Project Outline:
Eating and Drinking Ability Classification System for Children with Cerebral Palsy

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Children with cerebral palsy (CP) cannot use the range of physical movement available to most of us. Difficulties may occur in the development of walking, speech and hand function. The movements involved in biting, chewing and swallowing are frequently affected. Children with CP who cannot move their mouth muscles to eat and drink efficiently, are likely to have problems eating enough food to grow and to stay healthy. Some of them will have problems with frequent chest infections because particles of food or drink enter their lungs when they swallow. These difficulties continue throughout their lives.

Currently there is no agreement about how to rate the severity of a child’s eating and drinking difficulty, i.e. the child’s ability to move muscles to bite, chew and swallow. The words “severe”, “moderate”, and “mild” are all used without an agreed definition. For some researchers, a “severe” difficulty is when a child cannot feed themselves. Others have mistakenly assumed that only children with more severe general movement difficulties have problems with eating and drinking.

Other scales have already been developed to rate a child’s ability to walk and move (Gross Motor Function Classification System), and to use their hands (Manual Ability Classification System). These are both extremely useful and are increasingly widely used. We have received funding from the NIHR (Research for Patient Benefit) to develop an eating and drinking classification system for children with CP by consulting with parents, children and experts both nationally and internationally.

Once developed, the system will be tested to see how easily and reliably it can be used. There are many benefits to children and families within the NHS and other healthcare systems that would come from such a rating system. They include:

- Increasing awareness of the mouth movements necessary for efficient and safe eating and drinking and distinguishing them from other types of movement.
- Enabling clear and efficient communication about a child’s eating and drinking skills between professionals (e.g. children can fear hospital stays because of misunderstandings that have occurred at mealtimes).
- Providing a method by which limited resources can be directed (e.g. dietitian’s time) to those children with the most severe difficulties, highest risk of malnutrition and therefore the greatest need
- Increasing awareness and thereby reducing the risks to health whenever a child eats or drinks (e.g. particles of food and drink entering the lungs whenever a child eats, choking)
- Contributing to the identification of treatment needs of children with CP (alternative feeding methods, intensive movement therapy to improve skills etc)
• Providing a means to communicate clearly about appropriate formulation of prescribed medication – e.g. not fluids or cannot swallow tablets etc
• Enable the prediction of levels training and experience needed by care staff
• Facilitating research into this area

There are four distinct phases of the project which will take place over approximately 3 years:

• Construct a draft of the initial eating and drinking classification system
• Discuss the draft with a group of invited experts (Speech and Language Therapists, Parents, Young People with CP, Nurses, Paediatricians, Occupational therapists etc) using Nominal Group Process until consensus is reached about the classification system
• Extend the discussion to a wider group of experts (including parents and young people with CP) using a Delphi Group Survey with Questionnaires until a pre-defined consensus has been reached.
• Conduct inter-rater reliability studies for the system, comparing the ratings of individuals’ eating and drinking abilities by different Speech and Language therapists

If you are interested in taking part in any of the project, we would be happy to hear from you.

Project Team:
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Ms Sarah Ford, Research Assistant, Chailey Heritage Clinical Services
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