

Invitation to join a Lived Experience Advisory Group for a research project looking at TMS

Introduction

We are forming a Lived Experience Advisory Group (LEAP) to help Professor Richard Morriss undertake his research study. The details below refer to the 'public contributors' who will form the LEAP. By 'public contributor' we mean a service user or carer who brings their lived experience of managing depression to the task of improving the research project.

If you would like to apply to join this group, please contact peter.bates@ndti.org.uk.

Context – why do we engage public contributors?

The evidence¹ shows that research teams that seek advice from patients and the public do better work.

Organisations that provide funding for health research usually provide guidance about way in which health researchers should seek advice and guidance from patients and the public. There is a particularly rich resource available at Involve², which is part of the National Institute for Health Research.

Description of the research project

Depression is the second leading cause of disability worldwide and the third biggest killer in people aged 15-44 years. Antidepressants and talking therapies help two thirds of people with depression, but the remaining one third have 'treatment resistant depression'. Until recently, a few patients with treatment resistant depression were offered ECT but they sometimes refused this treatment due to its possible side effects, such as memory loss. A newer alternative treatment called transcranial magnetic stimulation (TMS) has recently been used employing magnets and not requiring an anaesthetic.

In December 2015, the National Institute for Health and Care Excellence (NICE) reviewed the evidence for TMS and advised that it may be used to treat depression. NICE reports that TMS is safe and effective in reducing symptoms for a short while and has asked for further research to be carried out.

Patients with depression experience changes in some parts of the brain. If the magnetism is targeted precisely to these specific parts of the brain, it may avoid unwanted effects and improve the outcome. In this research trial we will use a brain scan to pinpoint the specific point in the brain where we should deliver the magnetic pulses and then compare two kinds of TMS.

¹ http://www.invo.org.uk/wp-content/uploads/2011/11/Involve_Exploring_Impactfinal28.10.09.pdf

² <http://www.invo.org.uk/>

Once an eligible patient with treatment resistant depression has seen a doctor, they are invited to provide written informed consent and will be given a comprehensive clinical assessment from a researcher. Some pen and paper tasks are given to rate their symptoms, day to day function and memory. Following the assessment, they will have an MRI brain scan which may last up to 45 minutes. The researchers will analyse the scan to identify the brain regions that could benefit from the treatment and a week later the patient will start the treatment.

Patients will come into the clinic for a 45-minute treatment every weekday for four weeks. After the treatment, most people feel able to drive, go home or go about their business. After the treatment course is completed, they will be reassessed using the information gathered at the first assessment and will have another MRI scan at 16 weeks to observe any changes. There will be further follow up assessments of symptoms at 8, 16 and 26 weeks, comparing with the first assessment. They will be asked their views about the treatments and side-effects.

The research will be carried out in four centres - Nottingham, Northampton, Newcastle and London. We will set up an advisory group made up of patients, most of whom have already had the magnetic treatment. The research team will have regular meetings with this advisory group throughout the study.

The findings from the study will be presented at scientific meetings and submitted for publication in scientific journals. In addition, a summary of the findings will be presented to local clinicians and service users. We will show the progress of the study to NHS Clinical Commissioners annually and funding authorities as required.

Anonymity will be maintained when results are published so that results from individuals are not identified. The participants in the study will be informed of the overall study results through the advisory group. They will be offered copies of the publications from the study.

The host organisations and the key people involved

This research is a joint project across four areas of England – Newcastle, Nottingham, Northampton and London. Professor Richard Morriss is the Chief Investigator, while Peter Bates will support the LEAP. The study is funded by the National Institute of Health Research and sponsored by Nottinghamshire Healthcare NHS Trust.

The organisational structure

You are invited to join Group 4 in the table below.

Group 1	Patients with depression who will receive the treatment we are testing.
Group 2	Staff who provide the treatment
Group 3	Researchers who find out if the treatment is working
Group 4	Lived Experience Advisory Group who give advice to the Researchers

Dates, times and venue for meetings

During 2018, LEAP meetings will be held in Nottingham on Thursdays from noon to 3.30pm on the following dates: 14 June, 13 September and 20 December. We will provide a free sandwich lunch. The LEAP will continue to meet once every three months until 2021.

