BAPEN

PNGSIG
Patient Network Group

Experiences and views of support services for people living at home with an enteral tube:

It's time to listen and take action

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Foreword

Enteral tube feeding at home is far more than a clinical intervention – it is a complex, often life-sustaining treatment that touches every aspect of daily life for those that rely on it. From emotional wellbeing to personal independence to relationships and routines, it shapes the experiences of patients and their carers alike. Yet, despite its profound impact and growing prevalence, the voices of those living with enteral feeding have too often been missing from the design of the very services meant to support them.

This report presents the findings of a vital national survey that seeks to bridge that gap. What makes this work particularly valuable is its grounding in real-world perspectives, from practical challenges of training and equipment provision to deeper concerns around confidence, emotional adjustment, and the desire for consistency in care.

This is exactly the kind of work BAPEN and the PNG SIG are passionate about. It reflects our shared commitment to listening, learning, and acting on what matters most to patients and carers. This study offers a compelling argument for more patient-centred service design, guided by clear, evidence-based recommendations.

This report should serve as a catalyst for service improvement, policy development, and ongoing dialogue with patients and carers. It challenges us to build systems that are not only clinically sound but also relevant, coordinated, and responsive to the real complexities of life with an enteral tube.

On behalf of the PNG SIG and BAPEN, we commend both the authors and participants for their commitment to improving home enteral nutrition services across the UK and for contributing to an inclusive and compassionate approach to care.

Carolyn Wheatley MBE, Chair of PNG SIG and Dr Nick Thompson, BAPEN President

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Introduction

The number of people supported to receive nutrition or fluid via tube at home is increasing, although the exact number is difficult to determine (Buhl, Bourry, Seguy, & Lescut, 2024). In the UK it is estimated about 40,000 people rely on tube feeding (British Association for Parenteral and Enteral Nutrition, 2022). Nutrition and fluid can be given into a functional gut by a feeding tube (termed enteral nutrition and fluids) or directly into the venous system (termed parenteral nutrition and fluid). Both therapies are complex interventions and people discharged from hospital usually receive them long-term.

There is an increasing prevalence of home enteral nutrition (HEN) globally and the impact of HEN on patients' clinical care, nutritional status and quality of life is significant (Ojo, 2015, Byrnes et al., 2022). In England HEN provision is guided by National Institute for Health and Care Excellence (NICE) guidelines, which are broad nutritional care guidelines covering identifying risk of malnutrition as well as nutritional support (National Collaborating Centre for Acute Care, 2006). These guidelines do not specify in any detail the service that should be provided for people with enteral tubes at home. Services to support people with enteral tubes at home have developed organically and practice varies from geographical region to region (Green et al., 2013, Wong et al., 2018). Support may be provided by community teams or by hospital-based teams (Klek et al., 2011, Green et al., 2013, Majka et al., 2014). Hence, the governance of services for people with enteral tubes and access to services is variable (Wong et al., 2018, Flood et al., 2021).

There is evidence that multi-disciplinary primary care teams focussed on HEN services can provide cost-effective care (Dinenage et al., 2015) and HEN homecare companies increasingly provide nursing care and supplies. HEN services have been associated with reduced hospital admissions, lengths of stay in hospital and costs of hospitalisation.

Studies have explored patients and carers views on what services could support them to manage enteral tubes at home (Green et al., 2019, Byrnes et al., 2022). One study indicated that people managing enteral tubes at home, whether patients or carers, want regular contact with a healthcare worker, knowledgeable in the intervention, to provide routine support and access to urgent help when needed (Green et al., 2019). A recent scoping review, considering quantitative as well as qualitative studies summarised experiences of HEN service users in adults with HEN (Byrnes et al., 2022). This review highlighted the importance of initial education to support adaptation to HEN and the need for support from knowledgeable health care professionals (Byrnes et al., 2022). However, people with enteral tubes at home and their carers have reported limited access to support and variable quality of services (Green et al., 2019, Byrnes et al., 2022).

