**<u>Role Profile and further information for the HDR-UK's DATAMIND research hub,
Patient and Public Research Advisory Group</u>**

The Health Data Research UK (HDR UK) hub 'DATAMIND' supports mental health data research and is seeking to appoint at least 10 Members to sit on a Research Advisory Group. This opportunity is ideal for people who have not had a research advisory role previously – no previous experience is expected or required.

<u>HDR UK Hubs</u>

HDR UK is the UK's national institute for health data science. HDR UK health data hubs work with a range of organisations to support safe and secure use of health data so that it can benefit patients, the population, the NHS, and society. Using health data for research helps us understand diseases and health conditions better, such as understanding their causes and symptoms or knowing how many people are affected. It provides new ways of identifying people most at risk of becoming ill, diagnosing diseases earlier, and providing better care and treatment. And it helps health services to run more efficiently and effectively, so everyone can get the care that they need.

<u>DATAMIND</u>

DATAMIND, one of the newest of the health data hubs, focuses on mental health research. It is funded by the UK Medical Research Council and led by teams from Swansea University and King's College London, with contributions from research groups across the UK. It will support mental health research by providing a central index of relevant data, so researchers can find and use mental health data to benefit patients and the public and improve care. It will also develop methods to use mental health data in secure and better ways. Its ultimate goal is to support research to improve people's lives and help prevent mental ill-health. More information can be found at https://www.hdruk.ac.uk/helping-with-health-data/health-data-research-hubs/datamind/

Professor Ann John, Co-Director of DATAMIND, said: "We're really excited about DATAMIND. By working together with the public, patients, researchers, industry, and the NHS, we will transform both our understanding of mental health and the lives of people experiencing mental health problems. We will create a hub where researchers and others can find and use mental health data to benefit patients and the public and improve care."

<u>Overview of the role</u>

The Hub would like to work with people with personal experience of mental health illness, or those who care for people with that experience. We'd like your help to develop ways that universities, the NHS, the charitable sector, policy makers, industry, and others can work together to use mental health data in a "FAIR" (findable, accessible, interoperable, and reusable) and secure way. Your advice and views will help shape how the Hub works and may contribute to development of "best practice" guidelines for using mental health data.

This role will give you the chance to contribute to a major project that seeks to improve mental health healthcare. DATAMIND will only be successful if the public and patients have trust and confidence in the use of health data for research and innovation. It is important that we strike an appropriate and safe balance between the benefits and the risks of this work. We can only do this with your help to make sure the projects are in the best interests of people affected by mental health conditions.

We will try to get a mix of different types of people in the Research Advisory Group in terms of age, gender, background, region, and so on. Applications from younger people and

people from minority groups are particularly welcome. This opportunity is ideal for people who have not had a research advisory role previously – no previous experience is expected or required.

Role requirements

In this role you will be required to attend and actively participate in Research Advisory Group meetings. You will:

- Have a personal experience of mental health illness, or care for a person with that experience
- Prepare for and attend meetings (either a morning or an afternoon session, primarily on a weekday), via Zoom, using a laptop, computer, or tablet. Preparation includes reading the information we send in advance and thinking about some key questions. Should you be unable to Zoom from home, it is possible the DATAMIND Hub can organise a place for this to take place (such as a booked room in a local library).
- Attend meetings which will usually last for 1-3 hours approximately every 3 months. These meetings may be for the whole research advisory group, or there may be opportunities to be part of a smaller focussed project group. Some of the groups may require more regular commitment. We do understand that not everyone will be able to make all the meetings. Members will also be welcome to attend meetings of the whole DATAMIND team should they wish.
- Take part actively in additional meetings as required, and/or take part in correspondence and decision-making by email, to ensure that decisions are made in a timely manner.
- Contribute in a constructive and thoughtful manner to give your opinion, advice, and perspective as a patient or carer.
- Take part in training and other meetings and events as agreed in advance.

Experience and Skills

We're looking for people who:

- are or have been affected by a mental health illness, either personally or through a close family member/friend, and want to use their experience to influence and inform our work;
- have an interest in mental health research that uses health data, and a willingness to learn more about the role of research and data in improving health and healthcare for patients and the population;
- have good communication skills, including the ability to give constructive feedback (either written or verbally);
- understand that participants will share a range of experiences;
- respect the views and opinions of others, even when they don't agree;
- can consider the needs of a broad range of people affected by mental health conditions;
- have an open mind to explore new and challenging ideas;
- can maintain confidentiality;
- are from a diverse range of backgrounds and experiences: we need people of all ages, from different communities, ethnicities, regions, nationalities, and work/educational experience.

