilitator and the ECR found it challenging to manage the discussions effectively. We then revised the format by capping attendance at 10 PPIE contributors per session and asking the ECRs to deliver their session twice. This enabled up to 20 group members to participate overall while maintaining a manageable group size. The smaller groups also fostered different dynamics, resulting in more focused and meaningful discussions.
- **Collating feedback** – many of the PPIE contributors filled out the feedback forms following each session, but securing feedback from the researchers was more challenging due to workload and time constraints.
- **Behind the scenes work** – all PPIE is time and admin intensive, but with the added task of communicating with, supporting and advising the ECRs, these sessions took a lot of admin and prep time for our Project manager and the ECR Facilitator.

Positives

- The work package leads encouraged the ECRs to attend the sessions, and it was often mentioned at meetings that they should speak to the PPIE group about their work, identifying these sessions as an important part of the project.
 - An ECR was inspired by the work, supported the PPIE management group with writing conference abstracts for the ECR sessions and then expanded this into a paper. This has now been published, been presented at 2 conferences and is being implemented by a research group in Barcelona!
- [Click here to view the publication](#)**
- ECRs reported that the sessions supported the development of their PPIE skills, strengthened their confidence in communicating their research, and reinforced the value and purpose of their roles. Importantly, this helped them remain mindful of the individuals behind the data they were analysing.
 - PPIE contributors reported feeling meaningfully involved in decision-making processes and indicated that their perspectives were valued and respected.

Forum Theatre



| What is Forum Theatre?

Forum Theatre is an interactive type of drama developed to highlight oppressions and create resolutions or plans to address the injustices portrayed. During the performance or “Forum” of the production, the audience helps shape the story. Created by Brazilian director Augusto Boal, it invites viewers to become “spect-actors” – they can pause the play, suggest changes, and even act out new ideas to improve the situation shown.



| Forum Theatre in Research

In research, Forum Theatre helps explore real-life experiences. Participants create a play based on their own stories, and the audience’s reactions and suggestions become part of the research. It’s a creative way to understand people’s views and test different solutions.



Figure 4: AI-MULTIPLY PPIE contributors and Lawnmowers’ actors performing the patient informed forum theatre.



| Forum Theatre in AI-MULTIPLY

PPIE contributors were involved in all meetings and all aspects of the study. This level of involvement is unusual in most research, and particularly rare in AI and big data projects. We didn’t want to make an awareness raising piece showing what it is like to live with MLTCs, which is what is usually done with Forum Theatre in research. We wanted to show the entire project and the barriers and facilitators of delivering PPIE in research when you have MLTCs, and the challenges to the researchers of working as part of such a large team, with very different expertise and backgrounds.

We wanted to demonstrate how barriers between researchers and PPIE contributors can be identified, addressed, and actively mitigated, as we have done within AI-MULTIPLY.

Forum Theatre helped us understand these issues in a creative and inclusive way through the questions:

- **What stops people with multiple long-term conditions (MLTCs) from getting involved in research?**
- **Are these barriers different in AI and big data projects?**
- **What challenges do researchers face when working with diverse communities?**



| Collaborating and Co-production

Working with Lawnmowers research abilities group seemed like a logical collaboration.

“People with Learning Disabilities are likely to have MLTCs, we didn’t seem to have any representation of this lived experience in our existing PPIE group, and to co-create a theatre piece, something that could outlast the project, would be amazing”.

Victoria Bartle
PPIE Co-Lead

Our first performance of the Forum Theatre piece was in Sept 2025 in Newcastle, and we delivered the “forum session” to our PPIE group using the recording, at our PPIE meeting in October 2025. The recording was also shown to and formed with the SAfH PPIE group in Oct 2025.

The interactions with the audience, our “spect-actors” provided data to be used to create recommendations for best practice of delivering PPIE with people with MLTCs in an AI and big data project.

I Poems



I poems have been used in research as a creative, analytical technique that supports more traditional thematic analysis by foregrounding the multiple voices, subjectivities and internal contradictions contained within narrative data.

