RESEARCH ADVISORY GROUP HANDBOOK

Big Data and Artificial Intelligence in Childhood Epilepsy Research

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Medical Research Council

UKRI

KING'S College LONDON

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ABOUT THE RESEARCHER

EMMA CASEY

I am a PhD researcher in the NEST Lab at King's College London. My PhD supervisors are Dr. Charlotte Tye, Dr. Michael Absoud and Dr. Nick Cummins.

My research aims to identify early markers of developmental differences in babies with early-onset epilepsy, to improve our understanding of how developmental challenges associated with childhood epilepsy impact children and their families.

I am currently working on the **Brain Development in Early Epilepsy (BEE)** and **Early Lifecourse data Cross-Linkage in Research (eLIXIR)** studies at KCL.

You can read more about my PhD supervisors and their research by clicking on the links below or scanning the QR codes:

[Dr. Charlotte Tye]

[Dr. Michael Absoud]

[Dr. Nick Cummins]

FUNDING FOR THIS PROJECT

My PhD research is co-funded by a UK Research and Innovation Medical Research Council (MRC) studentship, and funding from industry partner vCreate.

More information about my research team and sponsors can be found by clicking on the links below, or scanning the QR codes:

- NEST Lab

- UKRI & MRC

- BEE Study

- vCreate

- eLIXIR Study

USEFUL TERMS TO HELP WITH UNDERSTANDING THIS STUDY

Language Skills

Language skills describes both receptive language and expressive language. Language skills can be affected by things like our age, our environment, or health conditions such as epilepsy.

Receptive language: the ability to understand what other people are saying when they speak or write.

Expressive language: the ability to communicate what we think and feel to others through speaking, writing, or other means such as gestures.

Motor Skills

The ability to move and control our bodies. Children learn to control their body as they grow. Some common motor skills that babies learn are crawling, walking, reaching and grabbing.

Maternal and Neonatal

Relating to or belonging to a mother (maternal) or to a newborn baby (neonatal). Maternal health records are health records belonging to mothers. Neonatal health records are health records belonging to newborn babies.

MORE USEFUL TERMS

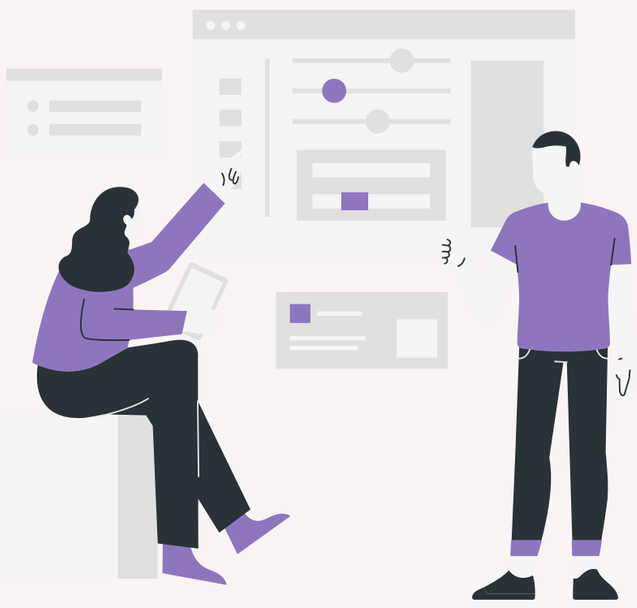
Perinatal

‘Peri’ comes from the Latin word for ‘around’ and ‘natal’ comes from the Latin word for ‘birth.’ The word perinatal describes the period of time around birth. This includes the entire period of time a woman is pregnant, and the first year after the birth of their child.

Artificial Intelligence

Artificial Intelligence (AI) is a term used to describe how computers can carry out tasks that are usually done by humans. Computers can copy or mimic human behaviours, which allows them to complete tasks like answering a question, making a decision, or solving a problem.

Big Data



Big Data is a term used to describe extremely large amounts of infromation. For example, health information you give to your clinician on a routine basis, or records of medications you are taking, or have taken in the past.

