



Cerebral Visual Impairment project

22 November 2017, South Cloisters, St. Luke's Campus

Family Faculty: Anna-Louise, Charlie, Julia

University of Bristol: Anna, Cathy

PenCRU: Chris, Silvia

Other: Emma, Paediatric Occupational Therapist & NIHR Intern (visitor)

The group discussed the prevalence study emerging findings and the forthcoming core outcome measures project about important impacts of CVI, and how to evaluate intervention for CVI.

Prevalence study results

- Cathy presented the main findings from the prevalence study. These will be made available formally when the final analysis has been done and papers published.

School recruitment:

- We were pleased that 11 schools participated. The research team found it challenging to get some mainstream primary schools to sign up to the study. However, schools that did participate in the study were generally committed and motivated.
- Schools were paid to participate in the study; schools received £165 per 30 students for teachers to complete the questionnaires.
- Members of the Family Faculty (FF) suggested that targeting special educational needs coordinators (SENCO) and their communities in schools may improve participation in the future. Cathy and Anna mentioned that in the schools that participated, it was often the SENCO whom they liaised with, and who would encourage the Head Teacher to participate in the study.
- One FF member, who is Governor at both a mainstream school and at a special school, explained how in her experience, income generation is very important for schools. For this reason, she suggests that in the future, communications to schools should explain that they would be paid to participate in the study. The group also discussed the advantages of contacting the school's Chair of Governors for study recruitment.
- To improve school participation in the future, communications to schools about the study should include positive anecdotes collected from the prevalence study, for example explaining how the study was not intrusive and was easy to coordinate. These communications could also include examples of how schools used the money they received for the study as a way of encouraging

participation. Also, an offer of some staff training on CVI may encourage schools to participate in the trial that is a later part of this project.

- Can also include prevalence results and highlight how some children with CVI may be getting extra support but that may not be the right/most effective support and this was revealed by the school taking part in our research.

Parent and child recruitment:

- Only one third of parents contacted to have their child participate in the vision assessments returned their consent forms.

Dissemination of study results:

- Different audiences will have different areas of interest for the results of the prevalence study. For example, schools will be interested to know that 83% of the 52 children identified as 'at-risk' were already receiving additional educational help.
- Targeted channels can be used to disseminate research findings in different formats.
- It is important to note the prevalence study suggested that more parents than teachers reported that a child had problems causing an impact on their behaviours. This information should be shared with schools, and can also be used as a way to empower parents.

Next stage of the study:

- The Family Faculty were keen at previous meetings that special schools be included. A special school has expressed interest to participate. This school has 200 eligible students, however due to concerns around interference in school schedule and lack of staff time to assist in the study, has stated they want to cap the number of children able to have vision assessments to 15, on a first come first served basis. One FF member suggested that she would be willing to help the school if she knew that the money the school raised would go towards the Parent, Teachers and Friends Association. Additionally, visual impairment advisory teachers, mealtime assistants and transport escorts could also help deliver the study in schools.
- The questionnaires to be sent out to special schools in the next stage of the study will be similar to those used in the prevalence study, but will contain a longer version of the 'Dutton questions' for cerebral visual impairment (CVI). It was suggested that this section of the survey offer the option of a free-text box for other comments. Children will be visited at schools so it will be easier to glean context or additional factors that won't be apparent from the survey alone.
- One FF member suggested the questionnaire should include some questions from the Christine Roman-Lantzy questionnaire as this includes questions more relevant to children with additional needs. Anna will circulate the full vision questionnaire being used.
- The group agreed that the study invite for parents should make it clear that CVI can be missed, as parents often focus on the child's 'primary' disability such as autism.
- The group suggested that providing mobile-friendly information and consent forms by email may increase the number of parents sending this document through.
- Anna and Cathy will check how special schools measure attainment for children with additional needs as there seems to be variation among schools using age related targets or P-levels.

Outcomes – impact of CVI

- Outcomes for children with CVI discussed by FF attendees included:
 - Frustration
 - Improved vision

- Better/easier education; receiving more accessible educational resources
- Reading
- Concentration
- Social interactions
- Improved eye contact
- Awareness of what is going on around them
- Communication
- Mobility
- Falling over

Interviewing children

- Anna asked the group how to best approach communicating with children with CVI for the next stage of the study.
- Chris suggested co-creating “a day in the life of” cartoon with the children, so that they can project their experiences onto a fictional character.
- FF members said that many children may not have an understanding of the impact of CVI on their lives, and don’t know how others see to be able to compare.
- Some FF members pointed out that interviewing children may not gather new information, and that conversations may be too guided.
- The group discussed how the interviews would cover broad topics that may or may not be impacted upon by CVI. The research team need to consider this and how they could filter outcomes as likely or unlikely to be related to CVI.
- Emma suggested asking the parent what motivates their child, and what they are drawn to and what they avoid. This may help the research team better interact with the child, however interviews would have to be bespoke.
- The interviewer could focus on environments (“where do you feel happy/calm/sad/angry?”) and use information collected from parents to prompt discussion e.g. If the child does mindfulness at school they could be asked about that.
- One FF member explained that her child with CVI, who goes to a special school, receives an annual review booklet which also includes the child’s perspective. Her son has a one to one session with communications staff at the school to compile this section of the booklet. She agreed to share an example of her son’s booklet with the research team. Some schools may also have child generated information as part of their own systems eg ‘Thrive’ program.
- Another way to gather the child’s perspective could be to observe the child and parent for a couple of hours. FF members have different views on whether they would feel comfortable personally doing this at their home, but agreed this could be done at school.
- The group agreed that it may be useful also to seek the perspective of siblings, as they may have different insights and experiences than parents.
- The group suggested best ways to recruit families to the interviews: offer a range of interview types (face to face, phone, email, skype) at times suitable (e.g. 1 hour after drop off or 1 hour before pick up at school).
- The FF group suggested researchers should focus on how the interviews will help to develop effective interventions for accessing support with CVI, to encourage families to take part.

Next steps

- We are waiting to hear back on ethics approval for the next stage of the research project.

- Cathy will return to PenCRU in spring 2018 to discuss the intervention and what outcomes will be measured. FF can help review progress and discuss refining the intervention, and review documents for the trial.
- FF can also help review the Delphi survey, to make sure the instructions are understandable. This task can be done remotely.