## Lived Experience Advisory Panel – Recruitment Advert

We are seeking people who self-identify as having personal lived experience of depression, to join our Lived experience Advisory Panel (LEAP). The LEAP will oversee and provide lived experience perspectives to a large research project called AMBER.

To help you decide whether or not you’d like to join the LEAP, please read through the attached information. If you have any questions about the LEAP, the research, or your potential involvement, please contact me [email address] and we will answer your questions to the best of our ability.

[a few sentence biography to introduce the key contact person / chair of the LEAP]

Although this role is considered ‘voluntary’, you will be offered payment for your time and expenses (see attached)

**The brief application form can be found at: [insert link]**It is designed so you can tell us as much or as little as you feel comfortable with.
**The closing date for applications is [date].**

Best wishes

[name]
LEAP Chair

**What does AMBER mean?**

AMBER stands for Antidepressant Medications: Biology, Exposure & Response.

Although antidepressants are one of the most prescribed medications, and clinical trials have demonstrated they are effective; we actually have very little understanding of how they work, why they work and who they might work for.

**Who is conducting the research?**

The AMBER project is led from Kings College London (Professor Cathryn Lewis),
but also involves researchers at The University of Edinburgh (Led by Professor Andrew McIntosh and Professor Sue Fletcher-Watson) and The University of Queensland (Australia, Dr Sonia Shah).

The LEAP will be led from University of Edinburgh.

**What is the research about?**

The AMBER project will use Big Data science, genetic and genomics (DNA) and cell-based models to investigate how anti-depressants work and how we might make prescribing more personalised in the future. But they cannot and should not do that research without the input and guidance of people with lived experience of depression.

AMBER is particularly interested in personalised medicine – finding the best treatment for an individual, rather than just a ‘standard pathway’ applied to all. They are interested in questions such as:

* What is it about a person’s genetics that makes them more or less likely to respond to a particular antidepressant?
* Are there any blood makers or other clues that might help us predict whether someone will or won’t respond to a particular anti-depressant?

This kind of ‘bespoke’ treatment is already used in some cancer therapies.

**What is the purpose of the LEAP?**

The purpose of the LEAP is to ensure that the AMBER project is carried out in collaboration with people with lived experience of depression and that lived experience perspectives are considered in all project decision-making.

## Who are we looking for?

We are looking for people who self-identify as having personal lived experience of depression. You do not need to have a formal diagnosis of depression; what matters to us is that you identify as having experienced depression yourself.

We do not have any set criteria that we are recruiting against. We will look at each application on its own merits. Overall, we are aiming to recruit 10 members to the LEAP and will be looking for a diverse group of people, who can feed give a range of perspectives to the project. (You may wish to bear this in mind when completing the application form – but please only write what you are comfortable with us knowing).

You do not need any previous experience of working with researchers or universities (although we expect that a few members of the LEAP will have this, and we will again look for a mix of experiences).

We are happy to accept both individuals and those who represent charities or organisations. However, the person that attends LEAP meetings must have personal lived experience of depression themselves.

## Details about the role

### What is the role and what is it for?

**The LEAP will oversee the entire programme of research and meet every 6 months to discuss priorities and to ask questions of the researchers.**
*[Training on this will be provided and the LEAP can prepare questions and discussion topics ahead of these meetings]*

To give some examples: Some decisions are tricky from an ethical perspective (accessing health records, or production of cell lines from living people); others require interpretation e.g. what does it mean when the data shows someone has changed anti-depressant several times, or what exactly is ‘difficult to treat depression’. Others involve choices e.g. which lifestyle factors should we be paying most attention to and which are less relevant?

**The LEAP will be chaired by a [name and brief descripton of them e.g. salaried or volunteer, role at university/other relevant organisation].** He will represent the LEAP at leadership meetings and help ensure that lived experience perspectives are included in all decision making and keep the LEAP up-to-date on all progress within AMBER.

**Each LEAP member will be offered the opportunity to take on a ‘focus roles’ (Data Science, genomics, or cell lines)** and receive subject specific training and support from our Training Manger. The LEAP member will then meet with the relevant researchers a few times a year and bring that knowledge back to LEAP meetings.
This part of the role is optional.

**The LEAP will also oversee and co-produce a set of patient engagement activities** (events, hands-on activities, online tools and resources, social media campaigns etc) in collaboration with our Knowledge Exchange Officer, Dr Iona Beange. This will help us reach communities who are not usually part of academic / research conversations.
We have budget set aside for these activities, that the LEAP will decide how to spend.

We will produce a bi-annual ‘You Said, We did’ email to show how the panel are influencing the overall AMBER project.

### What is the time commitment required?

* **The LEAP will meet online for approximately 2 hours, and at the start of the project these meetings will occur** **approximately every 3 months.**
**Attendance at these meetings is the minimum requirement for LEAP membership.**
The exact length and frequency of these meetings will be flexible and may shift across the course of the project. Early on in the lifespan of the LEAP these meetings may be more frequent as we get things up and running. The day / time of these meetings will be discussed and agreed with LEAP members, to make them as convenient as possible. NB: They may be in the evening or at weekends. You may be asked to read something in advance of these meetings / do something after these meetings. We do not anticipate this prep work taking longer than 1 hour in total.
* **Annual meeting with each LEAP Chair (1 hour)**
This 1:1 meeting with [name] is an opportunity for you to tell us how we can best facilitate your participation in the LEAP. It is also an opportunity for you to mention any skills that you would like to develop (see below) and any changes we should make to our processes.
* **LEAP members will be invited to take a ‘focus role’ linked to a specific element of the research (e.g. Data science, genomics, or cell lines). [Optional]**
If you choose to do this, it will involve additional time reading materials and meeting with researchers (estimated 5-15 hours per year). You will also be offered relevant internal and external training. As above, we will cover your time and expenses.
The details will be discussed and agreed and may look different for each person.
* **LEAP members will be invited to attend /participate in our annual in-person whole project meetings (2 days) [optional].** In 2025 this will be in Edinburgh.
Future meetings may be in London.
* **Personalised Participation / skills building**
If you are selected for the LEAP, we will take time to understand your interests and discuss options for skill development. If there is something you would like to learn, we will do our best to accommodate that (for example communication or social media skills, finance/budget management or participating in interview panels). These opportunities will take additional time and may be voluntary (unpaid).

