Introduction

- Thank-you for attending.
- Introductions of everyone involved in groups: RA, other research team members and their roles
- Introduction of participants – acknowledge that some participants may know each other in a personal or professional role. If this is the case – re-inforce confidentiality issues and clarify that they are comfortable with continued participation.
- Explain purpose of project and this focus group:
    - We are looking for feedback from people involved in treatments for eating, drinking and swallowing (EDSD) for young children with neurodisability that can be delivered by parents at home: parents, professionals and young people.
    - We want to know about their experiences of treatments for EDSD for young children with neurodisability, the practicalities – good and bad
    - No right or wrong answers – not a test of knowledge
- Ground rules – everyone's contribution is valued; confidentiality
- Consent – written – because we want to be reviewing content and analysing data.
- If participants have any questions about the care of a relative or client, these will be listened to by the RA, answered briefly, and they will be offered the opportunity to discuss with the team afterward. We will try to signpost them to someone locally who can help.
- Questions or concerns?

Ask participants to read and sign consent forms.

What we have found out about <u>strategies</u> for eating, drinking and swallowing for young children with neurodisability from the information gathered so far?

Brief discussion of information from survey, 1st focus groups, systematic reviews and mapping review) – discuss variations in practice (use model to discuss):

- Strategies used (use definitions sheet to give very brief definition)
- Mention that looked at age, clinical groups used with and setting used in – used at anytime with any group in range of settings

What questions do you have about the strategies?

- Are you surprised by any of the information above from the survey? If so – what is surprising?
- Are there any strategies we have missed?
- Are there any strategies on our list that are not delivered in UK or should not be tested in future research?

What we have found out about <u>important outcomes</u> for eating, drinking and swallowing for young children with neurodisability from inforamtion gathered so far?

- Brief discussion of information on important outcomes (use model to discuss)
- Ways to evaluate treatment success (professionals only)

What questions do you have about the outcomes?

- Are you surprised by any of the information above from the survey?
  If so – what is surprising?
- Are there any outcomes we have missed?

Designing a research study into strategies for eating, drinking and swallowing for young children with neurodisability:

If you were thinking about being involved in/recruiting to a research study to investigate strategies for eating, drinking and swallowing for young children with neurodisability – what would you think about:

- Modular approach:
    - If all strategies are potentially effective and are currently delivered within the UK, could a modular approach with an algorithm to determine which (combination of) strategies to use with a specific child be something that could work within the NHS? Would order be important?

- Randomisation:
    - Would it be acceptable to randomise children to receive either standard NHS practice (treatment as usual) or a modularised intervention package?

- Duration:
    - How long would the modular intervention need to continue for to ensure change is seen? (1 year/2 years?)
    - How long would a trial need to go on for?

Give Debrief information and vouchers