This method works especially well for research on multiple long-term conditions, polypharmacy, and ageing, where people's experiences are complex and shaped over time by their bodies, personal relationships, and the health and social care systems around them.

I poems are often used to distil and represent the 'voice' of an interview participant, preserving the integrity and complexity of their narrative while enriching more traditional thematic analysis.

What we did

In November 2025, we delivered two workshops to create two evocative I poems based on the transcripts of interviews with two participants living with multiple long-term conditions. In the workshops PPIE contributors received training on I poems and the Listening guide methodology before we created the poems.

Findings

The resulting poems give an emotional narrative on the trajectory of the lived experience of physical and mental health amongst older adults living with multiple long-term conditions and polypharmacy.

This supports and influences the Research Question from the Qualitative work and has been added to their analysis.

Qualitative research question: What are the key perceived influences on the development and trajectory of physical and mental health amongst older adults living with MLTCs and polypharmacy?

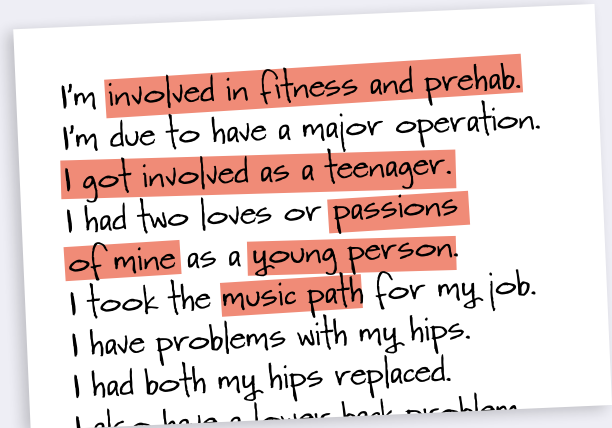


Figure 5: Picture of I poem being created by PPIE contributors during our in-person workshop.

What we learnt

- Creative Methods are used to amplify marginalised voices and open research to a wider audience.
- Upskilling of PPIE contributors and qualitative researchers.
- Immediate and impactful piece of poetry.

"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

Community Workshops



These were planned to reach out to and hear from additional voices who may not have been represented within our existing PPIE group.

We wanted to gain community views of AI tools being used in healthcare, especially around explainability and trust. Following some research into current tools being used in the North East, and discussions around the challenges of accessing and using secondary mental health care data in research we collaborated with members of the research team and developed a question for each of the groups. We then contracted an independent creative research specialist to co-produce and deliver the workshops.

We were able to deliver 2 workshops, 1 with an ethnic minorities women's group who all had experience of diabetes, either personally or as a carer. The second was with Re-co-co, a mental health recovery college supporting people with lived experience of mental health conditions.



| Diabetes Group

We used a diabetes risk progression tool being developed by WP 2 as an example and developed interactive and creative activities to gain people's opinions on AI tools like this being used by clinicians.



| Re-Co-Co Group

As the data from CNTW (Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust – providing mental health, learning disabilities and neuro-rehabilitation services) is separate to other secondary healthcare data, we wanted to understand how people with Severe Mental Illness (SMI) felt about often not being included in research for MLTCs and the challenges to creating and delivering holistic healthcare treating both mental and physical conditions, that this causes. We took the challenges being faced by WP 3 in organising the data from CTNW as an example and used creative activities to engage the group.

The workshops were very well attended; we were oversubscribed for the diabetes group and were requested to deliver it to additional groups which we unfortunately did not have the ability to do.

| Results

We are still in the process of analysing the data from these sessions, but initial findings are:

- People were happy for clinicians to use AI tools as risk predictors as they would have technology and human expertise combined – Human interaction is very important in healthcare.
- Concerns were raised around personal data being used in AI development and the fear of data breaches, potential identification and onward sale.
- Concerns around physical and mental health competing and 1 overshadowing the other rather than being seen as a whole person were highlighted.
- People with SMI did not want to be excluded from research because their data is separate or more difficult to analyse – happy for AI to be used to organise and prepare the data for research use.
- People hoped that tools being used would be overseen and authorised by appropriate bodies before being implemented into the NHS which would support trust in their use.



