## Supplementary Information: Involving parents and young people in the development of GPATH deliverables: the minimum standards of support

We also asked for input on one of the project deliverables, our minimum standards of support developed based on our findings. To illustrate how we involved the PPI group we have described this process in more detail below.

### Aim of PPI consultation

One of our deliverables was to establish minimum standards of psychosocial and emotional support. Our lay chair had advised that i-statements can be very effective so we wanted to know what other parents and children felt.

The aim of the PPI consultation was to get some feedback on the concept and wording of the i-statements and minimum standards. A brief was sent to Triangle requesting feedback from the young people and parent reference group using the mock-up of the standards detailed in Appendix 13. Back ground information was provided about the aim of the consultation and a number of questions asked about the standards, including the wording and what they should be called (see Box 1).

Box 1 Briefing to Triangle on the minimum standards

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| How can psychosocial emotional support in relation to decisions about gastrostomy feeding be embedded in care pathways and appointments to ensure it’s a priority and that children, caregivers and families get the support they want and need?   1. In what way could the minimum standards of support help children and parents to assert their rights to receive support? 2. What should we call the minimum standards of support? (alternative names appreciated)     Cue for example: Parent and young people’s charter for support about feeding decisions?   1. What do you think about the wording of the statements?   NB (children might view the i-statements in place of the general standards)   1. What do parents and children think about having two different versions? 2. What about the wording of each statement? Are statements clear? 3. Are there any words difficult to understand or emotive? 4. What do you think about the phrase “psychosocial and emotional support”? 5. Are the i-statements child friendly? 6. Is there anything else that we need to consider or add to the statements? |

## Consultation with young people: I-statements

We report on the involvement with young people on the i-statements, including what they thought and what improvements they suggested.

### Ground rules

Each young person was repeatedly reminded that there were no right or wrong answers and to think about the following for each of the I- statements. Children were asked to consider:

1. If the statements were good, Ok or rubbish?

2. What they would add or take away or change in terms of wording ?

3. Which pictures/images are needed (to make child friendly)?

### Participants

Three children participated (their comments are documented below). They use eye pointing to communicate yes and no and have different communication technology to help with their communication. All young people were given a voucher for their time. The finally agreed wording is included in italics. We report on feedback on three of the i-statements.

### I-statements for parents and children

1. I have the right to discuss my psychosocial emotional support (PES) needs when making a decision to have a gastrostomy for my child in appointments where the primary purpose is PES.

**Young person 1**: Good- put a teeth/talking photo or image

**Young person 2**: Good/yes don’t care about pictures

**Young person 3**: I think you will need to speak to the Dr to helping your child at first - I agree with having a talking picture

*Finally agreed statement; I have the right to communicate my feelings and thoughts to a Dr, psychologist or another when I am choosing to have a gastrostomy for myself or for my child.*

2. I have the right to know what to expect in these (replace these with /my/our) appointments and who will provide (replace with give) this support, how long I can expect to talk about things that matter to me and where these conversations (replace with communications) will take place, and who they will be shared with?

**Young person 1**: OK- put a picture of a question mark

**Young person 2**: Good/yes

**Young person 3**: Good - I like the idea of the picture of the question mark

*Finally agreed statement: I have the right to know what to expect in these/my/our appointments and who will give this support, how long I can talk about things that matter to me and where these conversations/communications will take place and who they will be shared with?*

3. I have the right to receive (replace with get) information and resources about the procedure/gastrostomy/operation, including what I feel about surgery and the gastrostomy, and how I will manage the tube and feeding on social occasions. I would like to know what to expect after a gastrostomy is placed and how it will affect my/our everyday lives such as feeding in school and going on holiday and how to use and obtain (replace with get) specialist equipment.

**Young person 1**: rubbish, too long, change into 2 - picture of aeroplane/holiday

**Young person 2**: good but better split into 2 like below

**Young person 3**: rubbish - you just need work around it (when on holiday) - I like to have a picture/symbol of sunshine

*Finally agreed statements:*

*a) I have the right to get information and resources about the operation, how I might feel about surgery and the gastrostomy, and how I will manage the tube and feeding at all times.*

*b) I want to know what to expect after a gastrostomy is placed, how it will affect my/our everyday lives (such as feeding in school, going on holiday) and how to use and get specialist equipment.*

Of interest, perhaps, one of the parents queried the use of the term “minimum standards”. We will rework our minimum standards and these will be disseminated through a short video co-produced with children and parents through professional and parental websites.