The meeting will happen in one of the buildings in the University of Nottingham Jubilee Campus, Triumph Road, Nottingham, and details will be confirmed nearer the time.

We can send you train tickets in advance of the meeting, to reduce your out of pocket expenses. Whilst we understand that a four-year commitment is hard, we hope that people joining the LEAP will make every effort to attend these meetings so that we can work together most effectively.

What will happen in the meetings?

The Chief Investigator, Professor Richard Morriss will attend each meeting, along with other members of the research team. They will give a short presentation that will describe the progress of the research and introduce the discussion topics for the meeting.

As a member of the LEAP, your opinion is valuable. This is a really important opportunity for the researchers to find out what it is like to live with treatment resistant depression. Very often, members of the LEAP bring out new ideas or different perspectives that are helpful to the researchers and change the way that things are done. Even where the idea has been heard before, your experience can bring it to life in a powerful way and make the researchers think again.

What skills or experience do I need?

The most important thing is that you need to believe that this research is worth doing. If you think that the treatment will never help anyone or is so wonderful that there is no point studying it any more, then the LEAP is probably not the right place for you!

You will need some relevant first hand experience of depression. We hope to form a LEAP that will bring together a variety of perspectives, such as:

- People who have been treated with TMS (four places on the LEAP)
- Relatives or friends of a person who has been treated with TMS (two places)
- People who have lived with treatment resistant depression (two places).

These plans may not work out perfectly, but we hope this gives an idea of the sort of group we hope to form. You are not expected to represent anyone else or any other group or organisation, but rather lend your perspective as an individual. However, if you do happen to know other people living in similar situation, then drawing on their experience too may help the research team.

You do not need to know a lot about how research is carried out when you start. From time to time, the researchers will provide short training opportunities on different stages of the research, so you can gain a better understanding. These are always designed with the group in mind, so should be just right, rather than too easy or too hard to understand.

The group usually signs up to a set of groundrules about how meetings will be conducted. This includes an expectation of courtesy and respect for all, as well as a clear obligation to maintain confidentiality about any personal information. More importantly, you need to be willing to speak out and share your views, as that is why you are there.

It is helpful to have access to a computer so the research team can communicate with you via email. However, other arrangements can be made if necessary.

Support

We recognise that living with depression can from time to time affect people's ability to be involved and so we aim to provide a supportive and flexible environment to accommodate these pressures. LEAP members will be linked to a member of the research team in their local area as well as working with Peter Bates for the national meetings. Do get in touch (peter.bates@ndti.org.uk) if you wish to discuss your support needs.

Are there opportunities outside the meetings?

From time to time, the researchers may send you a document and ask you to comment on it. This is especially valuable when the document is designed for a general audience, and members of the LEAP can check that it is easy to understand and respectful in tone.

We expect that opportunities will arise to get involved in the study in your local area too. There may be opportunities to get involved in other ways, such as by joining in with telephone conference calls or speaking at seminars and conferences. These will be discussed in meetings, and members of the LEAP will be able to choose whether they wish to get involved.

Payment and reimbursement

We are pleased to reimburse your travel expenses, and also offer a participation payment. Travel expenses normally means public transport costs at standard fares

(you will need to provide receipts) or mileage at 45p per mile. You need to agree with us in advance if you have other needs, such as carers costs, meals or you need to use a taxi.

For this particular research study, we can also offer you a participation payment of £60 per meeting, which you can claim or refuse if you prefer. As part of this arrangement, we expect you to read agendas and minutes in preparation for the meetings and participate actively and constructively.

Forms will be provided at the meeting for you to complete and sign. Remember to attach any receipts that you have. We normally make the payment into your bank account about a month after the meeting, although it sometimes takes a bit longer. Do contact us if there are any delays.

You bear the responsibility for keeping the Benefits Agency and Her Majesty's Revenue and Customs appropriately informed about your circumstances.

What to do if you are interested

If you wish to apply for a place on the LEAP, please send an email to peter.bates@ndti.org.uk giving a brief summary of your relevant experience. If there are more than two applicants from any of the geographical areas where the research is done, we will have to choose, and unsuccessful people will be invited to join a wider online group who will be kept informed about the project and may be consulted from time to time. We will make every effort to select people for the LEAP fairly, end up with a diverse group and meet the goals of the research study.