

## Call for Research Volunteers

### **Study title: Visual-spatial updating in patients with congenital and acquired Nystagmus**

We'd like to invite you to take part in our research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please ask us.

### **What is the purpose of the study?**

This study investigates how our brains process what we see in the world around us. In some disorders, the eyes lose the stability and a jumpy movement, called nystagmus, can lead to a blurry vision. However, most people with congenital nystagmus (people born with “jumpy” eyes) usually do not get blurry vision even though the eyes move constantly. This likely means that the brain has a mechanism to stop them from getting dizzy which we would like to understand better.

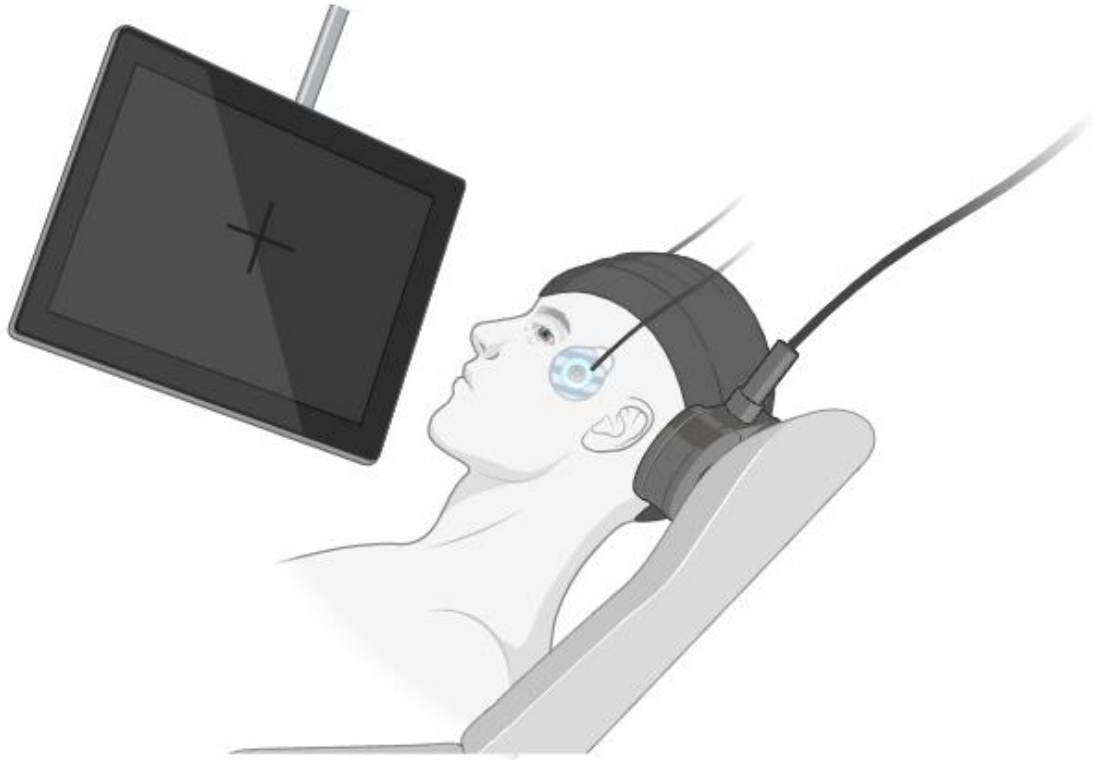
With the results of this study, we hope to understand better the mechanisms behind congenital nystagmus and get closer to creating targeted treatments for those who suffer from dizziness and unsteady vision.

### **Who are we looking for?**

- We are looking for individuals with congenital nystagmus, also known as infantile nystagmus, to volunteer. However, this study extends to those with any variant/other form of nystagmus.
- Please see “Common questions” for information regarding to specific participant criteria.

### **What should I expect?**

- The examination takes between 45 to 60 minutes, with only 1 visit required at Charing Cross Hospital
- You will be tested while laying down on a hospital bed with a touchscreen roughly 30cm in front of you.
- Small electrodes will be placed on the skin around your eyes to measure your eye movements.
- A magnetic pulse (Trans-cranial magnetic stimulation, in short “TMS”) will be elicited over the back of your head. This will make a small blurry light appear in front of your eyes.
- You will be asked to click the screen in the location where you saw this light.



### **Will my taking part in the study be kept confidential?**

Information regarding study protocol, data acquired, and patient information will be anonymized and kept securely on-site under lock.

Responsible members of the Imperial College Healthcare NHS Foundation Trust may be given access to data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

### **Will I be reimbursed for taking part?**

The cost of travel will be covered. This includes local transportation, unfortunately we are not able to cover if you are coming from further away or for an overnight stay.

### **Common questions**

- The procedure is not painful, but you will feel a twitch in your neck muscles from the magnetic stimulation which some people find unpleasant. If needed, we can always have a break in between the sessions.
- Phosphenes are transient flashes, there is no long-lasting effect of this study.
- You can always withdraw from the study if you change your mind, without giving a reason.
- Participant suffering from epilepsy cannot partake.
- For participants with metal implants, prosthetics, cardiac pacemakers, or metal work, please let us know when contacting to ensure compliance with our TMS equipment.
- Family members/company may be allowed to accompany you to the lab.

**If you are interested to join or would like further information, please contact:**

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