

Psychosocial and Economic costings – Parental questionnaire

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

Dear Parent/Carer,

We are inviting you to participate in the above research study which we think is important. The study aims to identify how services are delivering psychosocial support to children and families like you. We would like to ask you some questions about the care you receive.

What is the purpose of the study?

As part of this study we aim to estimate the cost of services providing psychosocial support to children and families. This will allow us to calculate the potential cost benefits of providing psychosocial support in the future alongside current care.

By psychosocial support we mean:

- The support you/your child need to make an informed decision about different feeding options, any concerns about feeding, the values you attach to the meaning of food, eating and feeding by mouth
- The support you/your child needs when making an informed decision to have a gastrostomy feeding tube inserted or removed, including emotional support
- Practical support in learning new nursing procedures, caring for the gastrostomy and dealing with any complications that may arise
- Support to maintain or reintroduce oral feeding post-gastrostomy where appropriate
- Support with blended feeding

What do I have to do?

In order to do this we would like you to complete the attached questionnaire. If you have more than one child please complete one questionnaire for each child.

We also ask your permission to access your child's clinical records to collect data on the number and type of appointments. We will be collecting this information for the last 12 months for all children who have had an appointment related to their feeding to estimate the cost of providing psychosocial support. This information will be reported as average costs and will be anonymous. Some services may hold information electronically in which case we will be able to access anonymised group data which will not require your consent as it will be anonymised.

However, where the information is held in paper records our project researchers at University of Hertfordshire might need to look at your child's clinical records. The researchers have training in research governance and confidentiality. They hold honorary contracts or research passports with the Trust which means they are complying with local governance procedures and the NHS Trust's duty of care. Please complete the attached questionnaire even if you do not wish the project researchers to access your child's records.

Consent

1. Please indicate whether you consent or not to researchers accessing your child's clinical records to cost psychosocial support.

Please tick **one box** only

I give my consent for the project researchers to access my child's clinical records for the purpose of this research study

OR

I do not give my consent for the project researchers to access my child's clinical records for the purpose of this research study

Name

Signature

Date

If you do give consent for the project researchers to access your child's clinical records, please fill in the details below.

Child's Full Name:

Please turn over and continue with the questions

About your child

2a. How old is your child?

..... years or months

2b. Has your child ever had a gastrostomy feeding tube? (Please circle)

YES NO

2c. Does your child currently have a gastrostomy feeding tube?

YES How long has your child had a gastrostomy feeding tube?

..... Years Months

NO

2d. If the answer to the above question is 'NO' has your child ever been recommended a gastrostomy feeding tube?

YES If "Yes" was this in the last 12 months? (Please circle) Yes / No

NO

3. In the last 12 months how many appointments has your child had in relation to issues around feeding/a gastrostomy feeding tube?

.....

4. Were any of these appointments arranged specifically to discuss the emotional or psychosocial aspects of feeding or gastrostomy?

YES (please specify how many appointments)

NO

4b. If no, would you have liked an appointment to discuss the emotional or psychosocial aspects of feeding or gastrostomy?

YES

NO

Please turn over and continue with the remaining questions

5. Please tell us about the appointments you had in the last 12 months where support/psychosocial issues were discussed and you received support or would have liked support

	Type of appointment where support/ psychosocial issues were discussed e.g. dietetic clinic, surgical clinic	Where did the appointment take place?	How long did the appointment last? (hours/minutes)	How long was spent discussing support issues? (approximate number of minutes)	Who was present? (e.g. dietitian, paediatrician, nurse)	What were the support/ psychosocial issues you raised/wanted to discuss?	Did you receive the support you needed? Please give details.
1.							

2.							
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3.							
4.							

For additional appointments please use the supplementary sheet at the end of this questionnaire

About the last time you needed psychosocial support

6a. More generally, the last time you had a worry or an anxiety about your child's feeding/feeding tube who did you go to?

.....

6b. Was this a professional?

YES

NO

If you answered **YES** to 6b, what type of professional was this and where were they based?

Type of professional

Where professional is based (e.g. feeding clinic, school)

If you answered **NO** to 6b, please tell us who you approached

What was the issue you wanted assistance with?

