

**Interview schedule /focus group topic guide: Parents**

**G-PATH SUPPORT STUDY: Gastrostomy feeding and psychosocial support  
[14/04/40]**

<p>1. <u>About child</u></p>
<p>Background Info on child: Tell me a little about your child . What is the child’s name? Age . Living arrangements.</p> <p>How does X usually eat? By mouth or tube? If tube how long I (if child has had a tube a long time focus more on present day issues)</p> <p>If they have a tube, do they eat anything by mouth? [tasters]</p> <p>Is feeding by mouth something you get help with or would like help with from professionals?</p> <p>[Good days/bad days]</p> <p>Blended feeding</p> <p>How is feeding managed,</p> <p>At home</p> <p>School</p> <p>going out in public places</p> <p>holidays</p> <p>social activities</p> <p>Does X go to residential care at all – how is feeding managed there?</p> <p>Who is the main feeder at home, school?</p> <p>Any issues</p>
<p>2. <u>Tell me about your feeding journey (if tube is recent)</u></p> <p>I’m interested in how you made the decisions you have made about feeding? When was this?</p> <p>Was it an easy or difficult decision? What support did you get? Was it helpful? What support did you want or need? What were your reactions/feelings when tube feeding was first suggested?</p>
<p>3. <u>Usual Care</u></p> <p>Can you tell me about X’s care in relation to feeding? Where does X usually go? What types of professionals are usually involved?</p> <p>During appointments, are there any opportunities to talk about emotional or practical aspects of feeding?</p> <p>Does X have a key worker? Who is this? [type of professional, where are they based, type of organisation].</p> <p>Role of schools in supporting child or family (age dependent question)</p> <p>Role of hospice (depending on use)</p>
<p>4. <u>Transitions</u></p>

Is X still cared for by a paediatric team or adult? If adult, can you tell me about any issues that arose in changing from paediatric team/hospitals to adult team/hospital? Support needed

5. IF YOU HAD/HAVE A PROBLEM...

The last time you had a problem with feeding or the tube, what was the problem? When was the problem? Could you tell me more about that? Who was the person you went to for help? Is that the person you usually go to for help? Was the issue resolved? If not, what was the reason? How helpful was that person in that situation? (Need to know professional background, where based)

How satisfied with the support you received.

More generally when there is a problem, who do you go to for help? Where are they based? In what way are they helpful?

In what way do you think care is integrated/joined up? If not how could services be better integrated?

6. Good Practice

Can you give me an example of a (recent) particularly good or helpful experience of support in relation to feeding? (within current configuration of care).

What was the support offered? Who from/type of professional? Where? What made it particularly good or helpful? How recent was that?

What sort of things do you value in the support you receive?

What else could be done to improve the support you receive?

7. Other parents

Ask about experiences of support from others such as parent groups

Do you ever contact other parents or voluntary organisations? What kind of problems and what kind of support offered. Is there a support group – can you tell me how about this.

How this is organised (formal/informal)? How helpful.

8. Information and support

Ask about information provided from services and any other information that is needed or found helpful.

Use of web based media

Have you accessed any web resources related to feeding? Which ones? Any particularly helpful?

Relate to things services say they offer eg. DVD [case study2]

9. Any other suggestions of how parents can be supported.

10. Is there anything else you would like to add about what we have discussed today?

Thank you for sparing the time to talk to me today.