Big Data can be studied using computers to help us find patterns or trends which may help us make new connections and deepen our understanding of a topic. For example, studying health records may help us understand why epilepsy affects some people, but not others.

BACKGROUND TO THIS STUDY

How could AI be helpful for epilepsy research?

New technologies using artificial intelligence (AI) have shown potential for studying language and motor skills in conditions like Epilepsy and Parkinson's Disease.

Early-onset epilepsy can affect several aspects of children's development, including language and motor skills. AI could help us learn more about how language and motor development are impacted by early-onset epilepsy. It could also help make it easier for children with developing language or motor difficulties to get a diagnosis or to access interventions.

What are the aims of this study?

Aim 1

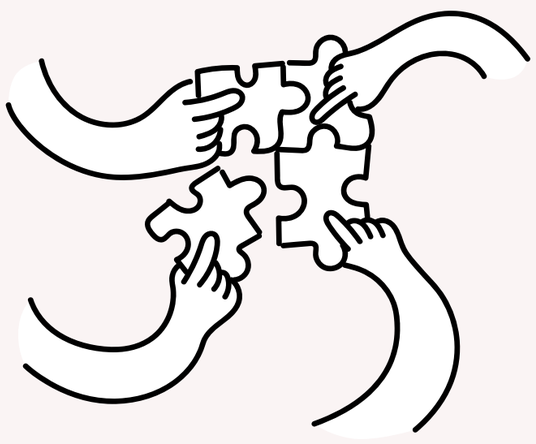
To understand patient and public opinions on using big data and AI methods in epilepsy research.

Aim 2

To work out whether assessments of language and motor skills usually done by a trained researcher or healthcare worker could potentially be done by a computer, using AI.

WHAT IS PATIENT AND PUBLIC INVOLVEMENT (PPI) IN RESEARCH?

Patient and Public Involvement (PPI) or Patient and Public Involvement and Engagement (PPIE) in research is research that is carried out **"with" or "by" members of the public rather than "to," "about," or "for" them** (National Institute for Health and Care Research).



PPIE aims to include lived experience voices from diverse groups and communities in shaping research. When it is done well, PPIE can improve the quality and impact of healthcare research.

You can find out more about PPIE in research by visiting the web pages below or scanning the QR codes:

- **Epilepsy Research Institute UK - Patient and public involvement**

- **HRA - Planning and improving research**

WHY JOIN A RESEARCH ADVISORY GROUP?

As a member of a research advisory group, you have the opportunity to:

- Shape the design and quality of scientific research
- Meet like-minded people who are passionate about research and advocacy
- Learn and develop new skills
- Work towards improving outcomes for people with epilepsy
- Earn some money.

HOW WILL I KNOW I'M MAKING A DIFFERENCE?

Emma will work with the advisory group to agree on how they would like to contribute to the project, and how we will measure the impact of their contributions.

We will regularly reflect on what is working well and what could be improved, so that everyone can get the most out of their experience as an advisory group member.

DO I NEED ANY QUALIFICATIONS?

No, you don't need any qualifications or training to be a part of an advisory group. Advisory group members will have unique experiences and opinions shaped by their lived experience of epilepsy.

These experiences and opinions are really valuable in shaping research, whether or not you have a knowledge of research methods, or medical or technical terms.

WILL I GET ANY TRAINING?

Yes, you will receive some basic training when you join the advisory group. Emma will be available to answer questions and support you throughout the research process, and can provide more training if advisory group members feel it is needed.

WILL I BE PAID FOR MY TIME?

Yes, you will be paid by the hour for your time in the form of a voucher or bank transfer - whichever you would prefer (though do **bear in mind that you may have to pay tax on any payments made into your bank account** - scan the QR code to learn more).

Advisory group members will be paid £25 per hour.

WHAT WILL I HAVE TO DO ?

We would like your help with:

- **Aim 1**: understanding patient and public opinions on using big data and AI methods in epilepsy research.
- **Aim 2**: working out whether assessments of language and motor skills usually done by a trained researcher or healthcare worker could potentially be done by a computer, using AI.