.....
.....

Was the issue resolved?

YES

PARTIALLY RESOLVED

NO

6c. On this occasion, how satisfied were you with the emotional/psychosocial support you received? (please circle)

1

2

3

4

5

Not at all
satisfied

Very satisfied

Talking to other parents/families

7a. In the last 12 months have you been offered the opportunity to talk to another parent or family by a healthcare professional?

YES NO

7b. Did you take up the opportunity to talk to another parent or family?

YES NO

7c. If you took the opportunity to talk to another parent or family how helpful did you find this?

1	2	3	4	5
Not at all				Very
helpful				helpful

Please tell us more about this, e.g. was there anything you found particularly helpful or unhelpful? Was your child introduced to another child with a gastrostomy feeding tube where applicable?

.....
.....
.....

.....
.....

7d. If you were not offered the opportunity to talk to another parent or family, is this something you would have liked?

YES NO

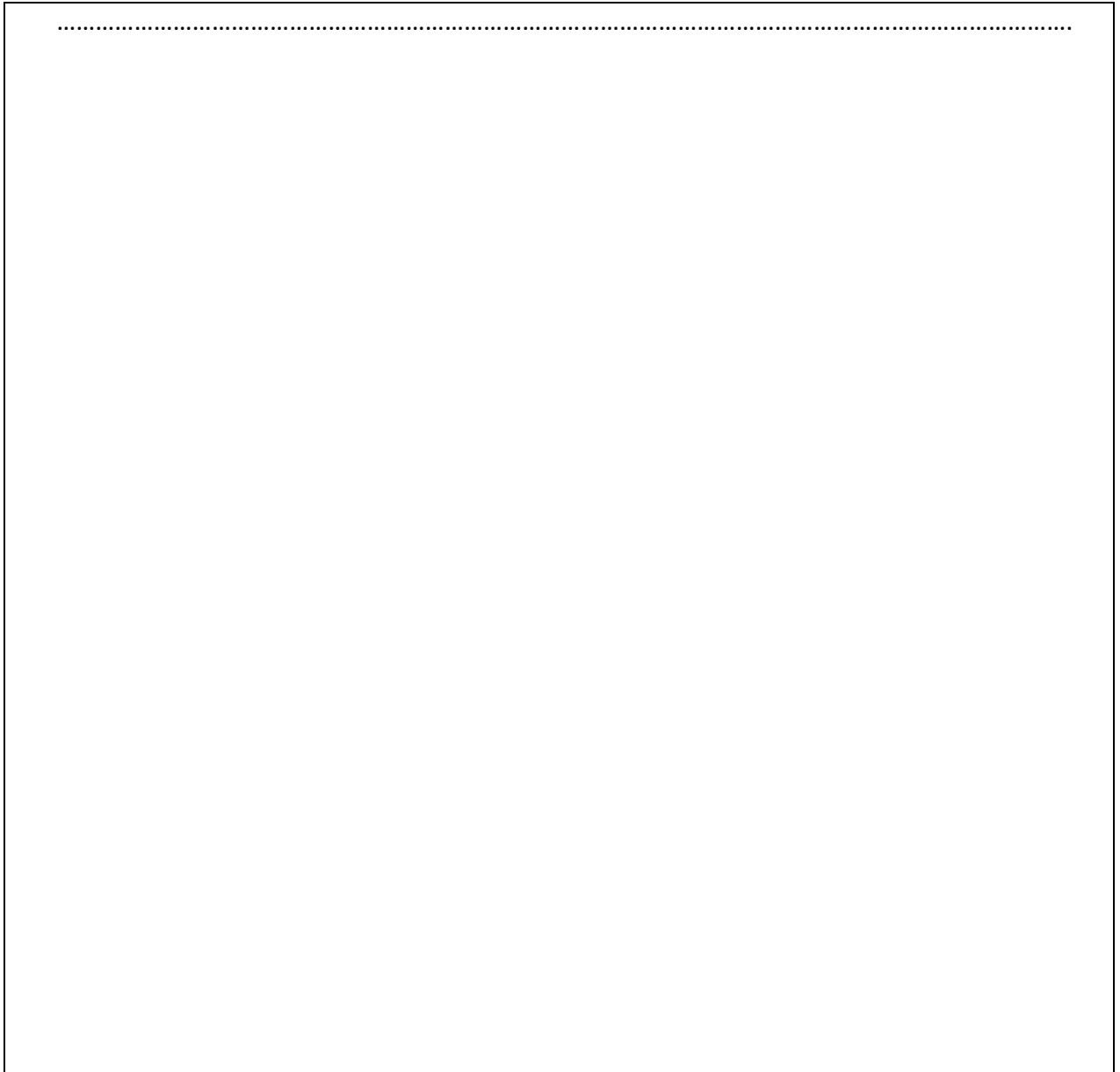
General satisfaction and any other comments

