

Improving communication with children with communication difficulties on the ward study

Steering Group Meeting

Wednesday 25th January 2012 12-2pm

Meeting Summary

1. Introductions

Present: Chris Morris, Amy Francis, Richard Tomlinson, Ellie Thomas, Camilla McHugh, Siobhan Sharkey, Claire Lloyd

Apologies: Becky Hart, Julie Choules, Rachel Howells

2. CM gave a brief overview of the three phases of the project:

Phase 1 – Review of the relevant literature regarding the broad experience of disabled children when they spend time in hospital

Phase 2 – Interviews with parents and children who had recently spent time in hospital about how they felt they were communicated with, and focus groups/one-to-one interviews with staff. Qualitative analysis of the transcripts

Phase 3 – We plan to use the issues identified in Phase 2 to develop a training package for staff to improve communication between staff and children.

CM fed back on Phase 1 of the project. The review is now in press and we expect it to be published shortly (Reference: Shilling, V. Edwards, V. Rogers, M, Morris C. (In press) The experience of disabled children as inpatients: a structured review and synthesis of qualitative studies reporting children's, parents' and professional views. *Child: Care, Health and Development*)

3. SS and CL fed back the emerging findings from the parent/child interviews, please see handouts for detailed feedback (**Note: These handouts are for attendees of the meeting, we would appreciate it if they were not shared publicly at this stage due to the interim nature of the findings**).

The next steps will be to incorporate data from the staff focus groups and one-to-one interviews.

4. The group discussed the absence of data collected directly from children and agreed that this needed to be addressed. RT suggested that we might approach school nurses and find out how

many children had been in hospital in the last 3/6/12 months. We could then send letters home to their parents asking if they would be interested in being interviewed about their experience. If we carried out interviews within the school environment then we would benefit from one-to-one support staff/SALTs etc that know the children and could facilitate the interviews.

This will involve a substantial amendment to the protocol.

Actions: RT to contact Ellen Tinkham for an idea of numbers of children we may be able to contact. CM/CL to work on change to protocol and submit substantial amendment to ethics