You do not need to have:

- any prior knowledge of the work we do;
- any previous Research Advisory Group experience;
- an understanding of research or health data;
- a scientific understanding of mental illnesses; or
- any prior knowledge/use of zoom meetings.

We need a mix of thoughts and opinions – all we ask is that you are respectful of the views of others and are interested in this area of work.

Training and Support

We will support you to carry out the role by providing:

- a guide on how to use Zoom, with a run-through before the first meeting if you'd like;
- an induction meeting over Zoom;
- an assigned key contact within the DATAMIND team who will provide you with relevant information and will be available to answer any questions;
- ad-hoc training as required or desired by you to fulfil this role;
- the information you need, two weeks before meetings;
- a safe and open environment for feedback, so that you can share your views about how the panel is working, compare your insights and perspectives with other panel members, and suggest improvements.

Basic facts

Length of Role

- Minimum of 12 months, up to 3 years. The project will last for 3 years in the first instance, but we appreciate that not everyone may wish to commit to this length of time.

Location

- Meetings will be held online by video conference (Zoom) in the first instance. We hope that in the future there may be an option for people to attend in person should they wish (these will be hybrid meetings so people can either attend in person or continue on zoom). Should you be unable to Zoom from home, it is possible the DATAMIND Hub can organise a place for this to take place (such as a booked room in a local library).

Time Commitment

- Due to the nature of the role, meetings will primarily be held on weekdays, sometime between 8am and 5pm, although there may be the opportunity to hold some of the meetings outside this time. We expect each meeting to last 1-3 hours approximately every 3 months. These meetings may be for the whole research advisory group, or there may be opportunities to be part of a smaller focussed project group. Some of the groups may require more regular commitment. We do however understand that not everyone will be able to make all the meetings. Members will also be welcome to attend 'whole Hub' team meetings should they wish.
- Please note the RAG and DATAMIND staff will set the terms of reference for the group. Unfortunately, participants who don't adhere to the group's ways of working may be asked to resign.

Honoraria and Expenses

- This is a voluntary position but remuneration to cover attendance at meetings and reviewing documents at rates set by NIHR Involve may be claimed (further info at: https://www.nihr.ac.uk/documents/payment-guidance-for-members-of-the-public-considering-involvement-in-research/27372
- It is important you consider what effect this may have on your tax or benefits. You can choose to decline payments for any reason. We will need you to complete a simple/brief claim form. Payments may take some time to be processed.
- We will refund reasonable travel where agreed in advance.

Application Process

If you are interested in this role, please see 'how to apply below'.

Successful applicants will be invited to an induction meeting over Zoom. This will be a chance for you to:

- understand more about the role of HDR-UK and the DATAMIND Hub;
- understand more about your role within the Hub;
- meet some of the DATAMIND staff;
- get to know the other panel members;
- ask any questions you may have.

How to apply

I'm ready to apply: Please fill in the application form with your expression of interest and send to Linda Jones, Patient and Public Coordinator for the DATAMIND Hub, at laj28@cam.ac.uk. The closing date for applications is 5pm on Friday 10th December 2021

I still have some questions: Please get in touch if you have a question or aren't sure whether to apply. In the first instance please email Linda Jones, Patient and Public Coordinator for the DATAMIND Hub, at laj28@cam.ac.uk, who can arrange a call or Zoom meeting.

What happens next?

We'll look at all the applications we receive and decide who we will invite to interview for the role. We will do this based on the answers you give in the application form, so that we have as diverse group as possible. We understand that some people may have difficulty with these questions because of problems such as dyslexia or because they have no previous experience. Please let us know if that's the case. Informal zoom interviews will take place after the closing date.

Equal Opportunities Policy Statement

We are opposed to all forms of unlawful and unfair discrimination. All volunteers and employees who work for us will be treated fairly and will not be unfairly discriminated against on any of the above grounds. Decisions about recruitment and selection, training or any other benefit will be made objectively and without unlawful discrimination.

Thank you for taking the time to read this DATAMIND Research Advisory Group advert.