**Appendix 3**

**Parent’s Perceptions of How Health Plans Communicate Health Needs**

**Lucy Riggs 28.08.15**

**Abstract**

**Background**

Children and young people with health needs may require care from multiple caregivers in addition to their family and friends. This care may be at home, in school, at leisure activities or during short breaks. Health plans (used to communicate health needs) are written by a variety of health professionals to direct care. They are written for use by parents and any additional caregivers. The aim of this study is to explore how health plans can be used to communicate the health needs of children and young people with additional/complex health needs.

**Methods**

This is a small scale, qualitative, exploratory study aiming to capture rich and meaningful data to gain insight into the perceptions of parents. The study uses thematic analysis of data collected from sixteen participants, collected from three semi-structured, audio recorded focus group discussions.

**Results**

Analysis of the data resulted in three inter-related themes; (i) **Importance of knowing the child,** exploring how health plans could encompass the detailed knowledge that comes from knowing the child, alongside the struggle that parents feel when leaving their child in the care of multiple caregivers, (ii) **Verbal information from parents,** including the frustrations felt by parents when relaying the same information again and again to various professionals and caregivers vs the feeling of then not being listed to or having their experience and opinions valued, (iii) **Using written health plans,** highlighting difficulties of health plans not being read and how health plans and health information is shared. Parents also identified some possible solutions.

**Conclusion**

The results of the study indicate that other than emergency plans, written health plans are not always in use and when they are in use, are reportedly not always read or shared appropriately.

Parents were able to leave an important message about the need for caregivers to know their children as well as knowing their health information. They also request to have their parental knowledge and experience respected and listened to, without being asked to repeat their story again and again to everyone involved.