Figure 6: The picture shows a workshop on AI Explainability during our showcase event 'Patient Journeys in Health – Bringing AI Along for the ride'.

PPIE Evaluation



We decided to use a combination of the CUBE, Pijaf and impact log tools to evaluate the PPIE within AI-MULTIPLY.

- **CUBE** questionnaires tracked the views of the PPIE contributors and how they felt their input was being received by the researchers.
- The **Pijaf** is a PPIE design and evaluation tool, but as our researchers were not familiar with it, we dropped this pretty quickly. Instead, we tried to work with the researchers to prepare them for the PPIE meetings, ensuring they had accessible slides, felt confident in presenting and had specific questions to ask the group.
- Our **Impact Log** has been being used since March 2023 and we have over 150 comments from the meetings we have attended.

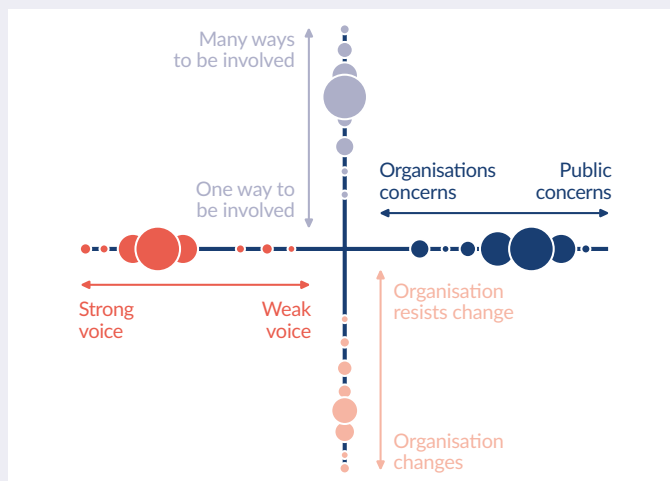


Figure 7: Crosshair plot depicting PPIE contributors' perceptions of their involvement within Work Package 1. The size of the circles indicates the number of members selecting that value on the scale.

Results

Our research questions were:

- **What, if any, differences are there in delivering PPIE within an AI/big data project compared to less technical research?**
- **What recommendations can we make for researchers to develop and deliver co-produced AI/big data research?**

Using CUBE feedback data from 5 PPIE sessions with researchers (1 from each work package), alongside the Impact log records, we discovered 3 themes:

- **Differing priorities** – public contributors wanted to see person-centred outcomes, while researchers focused on data-driven healthcare metrics, often limited by data availability.
- **Movement on both sides** – both researchers and contributors expressed early fears for full collaboration, but mutual trust and integration developed over time.

- **Importance of established guidance** – many issues raised came from areas which have longstanding PPIE guidance, namely ensuring clarity, feedback and facilitation.

We also noted that strong PPIE leadership, early expectation-setting and consistent facilitation are critical for success.

Positives

- We have lots of feedback from the PPIE contributors and the researchers to use in the evaluation.
- We have been able to split the evaluation into 3 papers – the quantitative review from the CUBE feedback forms, a qualitative paper using the researcher interviews and an overall review of the PPIE within AI-MULTIPLY.

[Click here to view the publication](#)

- We have used the feedback forms and the impact log to make improvements to the PPIE delivery throughout the study.

Challenges

- **The amount of data.** 150+ inputs to the impact log, feedback forms from all WP meetings, ECR sessions, Forum theatre events and community workshops. Recordings of Community workshop activities and “Forum sessions”. Researcher interviews and feedback forms from WP meetings and ECR sessions.
- **Identifying specific “you said, we did” impacts to the study.** By having PPIE contributors involved in all meetings and discussing work in progress, we have been able to influence the project, support the ECRs and keep the focus on patient benefit throughout, however, we have few specific impacts as we have been involved in the conversation throughout, and influenced the thought process of the researchers.

