

## Plain Language Summary

### **Why did we do this study?**

More children require long term tube feeding(gastrostomy). Formula feeds are recommended in England, but more parents are using home-blended meals. There is currently a lack of evidence on the symptoms or safety of this in comparison with formula feeds. We wanted to explore this, impact on parents' quality of life, and costs to families and the NHS.

### **What did we do?**

We spoke to parents of children who are gastrostomy fed, two children and healthcare professionals. They identified important outcomes and how we might measure these.

180 children who were gastrostomy fed joined this study and provided data at three time points over 18 months. We asked parents about visits to A&E and hospital for complications as well as gastrointestinal symptoms. We compared outcomes between children who are formula fed and those receiving a home-blended food.

### **What did we find?**

#### **Workstream 1**

Parents identified outcomes; impacts on physical well-being; digestive symptoms; sleep quality; and time required for gastrostomy feeding.

#### **Workstream 2**

Children receiving a home-blended diet were more likely to live in areas of lower deprivation; their parents had higher levels of education; they had higher dietary fibre intake. One hundred and thirty-four (74%) and 105 (58%) children provided follow-up data at 12 and 18 months. Children receiving a home-blended diet had lower gastro-intestinal symptoms at all time points and had higher calories/kg and fibre. Both groups had adequate micronutrient intake apart from low vitamin D in the home-blended diet group. Safety outcomes were similar between groups. Costs to the statutory sector were higher among formula-fed children but costs to families were higher for the home-blended diet group.

### **What does this mean for gastrostomy-fed children?**

Parents of children who are gastrostomy fed will be able to make more informed choices over their child's diet.