



About your service

In which nation is your service based?

- England
 - Wales
 - N. Ireland
 - Scotland
-

What is the name of your employing organisation or NHS Trust?

What is the name of the organisation that commissions your service?

Which geographical area does your service cover?

What is the name and post code of your service?

Are you completing this form on behalf of a:

- Child Development Centre
- Home enteral nutrition team
- School based service
- Paediatric disability service/team
- Other (please state)

Does your service for children/young people with neurodisability and complex feeding needs currently have any of the options below (please tick all that apply)

- Feeding team
- Feeding clinic
- Home enteral nutrition team (HEN)
- Multi-disciplinary review of children's feeding involving at least two members of the multi-disciplinary team
- School-based multidisciplinary review
- Other support (please give details)

- None of the above





You have indicated that your service currently does not have a feeding team/clinic.

Please tell us whether your service had a feeding team or clinic or HEN which has closed in the past 5 years and include any additional information regarding the date your service closed and the reasons why.

Your responses have indicated that you currently do not have a feeding team/clinic or service

This will allow you to exit the survey once you have provided your contact details.

If this is incorrect, please use the back button to continue with the survey.

I confirm my service does not currently have a feeding team/clinic





What is the age range of children/young people seen by your feeding team/clinic/service?

E.g. 0 - 5 years

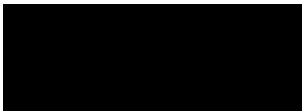
Is there a specific budget for the feeding clinic/team?

Yes (please specify how much)

No

I don't know/Not Applicable





About the Psychosocial Support Your Service Offers Children and Families

Does your service/team offer psychosocial support (as defined in the additional information sent with the survey link) to children/young people and families? Please tick all that apply.

- Parents/Caregivers
- Children
- Young People
- We do not offer psychosocial support. Please provide a reason.

When does your service offer psychosocial support? Please tick the options which apply for parents and children both before and after gastrostomy insertion.

	Parents/Caregivers		Children/Young People	
	During the decision making phase where a gastrostomy may be recommended	Post gastrostomy insertion	During the decision making phase where a gastrostomy may be recommended	Post gastrostomy insertion
Emotional support in coming to terms with a new way of feeding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Practical support in managing the tube and new nursing procedures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Is the provision of psychosocial support documented or formalised in any way? E.g. care pathway, dedicated member of staff.

- Yes (please give details)

- No

In your service do children/families have to meet specific criteria/a threshold in order to receive psychosocial support, for example a child must have at least two complex needs?

Yes (give details)

No

I don't know/Not Applicable



You indicated in the previous question that children/families have to meet specific criteria/a threshold in order to receive psychosocial support. Is an alternative offered to children/families who do not meet the threshold/criteria?

Yes (give details)

No

I don't know

Does your service provide support to maintain or reinstate oral feeding post gastrostomy insertion where appropriate or where a parent asks for this?

- Yes
- No
- Don't know



In the previous question you indicated that your service provides support to maintain or reinstate oral feeding post gastrostomy insertion where appropriate or where a parent asks for this. Is your service funded to do this?

- Yes
- No
- I don't know

Do you have a process in place (e.g. audit) or tool to measure the outcome of psychosocial support?

- Yes (give details)

- No
- Not applicable

Please tell us more about how psychosocial support is delivered in your service in your own words.

Please identify 3 key aspects of your service that you feel are examples of good practice in delivering psychosocial support to children and families.

In your opinion, how well do you feel your service supports children and families?

- Very well
- There is room for improvement
- Not very well
- No support is offered

Is there something you would like to do differently to improve the psychosocial support you offer children and families?

- Yes (you will be given the option to elaborate in the next question)
- No



In the previous question you indicated you would like to do things differently to improve the psychosocial support you offer children and families. Please tell us more about this.

What changes would you like to make?

What would help you to make those changes?

What barriers (if any) would you need to overcome to make those changes?



About Local Systems of Care and Referrals

Which centres do you refer children/families to for tests and investigations about children's feeding or for gastrostomy placement or support? Please list the names of the centre(s) and the reasons for referrals.

	Centre/Organisation	Reason for referral
1		
2		
3		
4		
5		
6		

<<

>>



About Policies and Care Pathways

A care pathway is defined as: "an intervention for the mutual decision making and organisation of care processes for a well-defined group of patients during a well-defined period". Does your service have any of the following? (please tick all that apply)

- A written care pathway
- Best practice statement guidance
- Multi-disciplinary guidance
- A written dysphagia policy
- Other (please provide details below)

The following criteria have been identified as the defining characteristics of an integrated care pathway. Please tick all those that apply to your service.