One of the most comprehensive reflections on this challenge was:

“It was difficult to say “you said – we did” more like you said and we understood a bit more about our work.”

Michael Barnes
Co-Principal Investigator

Next Steps

We are currently writing up the qualitative analysis from researcher and PPIE contributor interviews (PPIE evaluation paper 2) and analysing data from feedback forms and the impact log to complete a comprehensive evaluation of the project. The final PPIE evaluation paper will integrate findings from the previous two papers and provide recommendations for future collaborative PPIE within AI and big data research projects.

Conferences



UKRI MLTC Conference, Birmingham 2025

- Members of the PPIE management group were invited to speak on two of the panels.
- Nick Reynolds (PI on the project) presented on the AI-MULTIPLY project.
- Susan Mountain delivered a flash presentation about the ECR sessions.
- Alex Thompson presented a poster on the PPIE Evaluation.
- Carly Flowers, one of our project managers had a poster: "Setting up for Success: Insights from a Project Manager in AI-Driven Healthcare Research."
- Kieran Richards (WP 1 & 2) won an award for his poster: "Understanding the Pattern of Prescribed Medication".
- Additional members of our PPIE group also attended with other projects.



Figure 8: AI-MULTIPLY researchers and PPIE contributors at Participatory AI research Conference, Paris 2025. Here, they showcased a range of the PPIE work which has been taking place on the project, videos and posters of [which can be viewed at our website](#).

Participatory AI Research & Practice Symposium, Paris 2025

We submitted abstracts on:

- Art work with SAfH
- PPIE evaluation
- ECR sessions

The PPIE management group had no previous experience of writing conference abstracts and two of the researchers kindly volunteered to write the abstracts for the evaluation and ECR sessions and all abstracts were accepted!

Takeaways

- We were the only project with PPIE contributors at a participatory AI conference focused on diverse voices and inclusive governance.
- It felt like the PPIE group had invited the researchers, flipping the usual dynamic, and people noticed.

Highlights

- Our evaluation poster created lots of discussion.
- The presentation of the art work created by SAfH contributors sparked interest in creative methods in AI research.
- The ECR session presentation received lots of positive feedback and questions.
- Audience reactions showed surprise and genuine interest in how deeply PPIE was embedded in the project.

Creative Methodology Conference, Manchester 2025

- We decided to share our journey: how the collaboration between the AI-MULTIPLY PPIE group, our researchers and the Lawnmowers theatre group started, and what we hoped to achieve.
- We delivered a 1 hour session, presenting our journey with Lawnmowers to create the play and performed Scene 3 (a tokenistic PPIE meeting).
- People connected with the characters and asked to attend future performances. It helped show how creative methods like Forum Theatre can challenge and improve PPIE in complex projects like AI-MULTIPLY.

Highlights

- We presented our journey to co-production, not just the final product which was unusual.
- Scene 3 from the play sparked great discussion (a tokenistic PPIE meeting).
- Helped frame PPIE in technical AI research using creative methods.

Innovation Observatory Conference, Newcastle 2025 – Futures, Foresight and Horizon Scanning

- We submitted abstracts for the PPIE evaluation, our ECR sessions and the Forum Theatre Work. The Forum Theatre workshop was accepted, and they asked us if we were able to incorporate information about the other aspects of PPIE in AI-MULTIPLY into the workshop.
- The weather, transport and health issues were all against us on the day, and a team of 10 was reduced to 3 who managed to reach the venue.
- We were unable to present the workshop as designed but still delivered the overview of the unusual and creative PPIE in AI-MULTIPLY and showed the recording of the theatre production.

Highlights

- Feedback from the largely data driven researchers was positive, and many were interested in the co-production and creative methods delivered in such a technical and complex research area.