Some examples of things you might be asked to help with are:

- Planning PPIE activities such as focus groups
- Giving input and feedback at different stages of the project
- Sharing research findings with patients and the public
- Reviewing grant applications or ethics applications, co-writing research papers, presenting
- Designing leaflets for patients and the public.

WHAT WILL I HAVE TO DO ?

- Advisory group meetings will be held online.
    - If you don't have access to a computer or the internet, **please still get in touch** if you're interested. We may be able to help with this.

- Meetings will most likely be three times per year, but this might change depending on the stage the project is at.

- If we ask you to do work for the advisory group outside of meetings, you will be paid for your time.

WHAT SUPPORTS WILL BE PROVIDED FOR ADVISORY GROUP MEMBERS?

Emma will:

- Work together with the advisory group to create a Group Way of Working which will outline shared expectations around respect, participation and behaviour at advisory group meetings
- Deliver any necessary training for advisory group members
- Be available to answer questions during and outside of meetings
- Provide a way for advisory group members to share anonymous feedback and suggestions.

If advisory group members feel they need support outside of the group, they are welcome to reach out to **The Epilepsy Research Institute (ERIUK)** or **Young Epilepsy** to talk about any concerns or make suggestions confidentially.

The Epilepsy Research Institute (ERIUK):

shapenetwork@epilepsy-institue.org.uk

Young Epilepsy:

research@youngepilepsy.org.uk

IS THERE A TIMELINE FOR THE PROJECT?

- This research will be completed over a period of three years and the advisory group will be involved at various points over the three years.

- If you are interested in joining the advisory group, **we will ask you to commit to a minimum period of time**. This will most likely be a year, but Emma will work with the advisory group to figure out what is reasonable, and works best for everyone.

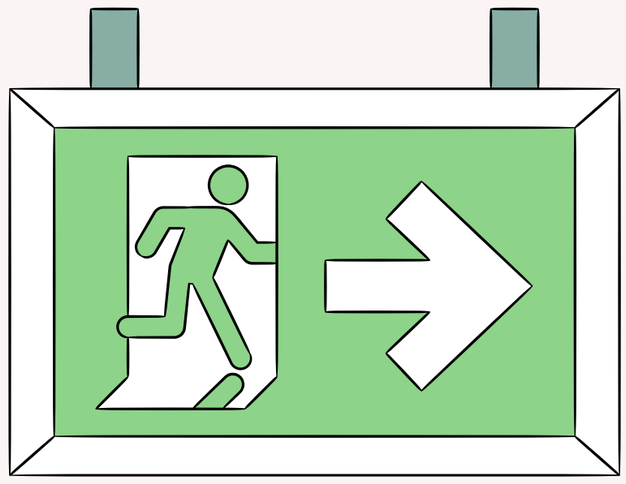
- Emma will also work with the advisory group to decide on the 'terms of reference' for this project. This is a document which outlines the purpose, scope, and structure of the project.

WHAT IF I WANT TO LEAVE THE ADVISORY GROUP ?

- You can leave the advisory group at any time. There will be no negative consequences to your leaving and it will not affect you if you want to get involved in research or PPIE opportunities in the future.

- You will still be paid for any time and input you have given up to the point where you leave, and we will be happy to share research findings with you if you would like.

- You don't have to let us know your reasons for leaving, but we appreciate if you can, as it helps us improve on how we do PPIE work in the future.
    - **For example**, if you're leaving because the format of the meetings doesn't work for you or the time commitment is too much, we may be able to come up with alternative ways of working which fit better with your schedule or working style.



HOW DO I JOIN?

- If you are interested in being part of the advisory group, you can contact Emma by email at: **emma.casey@kcl.ac.uk**




- You will be asked to fill out a short application form telling us a bit about yourself and your reasons for getting involved.

- We can then let you know if this project is a good fit for you.

If you have any more questions or would like to join the advisory group, please contact Emma at:

emma.casey@kcl.ac.uk