### When will the work take place? LEAP membership will begin in Summer 2024, and members will be invited to continue participation until Summer 2028, when the AMBER project ends.

However, no-one can predict the future, and we understand that LEAP members may need to pause their participation or leave the LEAP altogether during that time.

### How much is the financial compensation for this role?

**LEAP Meetings:**

* You will be offered a fixed sum of £65 to cover attendance at online LEAP meetings and preparation (e.g. time to read a document) beforehand. This will be paid into your bank account after each meeting that you attend.
* You will be offered £30 for your annual meeting with our co-ordinator [name] (see below).
* The anticipated total is therefore £290 per year. However, this may increase or decrease depending on the frequency of meetings that you attend.

**Additional Ad hoc hours (optional)**

* If you agree to do additional activities (follow something up after a meeting, attend training, speak to a researcher etc), you will be paid for that time too.
The total number of hours and amount of payment will be agreed in writing/email before you begin.
* There is no obligation to undertake additional work.

**Payment rates**

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| --- | --- |
| Up to 30 minutes | No payment |
| 30mins – 2 hours | £30 |
| 2-4 hours | £60 |
| 4-6 hours  | £90 |
| All day meeting  | £150 |

**What if I can’t accept payment?**

We recognise that there are many reasons why people may be unable or would prefer to receive payment. It is your choice whether you accept the payments or not, and you can make a different choice each time it is offered (i.e. accept it for one activity but not another).

Payments from us will be treated as earnings and may be subject to tax and national insurance / make you eligible to complete an annual tax return.
Payments may also impact your benefits.
Financial situations can be complex and are based on personal circumstances.
Please seek personalised advice from relevant experts e.g. your local benefits advisor, an accountant or tax advisor, [Citizen’s Advice Scotland](https://www.cas.org.uk/), [Disability Rights](https://www.disabilityrightsuk.org/) UK or [Turn2Us.](https://www.turn2us.org.uk/)

If you would like to discuss alternative options for receiving payment (e.g. a smaller amount or a training course or book instead), you can let [name] know in your 1:1 meeting and we will do our best to accommodate requests.
*Please note that while we can provide gift cards, these are treated the same as money by HMRC / Benefits office.*

If you choose not to accept payment, the money will remain in the AMBER Patient and Public Involvement budget and be used to support our other activities.

**Out-of-Pocket Expenses**

* We will cover all reasonable expenses, so that you can fully participate in our meetings. This may include (but is not limited to) contributions towards internet access and childcare/other carer’s expenses.
* If we ask you to come to an in-person meeting, we will cover the cost of your travel and other out of pocket expenses.
* You can always claim expenses – whether or not you decide to accept payment for your time. These are two separate items. Claiming expenses does not affect benefits / HMRC tax liabilities.
* You will need to keep hold of receipts or other evidence for claiming expenses.

###  Who else is involved in this project?

* The Psychiatric Genomic Consortium and DataMind are also involved as partners in AMBER. These are research consortiums = groups of researchers who agree to work together towards a common purpose, in this case, better use of data for health research.
* The research is funded by The Wellcome Trust, a UK charity dedicated to improving health through research.

### What are the benefits of taking part?

* Gain insight into the research process and interact directly with researchers.
* Influence how this project is done, including what might happen next, and shape the knowledge of the researchers involved
* Gain confidence speaking out and being able to communicate your point of view.
* Opportunity to gain additional skills (in areas such as communication or social media, finance/budget management or participating in interview panels).
* Those who undertake a focus role will gain knowledge in a particular field of research, and if keen to do so, may undertake courses to gain SCQF credits (or equivalent).
* Opportunity to be a Co-author on our journal paper(s) about establishing and running a Lived Experience panel.

### What type of working conditions can you offer?

* Our meetings will mainly take place online, to reduce the travel and time burden.
* We are happy to discuss accommodations, but here are a few things that we will do as standard:
	+ Take regular breaks
	+ Option to be sent a small catering / stationary pack through the post.
	+ Use of chat function to allow for those who prefer to contribute in-writing
	+ Circulate the agenda in advance (although we may occasionally deviate from it if conversations are headed in a productive direction)
	+ Option to contribute in-writing or voice notes before/after online meetings.
	+ Cover out-of-pocket expenses, including internet vouchers or childcare if needed.
	+ Discuss the use of technology and be willing to try new platforms / options (or not!) according to the preferences of the LEAP.
* When we meet with you 1:1 we will establish the best ways to support and communicate with you and create an individualised plan (e.g. what should we do if you disappear in the middle of an online call or stop replying to our emails? Would you like a text reminder the day before our meetings?).
* Although online meetings and emails do not suit everyone, for this project we have decided that this is the best method for regular communication with the LEAP.

## Where can I find more information?

* **[name and contact details]**
* **[project website link]**

## How do I apply?

You can access the application form on Google Forms at: [link]