



Can training with a computer game be used to help young people with visual field loss?

This leaflet provides information for parents and carers

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We would like to invite you and your child to take part in a research study.

Before you decide if you wish to take part we would like you to understand why we are doing this research and what is involved for you and your child. Please read this information booklet and take your time deciding. Feel free to ask us if you would like more details, and talk to others about the study if you wish.

If you decide to take part we will give you a consent form to sign to say that you are happy for your child to take part. We will also give a form to your child to say they agree to take part. We will make sure that if your child does not want to take part that they know they don't have to.

Who are we?

Professor Timothy Hodgson is a professor of neuropsychology from the University of Lincoln. Dr. Jonathan Waddington is a neuroscience researcher from the WESC Foundation, a specialist centre in Exeter for young people with visual impairment. Dr. Cathy Williams is a consultant pediatric ophthalmologist at University Hospitals Bristol.

What is the purpose of this study?

We have made a computer game which might help young people with visual field loss improve the way they use their vision. We would like to ask your child to play this game at home over six weeks, and assess how well they can perform simple searching tasks before and after they have finished playing.

What if I have any questions?

If you have any questions about any aspect of this study, we would really like to help answer them. Also, if you would like an electronic copy of this information you can contact:

Dr Jonathan Waddington (Chief Investigator)
WESC Foundation, Topsham Road, Countess Wear, Exeter,
EX2 6HA
Tel: 01392 454 349
Email: jwaddington@wescfoundation.ac.uk

What if there is a problem?

If you have concerns regarding your rights or your child's rights as a research participant, or wish to make a complaint please contact:

Dr. Patrick Bourke (Chair of the School of Psychology Research Ethics Committee at the University of Lincoln),
University of Lincoln, Brayford Pool, Lincoln, LN6 7TS
Tel: 01522 886 180
Email: pbourke@lincoln.ac.uk

If you have any concerns or wish to make a complaint about the eye tests performed at Bristol Eye Hospital, please contact:

Complaints & PALS team,
University Hospitals Bristol NHS Foundation Trust HQ,
Marlborough Street, Bristol, BS1 3NU

Thank you for reading this and considering taking part in our study

What if new and relevant information becomes available?

It is possible that we will get information about the rehabilitation program or about visual field loss more generally during the time that you are involved in this study. If so, we will let you know as quickly as possible. If the study is stopped for any other reason, we will let you know and the care of your child by your doctor or nurse will continue as normal.

What will happen to the results of the study?

A report of the study results will be completed. The report will be published in scientific journals and presented at conferences for researchers and healthcare professionals. Once the study is completed we will send a summary to you. All results and reports will be completely anonymous and your child will not be identified in any publication or presentation.

Who is organizing and funding the study?

This study is sponsored by the University of Lincoln and the WESC Foundation. It has been funded by the WESC Foundation, the Technology Strategy Board and the UK Medical Research Council. We are recruiting NHS patients from the University Hospitals Bristol and South Devon Healthcare NHS Trusts, and non-NHS patients from schools in the Devon and Torbay area.

Who has reviewed the study?

This study has been reviewed and given a favourable opinion by the National Research Ethics Service Committee North East (Newcastle & North Tyneside 1) and the University of Lincoln's School of Psychology Ethics Committee.

Why have my child and I been invited to take part?

You have been invited to take part in this study because your child is between 8 and 25 years old and has (or is believed to have) a visual field loss.

Do we have to take part?

No, it is up to you whether or not you want your child to take part. Deciding not to take part will not affect the care you or your child receives from your doctor or nurse, now or in the future.

If we decide to take part, what will happen?

If you decide to take part, your involvement in the study will last for approximately 14-16 weeks. During that time we would like your child to spend 6 weeks playing the computer game that we have made. One game session takes 20-30 minutes and we would like to ask your child to complete 30 game sessions over the 6 weeks (approximately 5 days a week).

To play the game, your child will need access to a computer or a laptop at home, and time to play. We will provide you with a diary that you may use to note which days your child plays the game.

We would like your child to visit the eye hospital in Bristol, or another approved research site if you prefer, once so that our doctor (Dr. Williams) can check that their eyes are healthy and measure their vision. We may have to put drops in their eyes, but we will use information from existing records if we have your permission to access them or request a copy.

We would also like your child to visit us at the WESC Foundation in Exeter or at the eye hospital in Bristol if you prefer, on four different days: 1) four weeks before starting to play the game, 2) just before starting to play the game, 3) just after the last time they play the game, and 4) four weeks after the last time they play the game.

We will ask your child a few questions about how they think their eyesight affects their life. We will assess how quickly they can find objects on a table and sort them by their size and shape. We will also assess how quickly they find brightly coloured cards along the walls of a corridor.

The computer game won't be finished when the study is over so we would ask you to return your copy so that we can make a final version of the game that we can give to you in the future.

What are the possible disadvantages and risks of taking part?

The main disadvantages in taking part are travel expenses and the large time commitment involved, although we hope that the game itself is enjoyable to play and not too much of a burden.

We do recommend that if your child has a diagnosis of epilepsy that you check with your doctor whether or not they should be able to play computer games. A small percentage of people with epilepsy are photosensitive, which means that flashing lights or certain colour sequences can trigger seizures.

What are the possible benefits of taking part?

We do not know whether the training will improve your child's functional vision so there may be no immediate benefit to your child taking part. However, improving our understanding and the effectiveness of vision rehabilitation may benefit your child and other young people in the future.

Will I be compensated for taking part in the study?

You will be reimbursed for travel expenses to and from the WESC Foundation to a maximum of £30 per visit but there will be no other compensation for participating in this study.

Will my taking part in this study be confidential?

Yes, all information collected about your child during the research will be kept strictly confidential in accordance with the Data Protection Act. However, we will ask to send a letter to your child's GP and their consultant neurologist to let them know that your child is taking part in the project.

What will happen if we don't want to carry on with the study?

You and your child can leave the study at any time, without giving a reason. This will not affect the care your family receives now or in the future. If you do decide to leave the study, you may also choose to remove your research notes from the study, and we will not collect any more.