8. In general how satisfied are you with the emotional and psychosocial support you have received in the last 12 months from health professionals? Please circle.

1	2	3	4	5
Not at all				Very satisfied
satisfied				

9. Is there anything you would like to tell us about your child's feeding and the psychosocial support you and your child would like to receive or have received?

.....
.....
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.....
.....



Demographic Information

16/LO/0214 (REC ref)
Study number 178366 (IRAS project ID)
Demographic Form Version 1 08.11.16

1. Are you: Male Female

2. What was your age in years on your last birthday? Years

3. What is your child's date of birth? DD MM YYYY

4. Please tell us about any adults who live with you (tick all the boxes that apply to your household).

I live:

- with my partner/husband/wife/boyfriend/girlfriend single householder
- with other family members (parents/sisters/brothers) Other (please specify) _____
- with friends

5. Please tick the box next to the highest level of your educational qualifications.

- No formal educational qualifications Bachelor's degree (e.g. BSc, BA)
- GCSE, CSE, GCE O Levels or equivalent Masters or Doctoral degree
- GCE A Levels, HNC, GNVQ or equivalent Other (please specify) _____
- HND, other Diploma, professional qualification or equivalent

The following questions ask for background information about you, your child, and your family. Please tick the appropriate boxes or write in the spaces provided.

6. What is (or was) your main job/occupation? (Please give a job title and a very brief description of your main duties).

If at present you do not work outside of the home, please tick this box

Full job title _____

What do (did) you actually do in this job? _____

What does (did) his/her employer make or do? _____

7. What is (or was) your partner's main job/occupation? (Please give a job title and a very brief description of his/her main duties).

If at present your partner does not work outside of the home, please tick this box

If at present you do not have a partner, please tick this box

Full job title _____

What does (did) he/she actually do in this job? _____

What does (did) his/her employer make or do? _____

8. What is your ethnic group? (Tick one box)

A. White

English / Welsh / Scottish / Northern Irish / British

Irish

Gypsy or Irish Traveller

Any other White background, write in _____

B. Mixed / multiple ethnic groups

White and Black Caribbean

White and Black African

White and Asian

Any other Mixed / multiple ethnic background, write in _____

C. Asian / Asian British

Indian

Pakistani

Bangladeshi

Chinese

Any other Asian background, write in _____

D. Black / African / Caribbean / Black British

- African
- Caribbean
- Any other Black / African / Caribbean background, write in _____

E. Other ethnic group

- Arab
- Any other ethnic group, write in _____

9. What is your relationship to your child (e.g., mother, father, stepmother, grandmother, adoptive parent)?

10. Does your child (please tick one box only):

- Normally live with you (excluding any respite care) **OR**
- Normally live somewhere else (e.g. with another parent, other family member or in residential care)

11. Please list any medical conditions your child has (e.g. cerebral palsy, epilepsy, Down's syndrome)

- | | |
|----|-----|
| 1. | 6. |
| 2. | 7. |
| 3. | 8. |
| 4. | 9. |
| 5. | 10. |

12. We would like to know about any other children you have who have a gastrostomy or where feeding has been raised as an issue by health professionals.

Do you have more than one child with a gastrostomy? Yes No

If yes, please state how many additional children have a gastrostomy

13. Should we need to contact you about any of your answers, please provide a contact telephone number

Telephone:

Thank you for completing this form. Please now return this form to the research team using the stamped, addressed envelope provided.