ABATED

NEWSLETTER

HIGHLIGHTS

1 RECRUITMENT OF ABATED STEERING COMMITTEE

2 NOVEMBER FOCUS GROUP

3 COMING SOON: THE EQUATED STUDY

IN THIS ISSUE

Welcome!

Welcome to our first Automated Brain Image Analysis for Timely and Equitable Dementia Diagnosis (ABATED) study newsletter. In this issue we will introduce you to the ABATED study, the team (including our Chief Investigator and steering committee), as well as summarising the outputs from our first study focus group.

– The ABATED team

MEET THE ABATED TEAM

Team Org Chart

Chief Investigator
Charles Marshall
Queen Mary University of London

Principal Investigator
Hojjat Azadbakht
AINOSTICS

Co-Lead for Patient and Public Involvement (PPI)
Ijeoma Uchegbu
Queen Mary University of London

Helen Beaumont
AINOSTICS

Lead for Recruitment and Retention Planning
Alastair Noyce
Queen Mary University of London

Post-Doctoral Research Assistant
Avinash Chandra
Queen Mary University of London

Research Assistant
Rifah Anjum
Queen Mary University of London

PPI Steering Committee
Reshma Punjabi
Samina Begum

Focus Group
Members of the Focus Group
NIHR People in Research
HCEO Hackney Caribbean Elderly Organisation
DARUL UMMAH
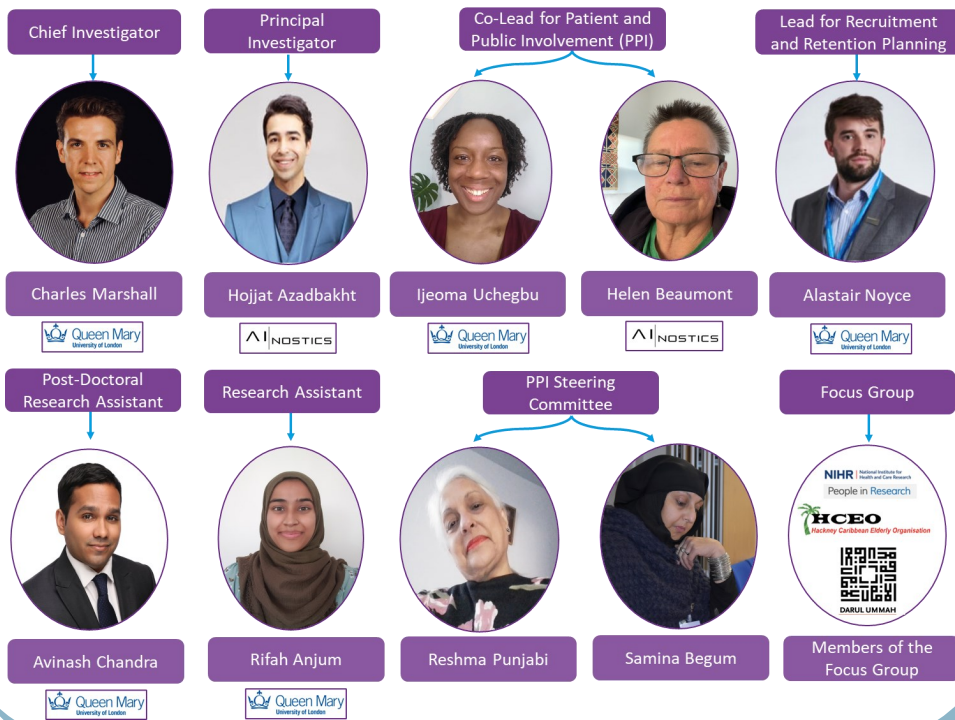
PPI Steering Committee

Introducing Reshma and Samina, the ABATED Patient and Public Involvement (PPI) steering committee members! Reshma and Samina have reviewed our study documents and have helped organise and facilitate our first focus group (Page 3). See what they have to say about working on the ABATED study below.

> I am a member of the PPI group on the ABATED study and recently attended the first in-person meeting with the rest of the group where Rifah and Avinash, who are part of the research team, presented the study. On a personal level, I have understood more about artificial intelligence (AI) and I have been encouraged to see how AI is used in medicine to positively impact patient care. As a PPI member, I am able to contribute together with the rest of the PPI team in making suggestions on how to explain the science in the most accessible and digestible way to the patient population. It is really important that a wide and diverse range of patients can relate to and engage with research as this will benefit everyone.
> – Reshma

I am able to contribute together with the rest of the PPI team in making suggestions on how to explain the science in the most accessible and digestible way to the patient population.

> I am excited to be working as a public contributor on this project. In my community, dementia is seen as a normal ageing process where you forget things or become confused. The focus groups discussions focused on what needed to be done to raise awareness about dementia and early diagnosis. Using brain scans and AI to identify who may be at risk of developing dementia and when, means individuals get an earlier diagnosis therefore are able to access support early.
> – Samina

Using brain scans and AI to identify who may be at risk of developing dementia and when, means individuals get an earlier diagnosis therefore are able to access support early.

The Recruitment Team

Our recruitment team consists of researchers at Queen Mary University of London (QMUL) (Avinash and Rifah) and Clinical Studies Officers from East London NHS Foundation Trust (Zainab, Nargis and Refah). In the near future we will also be working with Waltham Forest Memory Clinic to help recruit more patients for the study.

