

Cerebral Visual Impairment (CVI) Project Meeting

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Family Faculty: Kirsty, Julia, Anna-Louise, Sally, Kate, Charlie

PenCRU: Sharon, Hannah, Chris

Other colleagues and visitors: Cathy Williams and Anna Pease (Bristol University)

Apologies: Sharon (Family Faculty)

The aim of this meeting was to discuss the method for recruitment of families to the prevalence of CVI study and review the information that parents would receive about the study.

- Chris welcomed everyone to the working group for the CVI research being led by Cathy and Anna from Bristol University.
- Cathy gave an overview of what the CVI research will entail:

The CVI study is being funded by the National Institute of Health Research (NIHR). It will look at how to get evidence that can be spread out not just to the medical profession, but wider, to teachers and families about CVI, the support they can receive and the benefits the support can bring. There are currently pockets of expertise but the aim is to provide evidence to develop equitable policies/services. CVI is a broad umbrella term, some shared themes but big differences between a child's individual abilities.

The pitch for this research was that while children with impaired acuity can have help from a vision support teacher, children who don't have impaired acuity but still have vision problems related to their brains (CVI) cannot. These children have nowhere officially to go. Even for children with impaired acuity, there is still a lack of information about CVI. However, the focus of this research is on the children who do not have impaired acuity but have CVI, as this is the identified clear gap where children are not receiving any support.

There are three aspects to this funded CVI study:

- 1) The prevalence study - finding out how many primary school children might have CVI.
- 2) The impact study - looking at what aspects of a child and families lives are affected by CVI so we can work out what we are trying to improve
- 3) The RCT - Setting up a trial to see whether setting up a service to pick up primary school children with CVI and help them does any good.

Today's meeting focus is the prevalence study which aims to try and estimate how many primary school children have CVI. This is challenging as there isn't an agreed definition of CVI. Once we have an estimate, say 0.5%, then we can start to design a service and a trial to test this service.

Cathy expressed her thanks to attendees for coming to provide feedback on the design of this first part of the overall study.

- Sharon gave an overview of public involvement in research. This working group have been funded to meet four times over the next three years, with some additional input from time to time via email. The objectives for this working group in respect of the research are:
 - o To inform ethics application & recruitment of participants
 - o To measure outcomes that are important to families
 - o To provide 'community validity' to the analysis
 - o To support dissemination of the findings

The objectives for the working group itself are:

- o To provide opportunity for mutual learning
- o To be an empowering experience
- o To be an enjoyable experience

Each individual wrote down their individual expectations for the working group. These will be reviewed at the end of the project to see if they were met or if there were any different outcomes.

The proposed recruitment method for the Prevalence of CVI study

- Cathy described the proposed method:

The design of the recruitment process has been based on other research projects carried out in primary schools that the NIHR has funded. In those studies, rather than contact individual families, the school was recruited and parents were given a choice to opt-out. This approach is important as it is likely to mean higher number of families taking part but it is important that families have enough information to make an informed choice as to whether they wish to participate.

There are two study areas; Southampton and Gloucester and the aim is to recruit five primary schools and one special school (moderate difficulties) from across different social economic areas of each study area (10 in total).

- The group asked about the inclusion of special schools. Cathy has been surprised from her own personal practice how many children with CVI attend mainstream schools so feels it is very important to look at the prevalence and how to support these children. Attendees asked why PMLD schools were not included as their experience showed them that there was a need for CVI awareness and assessment of children with profound difficulties.
- Cathy acknowledged that by excluding PMLD schools, the prevalence estimate would not be for all children but explained that the CVI assessment that is going to be used in this study requires a certain level of cognitive function. Different diagnostic tests would need to be added to incorporate children attending a PMLD school. Cathy will reflect on whether the priority is to get an overall figure for prevalence or to test the particular diagnostic tools.

Once a school is signed up, they will distribute study information sheets which include the opt-out form to all parents of children in years 1 – 4.

Prevalence Study Information Sheet

The group discussed the draft information sheet, key points from the discussion were:

- The inclusion of 'prevalence' in the title was questioned – 'how common is cerebral visual impairment' was preferred as plain language.
- The use of 'brain-related sight problems' was questioned – possibly inferring 'brain damage' could put parents off/be concerning. It was suggested that visual processing or pathways could be more appropriate but not plain language/accessible.
- Referring to a 'small percentage of children may have CVI' was thought better than describing CVI as 'probably rare'.
- It was suggested that the text 'The goal is to develop an intervention that improves mental, behavioural, social and academic outcomes for children with CVI, which may also indirectly bring benefits for all the children and staff in the class' could be clarified and used as the 'hook' to get schools to participate.
- As most people do not separate 'vision' into what the eyes see and how the brain makes sense of the images, in the explanation of CVI it was felt that a clear difference needed to be made between vision difficulties that require glasses (acuity) and visual processing. For example:

CVI means that children have problems interpreting and therefore understanding, or acting upon, things they see. They do not necessarily have trouble seeing although they may need to wear glasses too.

- The group liked the description of CVI manifesting in different ways and thought more could be added to explain the spectrum; different characteristics, severity, types of CVI. Knowing this would help minimise concern if child is selected to attend CVI clinic or is given feedback to ask GP for referral to specialist.
- However, parents also highlighted a concern that in describing the different ways CVI manifests, families may jump onto CVI as the explanation for their child's behaviour/difficulties. Expectations will need to be carefully managed.
- It was felt that it was good to highlight the 'hidden' nature of CVI and that uncovering it, like diagnosing dyslexia, can remove a lot of frustration and create better understanding.
- Be good to advise that data reported will be anonymised so no-one will be identifiable.
- It was suggested that it wasn't necessary to state the location of where the records were held – parents know that schools keep records, so could simply say securely with other records at the school.
- Need to include contact details for further information about the study and links to reputable information about CVI for parents who might want to go and 'google CVI'.
- The schools are to receive money to cover their costs for taking part in the study. We discussed whether telling the parents this would encourage families to take part. The group decided that it was better not to mention the money, as it brought up the question as to why the school was being recompensed but not the families for their time.
- It was recognised a balance had to be struck by avoiding being too long but providing the information that ethics committee will expect/want to see.
- OVERALL it was felt that the information for parents needed to be much shorter, less text and add picture(s).