- multidisciplinary with identified roles and responsibilities
 - crosses different levels of service eg, health, education, social care
 - recorded in single documentation and standard format
 - outcomes orientated
 - audited on a regular basis as part of quality monitoring
 - deviations from the care pathway/guidance are recorded
 - none of the above apply to our service
-

Does your care pathway/guidance/policy cover transitions into adult care?

- Yes
- No
- Don't know





About the role of schools in supporting children and families

Please tick the options which apply to your service regarding formal/informal care pathways/guidance /arrangements involving schools.

- We are a health care service with arrangements in place with special/mainstream schools (give details)

- We are a special/mainstream school-based service with arrangements in place with health care services (give details)

- None of the above





About Service User Involvement

Were parents/carers or children/young people involved in developing your service, care pathway/guidance? Please tick the appropriate boxes for each group.

	Yes	No	I don't know	Not Applicable
Children/Young People	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parents/Carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are parents/carers or children/young people currently involved in auditing or evaluating your service, care pathway/guidance?

	Yes	No	I don't know	Not Applicable
Children/Young People	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parents/Carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you/your team offer parents referrals to other parents who have experience of gastrostomy as part of your practice?

- Yes
- No
- Don't know

[<<](#)[>>](#)

Is the referral formalised in any way? (e.g. specifically detailed as an aspect of care in the care pathway, audited, parents receive reimbursements or training etc.)

Yes (give details)

No

Don't know

Are there any established parent or voluntary groups that you work with as part of your service?

Yes (in what way are they involved?)

No

Don't know

Does your service offer out of hours appointments?

Yes

No

<<

>>

Resolving conflicts about children's feeding

Does your service have any written guidance or approaches to managing conflict when parents/children disagree with the recommendation of a gastrostomy feeding tube?

Yes (give details)

No

Do clinicians/therapists receive clinical supervision or other forms of support or guidance when working with children/families who disagree about a child's need for a gastrostomy tube?

Yes (give details)

No. If no support or guidance is available for professionals, what kind of support might be helpful in working with children/families who disagree about a child's need for a gastrostomy?

In the last 12 months have any children's feeding, weight or growth raised concerns about safeguarding?

Yes (please specify how many children)

No

Don't know








In the last 12 months have you or your team used safeguarding legislation in relation to children's feeding/weight/growth?

Yes (please indicate how many children)

No

Don't know

In the last 12 months (please give approximate numbers)

	Number of children
How many children with a neurodisabling condition have been considered for a gastrostomy?	<input type="text"/> 
How many of these children would be described as having cerebral palsy?	<input type="text"/> 
How many children were referred to a specialist centre for an opinion about the suitability of a gastrostomy?	<input type="text"/> 
How many children had a gastrostomy placed?	<input type="text"/> 
How many children had a gastrostomy removed?	<input type="text"/> 
How many children had a gastrostomy reinstated?	<input type="text"/> 
If you answered 'don't know' to any of the above questions please tell us the reason	<div data-bbox="149 727 1025 987" style="border: 1px solid black; height: 133px; width: 652px;"></div> <input type="text"/> 

We would like to know about your information management system.

Does your service have electronic records?

Yes

No

Have any questions in this survey been difficult to answer because of data access issues?

Yes (please give details)

No





If your service is selected for further study, would you/your service be willing in principle to participate in the second phase of the research involving in-depth case study research? Our researchers would visit your site and conduct up to 20 interviews and two focus groups with staff members, children and their families and observations (up to 20 hours) of key nodes of delivery such as care planning meetings. We will also aim to estimate the cost of different service models. Please note the study has been adopted on the Clinical Research Portfolio and is eligible to receive NIHR Clinical Research Network (CRN) Support: CPMS ID 31085/IRAS ID 178366.

- Yes, we are interested in taking part
- No, we are not interested in taking part
- Unsure

About you

What is your job title?

What is your professional background?

What is your role in relation to the feeding team/clinic/service? e.g. Clinical Lead

We may wish to contact you to clarify aspects of the information you have provided. Do you agree to the research team contacting you? If 'Yes' please provide an email contact and telephone number

Email

Phone number

Mobile

Name:

