

## OK I'm fine with all that, what happens now?

If you are happy to take part in the study, please fill out the attached survey by hand or online.

## What if I don't want to take part?

That's fine, you don't have to do anything if you don't want to take part, just don't fill out the survey.

If you don't want the school to share with us any information about your child, or for your child to be invited to the looking activities session, just let us know by signing and returning the opt-out form attached to the letter.

## SPONSORSHIP AND FURTHER INFORMATION

The project is being funded by the National Institute for Health Research (NIHR). The University of Bristol sponsors the research and holds all the necessary insurance and indemnities. If you would like any further information about the study, please feel free to contact the study manager Anna, her details are below:

Anna Pease  
The CVI Project Study Manager  
University of Bristol  
Oakfield Grove, Bristol, BS8 2BN  
Tel: 0117 331 3310  
Email: [cvi-project@bristol.ac.uk](mailto:cvi-project@bristol.ac.uk)

For more information about this research you can go to:  
[www.bristol.ac.uk/ccah/research/childdevelopmentdisability/thecviproject](http://www.bristol.ac.uk/ccah/research/childdevelopmentdisability/thecviproject)

**FOR MORE INFORMATION ABOUT CVI IN GENERAL YOU CAN GO TO:**

**The Scottish Sensory Centre:** [www.ssc.education.ed.ac.uk](http://www.ssc.education.ed.ac.uk)

**Cerebra:** [w3.cerebra.org.uk/about](http://w3.cerebra.org.uk/about)

**The CVI Society:** [www.cvisociety.org.uk](http://www.cvisociety.org.uk)



**NHS**  
National Institute for  
Health Research

Gloucestershire  
Hospitals **NHS**  
NHS Foundation Trust



# THE CVI PROJECT

How common is Cerebral  
Visual Impairment?

## New Research Study

Your school has agreed to participate in a new research study to try to **understand more about children with visual processing problems**. Children with these types of problems, also known as “Cerebral Visual Impairment” (CVI), have difficulty interacting with the world around them. This can contribute to all sorts of problems including social, academic and behavioural difficulties. We think that very few children will have CVI, and that most of the time it goes along with other diagnoses, so children with CVI are usually already known to doctors. We want to find out if this is true and the best way of finding out who is most at risk of CVI. There are simple strategies for teachers and families that can help children with CVI once their problems are recognised.

### What is CVI and why is it important?

The problem of CVI might be hidden as children can appear to be able to see objects normally. Some may wear glasses, but these don't help with processing problems. This means that **children with CVI might not get enough support** or they might get the wrong kind of support, which is not good for them or a good use of school resources.

CVI can show up in many ways - like being unable to find things on a cluttered page; or avoid bumping into people; or change eye position so as to keep focused on a task. In a young child

this can look like not understanding; clumsiness or poor attention, or as social and communication difficulties. The visual impairment underlying these problems can be hidden and their difficulties are put down to other causes. To make a definite diagnosis of CVI several people need to agree, for example a paediatrician and an ophthalmologist. This is because it is important to compare the child's vision processing skills with what is expected for their age and level of development.

We are conducting this research to estimate how many children in years 1-6 might have CVI and how best we can identify children at risk. Once we know this we plan to do a future study to find out the best way to support them at school. **Our goal is to improve life for children with CVI and their families.**

### Why have I been invited?

Your school has agreed to take part in the study and so we are writing to all parents of children in years 1-6 to ask for your help in finding out who is, or is not at risk of CVI.

### What about confidentiality?

We have used school systems to communicate with you and given each child a study number which will be linked to all the research information about them. We will not store any personal information about children or parents. All the data for the study will be saved on secure, encrypted University of Bristol computers.

### What does taking part involve?

We would like you to complete **no more than 6 questions** about whether your child has any difficulties in their day-to-day life. We'd also like you to answer 5 questions that have been written especially for identifying children with CVI. This can all be done now by filling out the attached form, online, on your mobile device, or by phone. There is a link in the letter to do this.

**Your answers will be kept strictly confidential.** The school will share basic information about the ages and ethnicity of all children in years 1-6 and how many have extra help. Teachers will also complete a standard questionnaire for each child. Individual results on the questionnaires will not be fed back to teachers or parents/guardians.

In the next few weeks a small number of children (about 1 in 10) will be invited to a special **'looking activities' session** (on school premises), to find out more about their vision. If we find out that any child is really struggling with the looking activities, we will send home a letter for you, your child's GP and their paediatrician if they have one. This will explain about any relevant test results and suggest referral to the local Eye Unit or to a high street optician, if appropriate.

### What are the benefits of taking part?

**Any children who we find have vision problems will benefit** if they are able to access treatments or support that helps them. We will give the teachers and school general advice on cheap, simple and effective ways to support children with CVI or other vision problems.

In the long term, the information we get from this study will help us learn more about CVI and how to identify children with the problem. Then teachers can help these children better academically and in their social and personal development.

### What will happen to the results?

The results from this study will be used to estimate how many children in years 1-6 may have CVI and how best to identify children at risk. These estimations will be used to design a larger study testing out the benefits of offering a service to support children with CVI. The results from this study will be analysed and sent to academic journals for publication. We will also present the results at conferences and in magazines and journals for teachers, parents and doctors. All information reported will be unidentifiable. Data will be stored on secure computers for up to 7 years in accordance with the Data Protection Act (1998).