Questionnaires for Parents

The group then discussed the proposed questionnaires parents would be asked to complete for the study:

- Questionnaires more likely to be completed if parents are a captured audience – ie ask them to complete them at an event held at the school. However, it was recognised that it can be difficult for parents to attend events during day and holding an event after school can be even trickier re teachers being available/childcare etc.
- It was questioned whether it was possible to complete the SDQ over the phone with a researcher? A protocol for this would need to be developed.
- It was also noted that it was important to check if the questionnaires appeared ok on smart phones as many parents may prefer to participate via mobile technology.
- The group felt that it was important to emphasise to parents the different ways they could complete the surveys.
- While some thought the Strengths and Difficulties Questionnaire (SDQ) with its easy tick boxes was quick and simple to complete, others thought that it could cause upset to parents and put them off being part of the study.
- A concern was raised that if parents tick a lot of the difficulties in the tool, what help would they be offered if child didn't have CVI? The SDQ could open floodgates to concerns parents have.
- The majority felt that the SDQ should be completed by the teachers only. If it was necessary to ask parents to complete the SDQ, more information should be added to explain that it is exploratory. The SDQ would not be suitable to use within PMLD school environment.
- However, the majority liked the Dutton and Bax CVI specific questions. It was felt that this would be intriguing to parents and linked more readily with vision difficulties.
- It was suggested that if parents are asked to complete a questionnaire, a comments box should always be offered for parents who feel the need to explain something.
- It was thought appropriate for text messages to be sent out to parents from the schools (eg via Parentmail) to remind them to complete the surveys.

Invitation to clinic and consent form

The group discussed the letter parents would receive if their child was invited to attend the eye clinic to have tests for CVI and the consent forms the parent and child would be asked to complete. Key points from this discussion included:

- The researchers were asked to consider if a familiar adult to the child would be present at the clinic? The school SENCO/teacher or would parents be given the option to attend the clinic with their child if they wanted to? The group felt that having someone familiar to the child in the clinic could then advise if behaviour is atypical.
- The group discussed where was best to hold the clinic. Offering to visit child at home was considered to be the most natural environment but it was agreed that holding the clinic within the school was best. The importance of the clinic being held in a quiet room was emphasised and it was agreed that schools would have to guarantee this at the time they agree to take part in the study.

- Discussion was had about the best time of year to hold the clinics to fit with school terms. It was suggested best to avoid end of term when children are exhausted and cold/flu season (Oct-Feb). However, it was agreed that the latter was difficult to avoid, so better to look at holding clinics on different dates in each school so that children who are off-school can have re-arranged appointments.
- We discussed how best to describe the 'tests' – vision games and looking games were offered as alternatives to vision activities. Although caution was advised in using 'games' as this may raise kids expectations unrealistically!
- Second paragraph could be softer – avoid use of word 'sample' and 'test'. For example
We would like to invite a number of children, including your child, to a 'vision activities' session which will tell us more about how they use the information they receive through their eyes.
- Be good to add in a sentence about how long the vision activities/clinic will take – eg 20 minutes within the school day AND again add in links to reputable information about CVI.
- Also good to include words such as 'simple, fun, interesting' when describing the vision activities. Or add something along the lines of 'the activities will be enjoyable for children'.
- The group asked if the information the clinic collected about the child's general health would be confidential. Would this be shared with the school or is this held by the researchers only – need to make it clear.
- Rather than ask parents to complete additional questions before the clinic, the group asked if it would be possible for these to be asked within the clinic. With the busy nature of family's lives, keeping requests for information to a minimum was considered likely to support recruitment of families to the study.
- It was suggested that the 3rd paragraph from the bottom (starting with 'In order to agree...') should be reordered so that the second sentence goes before the first sentence. Will a paper copy be available for those who prefer not to email or have limited access to internet?
- The group discussed how to remind parents who had not returned their consent forms. The group felt that reminders could go out in school newsletters and individual parents could be sent a reminder once, a couple of weeks after the initial letter is sent out.
- The consent form refers to parents having spoken to a researcher – this isn't available so needs to be removed.
- Child consent form – the second sentence needs to be changed to say 'you and your child can colour or mark the stars when they understand each bubble'. Rather than use 'grown-up' refer to parent and separate out each of the sentences into five separate bubbles. It was discussed whether 'vision activities' sounded fun to a child – 'looking games' was thought to be more descriptive and appealing.

Feedback to parents after child attends clinic

We briefly discussed what information to provide to parents after the child has attended clinic:

- It was agreed that all parents should receive feedback on the results from the clinic.
- For children who do not have any symptoms of CVI this could be a simple slip like school nurses send out following hearing tests in schools – ie *Today (provide date) your child (name of child) took part in some exercises to test his/her vision. No problems were identified.*

- For children who are picked up by the clinic as needing further testing for CVI, it was agreed that it would be useful if parents could be provided with a pro-forma letter that they can take to their GPs to get a referral to local named specialist.

Next steps:

- o Cathy and Anna will be revising the research information and consent sheets and sharing them with professionals (clinicians/VI teachers) for their feedback.
- o Once the revisions have been made, the revised documents will be circulated for final thoughts by email before ethics submission.
- o The next meeting will be held towards the end of 2016/beginning of 2017.