QMUL Student Placements

Sara is an undergraduate student and has helped the ABATED team set up our first focus group (Page 3) and designed a questionnaire to collect feedback from attendees for her Engaging Public in Science module. Sara has collected valuable feedback from the group about how they found the focus group which will help us improve our future focus groups in the coming years. This term we welcome Monica who is an undergraduate student also studying the Engaging Public in Science module. Monica has helped us review the design of our first newsletter, its distribution and designed the newsletter survey (Page 4). Finally, Rajan and Krishna, both of whom are medical students, have been helping us by carrying out some of the assessments during study visits. A big thank you to all the QMUL students who have been helping us with the ABATED study!

◼️ABATED **FOCUS GROUP**

Next Steps:
The EQUATED Study

When we asked what you would change about our study, you said:

> ❝ Thought-provoking and interesting ❞
>
> ❝ Very informative ❞
>
> – Focus group members

> ❝ GP should comprehend the concerns of the patient ❞
>
> ❝ Make sure the GP takes us seriously and sends for future tests ❞

In response to this, we designed and obtained funding from NIHR for the EQUATED study (Towards Equality of Opportunity for Timely and Equitable Dementia Diagnosis). In this study we will be looking at how people describe changes to their GP before getting a diagnosis, and how we might make the process of being referred to memory clinics fairer. Watch this space for opportunities to join the patient and public involvement for EQUATED!

We hosted our first focus group for the ABATED study in November to obtain feedback on our study. Fifteen members of the public attended from diverse backgrounds (including South Asian, Black Caribbean and White) from the Darul Ummah Mosque, Hackney Caribbean Elderly Organisation and NIHR People in Research as well as our steering committee. We presented the ABATED study and asked you about your thoughts on the study, including the design, recruitment strategy, and what else you would have wanted to know about the study. Overall, we received a lot of positive feedback. Read some of the questions you asked during the focus group on Page 4 and our answers. You also suggested using social media to promote the study. Following this we will now be posting more study-related updates and news on our Twitter page (**@ABATED_Study**). Additionally, you expressed interest in receiving study-related news and updates via a newsletter which is why we are now introducing the ABATED newsletter! If you have any comments or feedback on our study, or would like to join future ABATED study focus groups, please email us at **wiph-abated@qmul.ac.uk** - we look forward to hearing from you!

> ❝ More time needed for discussions ❞
>
> – Focus group member

> ❝ Whole-room and group activities maintained interest and gave opportunity for quieter people to participate ❞
>
> – Focus group member

FREQUENTLY ASKED QUESTIONS

How does this technology benefit patients from ethnic minority groups?

Research shows that some ethnic groups and individuals from poorer areas are diagnosed with dementia later and less well. We want to test our artificial intelligence (AI) technology on patients from East London memory clinics as this represents an ethnically diverse and underserved population. If our technology is accurate, and if it can be used in the clinical setting in the future, then it can help to provide a fair and accurate diagnosis across diverse groups.

Will this AI technology replace doctors in the memory clinic?

No, we hope that our technology will be used by doctors, alongside other assessment tools used in the memory clinic, to help reach a more accurate diagnosis quickly.

## Will participants receive individual results from the study?

No, all participant information will be anonymous and analysed collectively, and we will not feedback any individual results from this study. We need to manage participant records in specific ways for the research to be reliable. This means that we will not be able to let participants see or change the data we hold about them.

Will participants' data be kept confidential?

Yes, we will keep all information about participants safe and secure. All participant data will be anonymous and will be assigned a code number.

Coming Soon: The ABATED Website

We are currently working with the QMUL web team to create a webpage for the ABATED study where we will upload more information about our study and will post answers to more of your questions. Keep an eye on our Twitter page (**@ABATED_Study**) to find out when our webpage launches!
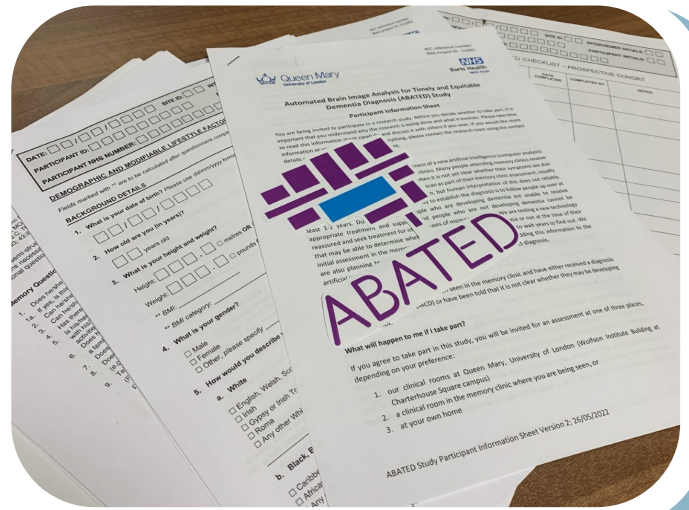
Tell Us What You Think!

To let us know whether you enjoyed the first issue of our newsletter and if you have any suggestions for improvement, please complete our short survey by either scanning the QR code or visiting the link below. We really appreciate your feedback!

https://forms.office.com/e/j6CBDKXvGm