



UNDERSTANDING AND ASSISTING DIFFICULTIES IN EVERYDAY NAVIGATION



INVITATION

We invite you to take part in a study exploring the skills that underlie finding your way around, also referred to as **navigation**. Navigation is our ability to know where we are, to remember where we have been, and to plan how to get from one place to another. Some people with hydrocephalus can struggle with these abilities and we would like to explore why – this is the first step towards helping people to improve. If you decide to take part, you will be invited for 4 sessions to complete some navigation and reasoning tasks. Each of these sessions will last around 1 and a half hours. To thank you for your time, you will receive an Amazon voucher of £8 for each hour of your time with us. Deciding whether to take part is completely up to you.

Please note: in order to take part you must have access to two types of devices:

1. A computer or laptop with a camera and microphone
2. Android or Apple smartphone or tablet (note that Microsoft phones/tablets are not compatible)

In addition, you must be 18-65 years old, fluent in English, and have normal or corrected-to-normal vision (normal with glasses or contact lenses), not have an ongoing psychiatric illness, not have a history of head injury or neurological conditions (other than hydrocephalus or spina bifida), and not have alcohol dependency or recreational drug problems.

If you would like to find out more, please contact the researcher using information below:

Dr Tara Zaksaitė

Telephone: 01752584811

Email: tara.zaksaitė@plymouth.ac.uk

Address: School of Psychology, University of Plymouth, Drake Circus, Plymouth PL4 8AA

Please note that this research is a collaboration between Dr Tara Zaksaitė, Dr Alastair Smith (University of Plymouth), Prof Catherine Loveday (University of Westminster), Dr Trudi Edginton (City, University of London), and Prof Hugo Spiers (University College London), who are not part of the NHS or the hydrocephalus clinic. This research is funded by the ESRC.

If you are dissatisfied with the way the research is conducted, please contact the researcher in the first instance: tara.zaksaitė@plymouth.ac.uk; Chief Investigator in the second instance: alastair.smith@plymouth.ac.uk. If you feel the problem has not been resolved please contact the secretary to the Faculty of Health and Human Sciences Ethics Committee: hhsethics@plymouth.ac.uk, 01752 585339.



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PARTICIPANT INFORMATION SHEET

IRAS ID: 256557; Date: 26/01/2021; version 4

We invite you to take part in research exploring **navigation**. Navigation is our ability to know where we are, to remember where we have been, and plan how to get from one place to another. Some people with hydrocephalus can struggle with these abilities and we would like to find out why. If you would like to take part, and you meet the study criteria that are listed below, we will invite you to attend four sessions, each lasting around 1-2 hours, held entirely online via software called Zoom. To thank you for your time, you will receive an Amazon voucher of £8 for each hour of your time with us.

Please note that to take part in this research you must:

- have access to a computer or a laptop with a microphone and a video camera
- have access to an Android or Apple smartphone or tablet (note that Microsoft phones/tablets are not compatible)
- be aged 18-65 years old
- be fluent in English
- have normal or corrected-to-normal vision (normal with glasses or contact lenses)
- not have a psychiatric diagnosis
- not have a history of head injury or neurological conditions (other than hydrocephalus or spina bifida)
- not be dependent on alcohol or drugs.

What will be expected of you as a participant?

In the four sessions we will ask you to do a series of tasks. They will be of the following types:

- Computer tasks: learning where an object is located in a circular area over a series of trials
- Tablet/iPad tasks: judging which out of three objects is closest to a chair, a wall, or which object changed position; navigation-related game

in which you will be asked to steer a boat in search of sea creatures; pressing buttons on the screen in a demonstrated order

- Learning and reasoning tasks: remembering a series of words over a period of time, remembering sequences of letters and numbers and recalling them in order, providing the best route on a map to reach a goal location, reading words aloud, finding simple shapes within complex figures, and mentally rotating an object
- Questionnaires: we will also ask you to fill in some questionnaires on your experience of hydrocephalus, navigational ability, and your general habits and feelings. Your answers will be recorded on paper or with the use of recording devices, with your permission. You will not have to answer any questions you don't wish to

Some of these tasks you may have done before and others will be new to you. Regardless of how well you do, your data will still be very useful to us. There will be plenty of opportunities for breaks between tasks, and you can take the sessions at your own pace.

You can stop the study at any time, without giving a reason and with no consequences – just let the researcher know you would like to leave the study. If you change your mind about taking part in the study after the study is finished, you can ask for your data to be destroyed up until two months after participation.

This study has been approved by the NHS Health Research Authority Ethics Committee on 17/06/2019. This research is funded by the ESRC and the sponsor for this research is University of Plymouth.

Thanks for taking the time to read this. You can find out further about how we use your data on the next page.

Dr Tara Zaksaitė: tara.zaksaitė@plymouth.ac.uk 01752 584811

Dr Alastair D. Smith: alastair.smith@plymouth.ac.uk 01752 584869

Dr Trudi Edginton: Trudi.Edginton@city.ac.uk 02070 408558

Prof Catherine Loveday: C.Loveday@westminster.ac.uk 02079 115000

Prof Hugo Spiers: h.spiers@ucl.ac.uk 020 7679 7553

This project is funded by:

Our partner institutions:



FURTHER SUPPORTING INFORMATION

Confidentiality

The information we collect will be confidential, which means that only researchers directly associated with the project will have access to your data. Personal information, as well as any data you provide, will be stored either in a password protected computer location and secure university online drives (electronic) or placed in a locked cabinet (paper). Confidentiality will only be broken in exceptional circumstances where there is a risk of harm to you or others.