Figure 9: AI-MULTIPLY PPIE contributors along with Lawnmowers Creative Director Claire Hills-Wilson and Lawnmowers actor Francis, at the Creative Methodology Conference 2025. Here, they shared their journey working with Lawnmowers Theatre Company, highlighting how involving people with Learning Disabilities in the AI-MULTIPLY project enriched the research process and challenged conventional ideas about research. [This work can be seen on our website.](#)

Our PPIE Impact



PPIE has had a huge impact on the AI-MULTIPLY project, we have been involved in all aspects of the study from question design and co-creating the funding application, to delivering an innovative and replicable PPIE plan and being involved in the majority of the outputs from the study.

Our evaluation will have recommendations for effective and inclusive PPIE within AI and big data projects, and we have a committed and experienced group of PPIE contributors who can go on to influence research projects in the future.



You Said, We Did Examples

Meeting	Idea/comment	Impact
WP 3 Whiteboard Meeting Nov 2024	PPIE contributor challenged the numbers which the researcher is going to review and maybe remove patients on short term drugs and stick to long term to see if that makes more sense.	Timescale being looked at was changed.
ECR Session – MLTC-PP Risk Tool WP 1&2 researcher April 2025	“The way of delivering scientific information looks at deprivation differently from patients. They also care about privacy and want to be treated as a holistic person rather than just a patient.”	The session “helped me refine my idea into more actionable insights and I gained knowledge of communication and a patient-centred mindset. I also learned some new metrics of deprivation.” – feedback from a PPIE contributor



Continual Improvement Examples

Issue	What we did	What we'd do in the future
Found out about the Newcastle University £500 PPIE contributor payment limit in 2024	Informed the PPIE group, kept track of payments nearing the limit. Supported with casual worker contracts and RTW documentation where required.	Tried to get an exemption from the University for our study, or ensure that we explained this issue to the contributors at the outset so that they were able to make an informed decisions about their involvement.
Not enough time for discussion in ECR sessions when 15+ people started to attend	We restricted the ECR sessions to 10 attendees per meeting to allow for more discussion and inclusion.	Create a system to manage this as it was difficult in terms of admin to track attendance.

Conclusion



Our goal of fully embedding PPIE throughout this complex research project has been challenging but hugely rewarding. As PPIE contributors, we have all learnt a great deal from working on this study and are keen to take our ideas forward to other projects in the future.

Our innovations and activities have been commended by NIHR, “The PPIE activities seem to be particularly strong, with 2 papers published.” Feedback from 2025 annual report, and members of the research team have also shared their support, and plans for future adoption of more co-produced PPIE which can be seen in the funding applications being created to pursue follow on work, and quotes from Qualitative interviews completed for the 2nd PPIE evaluation papers.

All future PPIE publications will be shared via our website and we will continue to promote this method of PPIE in a variety of ways:

- Building on the success of our Forum Theatre production, we plan to develop a Legislative Theatre piece to advocate for systemic change in how PPIE is embedded in research.
- We see the importance of training ECRs in PPIE skills and empowering contributors to influence day-to-day project decisions, which we feel could be delivered in other research studies and infrastructure.

Our long-term goal is to move beyond tokenistic approaches, ensuring that public contributors are equal partners in creating research that genuinely improves lives.

We hope that you have enjoyed learning more about the public involvement delivered in AI-MULTIPLY.

“AI-MULTIPLY’s standout innovation is the patient–researcher interface – giving our Early Career Researchers the insight to make AI for MLTCs and polypharmacy truly fit for purpose.”

Mike Barnes
Co-Principal Investigator



“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



Figure 10: AI-MULTIPLY PPIE session in action.

Find out more

Website: ai-multiply.co.uk

Bluesky: [@ai-multiply.bsky.social](https://bsky.app/profile/ai-multiply.bsky.social)

Email the Project Team: AI.MULTIPLY@ncl.ac.uk

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