Anonymisation

Your data will be pseudo-anonymised which means that immediately after study completion, your data will be assigned a code by which your responses will be identified. Any personal information that is collected, such as your name and email address, will be stored separately from your responses in the study. Your data may be submitted for publication, presented at conferences, and used in relevant future research. Quotes about your experiences with navigation may also be included in these publications. However, none of these data will be associated with any identifying personal information.

How we use your data

We will use your data for research and scientific purposes only. Your anonymous data will be made publicly available, for scientific transparency purposes, but none of your personal identifying information will be shared with anyone outside of the research team. Your responses about your condition and experiences with navigation (recorded on paper or using recording devices) will be securely stored for 10 years following publication, at which point they will be destroyed. Consent forms will be kept for at least 10 years following publication, for scientific archival purposes, however your contact details will be destroyed within a year of the end of the project (expected date: 31/03/2022). If you indicate that you would like to hear from us about similar studies in the future, your contact details will be stored for up to 10 years for this purpose. You can find out more about how we use your information by contacting the University Data Protection Officer (at: dpo@plymouth.ac.uk) or by simply visiting the following websites:

- <https://www.plymouth.ac.uk/your-university/governance/information-governance>

- <https://www.plymouth.ac.uk/your-university/governance/information-governance/privacy-notices>,

Withdrawing from the study

Remember that you can stop the study at any time, without giving a reason and with no negative consequences. Just let the researcher know if you would like to do so. If you withdraw within two months after you have taken part (31/03/2021), all of your data we have collected up to this point will be deleted. However, after this date you will no longer be able to withdraw your data.

Risks and benefits

There are no expected risks or direct benefits to you in taking part. However we expect that, in time, this research will inform strategies to help people improve their navigation. This will not only help people with hydrocephalus, but also other groups of people that struggle with everyday navigation.

Breaks

The researcher will offer you the opportunity to take a break after every different task, and this can be as long as you would like it to be. There is no pressure for you to perform as fast as you can, and you can take the study at your own pace. If you need an additional break, just let the researcher know.

Complaints and Issues

If you are dissatisfied with the way the research is conducted, please contact the researcher in the first instance (tara.zaksaite@plymouth.ac.uk), and the Chief Investigator in the second instance (alastair.smith@plymouth.ac.uk). If you feel the problem has not been resolved, please contact the secretary to the Faculty of Health and Human Sciences Ethics Committee: hhsethics@plymouth.ac.uk, 01752 585339. You can also contact Patient Advice and Liaison Service (PALS) which offers confidential advice, support and information on health-related matters. There is a PALS office at the Chelsea and Westminster Hospital. Alternatively you can find your local PALS at [https://www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-\(PALS\)/LocationSearch/363](https://www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363) or by calling 111.



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CONSENT FORM

IRAS ID: 256557

Date: 26/01/2021; version 4

Please circle "YES" or "NO" as appropriate:

- Have you read and understood the information sheet dated 26/01/2021, version number 4? YES/NO
- Have you heard and understood the researcher's summary of further information? YES/NO
- Have all your questions about the study been answered satisfactorily? YES/NO
- Have you received enough information about the study? YES/NO
- Do you understand that you are free to withdraw from the study:
 - at any time during the study and up until 2 months afterwards? YES/NO
 - without having to give a reason? YES/NO
- Do you agree to take part in the study? YES/NO

"This study has been explained to me to my satisfaction, and I agree to take part. I understand that I am free to withdraw at any time."

Signature of the Participant:

Date:

Name (in block capitals):

"I have explained the study to the above participant and he/she has agreed to take part."

Signature of researcher:

Date:

Name (in block capitals):



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DEBRIEF FORM

IRAS ID: 256557 Date: 18/04/2019; version 3

Thank you for taking part in our research project, which has been funded by the UK Economic and Social Research Council (ESRC). Our aim is to shed light on which factors might contribute to strengths and weakness in daily navigation. We have previously found that some people with hydrocephalus experience difficulty with everyday navigation, and if we can identify the underlying causes then it may be possible to develop strategies to help them. In this stage of the research we invited people with hydrocephalus to complete a variety of tasks. Some of those were standard measures of vocabulary, learning, and reasoning, and some were specifically related to spatial navigation. Knowing your pattern of performance across this collection of tasks will allow us to compare findings between different people with and without hydrocephalus.

Any personal information obtained during the study will be confidential, and we will keep you informed of the outcome of this research, if you would like us to do so. A summary of the findings of the full project (once available) will be uploaded to our project website, as well as to the SHINE website, a charity for Hydrocephalus and Spina Bifida: www.shinecharity.org.uk. SHINE also provides specialist support for people living with these conditions. If you would like support with your hydrocephalus and/or spina bifida, you can contact them by emailing firstcontact@shinecharity.org.uk or by calling 01733 555988.

Complaints and Issues

If you are dissatisfied with the way the research is conducted, please contact the researcher in the first instance (tara.zaksaite@plymouth.ac.uk), and the Chief Investigator in the second instance (alastair.smith@plymouth.ac.uk). If you feel the problem has not been resolved please contact the secretary to the Faculty of Health and Human Sciences Ethics Committee: hhsethics@plymouth.ac.uk, 01752 585339. You can also contact Patient Advice and Liaison Service (PALS) which offers confidential advice, support and information on health-related matters. There is a PALS office at the Chelsea and Westminster Hospital. Alternatively you can find your local PALS at [https://www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-\(PALS\)/LocationSearch/363](https://www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363) or by calling 111.

We are always happy to discuss any issues raised by the study, so please do not hesitate to contact us using the details below.

Thanks again for taking part.

Dr Tara Zaksaite: tara.zaksaite@plymouth.ac.uk (01752 584811)

Dr Alastair D. Smith: alastair.smith@plymouth.ac.uk (01752 584869)

Dr Trudi Edginton: Trudi.Edginton@city.ac.uk (02070 408558)

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