The NHS Long Term Plan focuses on a service model in which patients get more options, better support, and properly joined-up care at the right time in the optimal care setting (NHS England 2019). Further it prioritises care quality and outcomes improvement. Organisation of services to support people with enteral tubes living at home should be informed by people with lived experience of an enteral tube and the regional context. In this way services can ensure offering an equitable and supportive experience. There is a need to develop an understanding of the patient pathway including assessment components and frequency, education and training to support the development of services. This can inform key performance indicators and quality standards for teams supporting people with enteral tubes. Financial transparency in terms of cost is also important. Nutrition and fluid via enteral tubes is a costly intervention and supplies can be wasted. The first step to service organisation is to determine what people with tubes living at home and their carers across the UK want from a service to support them.

The research question that arises therefore is: what do people with enteral tubes and their carers in the UK want from services to support them to manage at home with the tube?

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(minimum length of 4 with synonyms).

Methods

Aims and objectives

The aim of this study was to undertake a national UK questionnaire survey to identify what people managing enteral tubes at home want from services to support them to manage the intervention.

The specific objectives were to:

- Develop and pilot a valid and reliable questionnaire survey to elicit the views of people with enteral tubes and their carers on services that they consider will support them best to manage their tube.
- Disseminate the questionnaire electronically to people with enteral tubes and their carers across the UK using patient and carers support group networks.
- Summarise the findings of the questionnaire and supporting published research to inform the development of a framework outlining recommendations for the provision of services to support people living at home with an enteral tube in the UK.

Patient and public involvement

The research team included representatives of a national support group entitled PINNT, Support and Advocacy for People on Home Artificial Nutrition. (PINNT, 2025).

This group represent people receiving HEN across the UK.

Study design

A cross-sectional questionnaire survey design was employed. This study design supports the collection of quantifiable information directly from people with an enteral tube living at home and their carers. This facilitates an upward flow of information towards those who manage and deliver services in the UK (Jackson and Furnham, 2000).

Study population

The survey was administered to people with an enteral tube living at home and their carers. Carers could complete the form with or without the person with a tube for whom they care. Equality, diversity and inclusion were considered by ensuring the survey was available nationally via the patient support group PINNT.

Recruitment took place via advertisement on the PINNT website and online social media such as X (formerly known as Twitter) and Facebook (see Appendix 1 for the recruitment advertisement). It was anticipated that this would result in a representative sample of the population. Paper copies were available on request from PINNT.

Inclusion criteria included: adults with an enteral tube living at home; adult carers of people living at home with an enteral tube. Exclusion criteria included: people unable to give informed consent; children and young people under the age of 18 years.

Sample size

A convenience sample, which included people with enteral tubes and their carers, was used. In 2015 it was estimated that at least 23,235 adults received HEN (British Artificial Nutrition Survey Committee, 2018), later figures are not available but are likely to be higher. A sample size of 378 (based on a population of 23,235, 95% confidence interval and 5% margin of error) was aimed for in the survey. However, whilst a sample size that can determine statistical difference can be useful in terms of determining which issues are of most importance, valuable information from individual patients about their needs and experiences can be obtained from any sample size.

Development of the survey

A scoping review of the literature identified a self-administered survey for patients and carers used to evaluate service provision of HEN in Ireland (Boland et al., 2017). This was used with one of the author's permission to form the basis of the present survey. Some questions were adapted, some removed, and some questions added by the authors of the protocol during a consultation period based on their experiences as a healthcare professional or service user. A meeting of the authors of the protocol on 26/1/23 finalised the questionnaire following small group discussion.

The survey comprised of items used to gather data from respondents about their experience of a tube and their opinions of what is required of a HEN service. Items consist of closed and open question to provide quantitative and qualitative data. Thirty-seven main questions are included in the survey excluding the inclusion and consent questions. Some questions contain subsections to clarify the response or provide an opportunity for short free text responses. The questionnaire is shown in Appendix 2.

The first group of items asks for responses relating to participant characteristics. The second group of items elicit responses focused on participants experiences and views.

Content validity and inter-rater reliability of the survey was determined by a small convenience sample comprising of two members of PINNT, a nutrition nurse and a dietitian. This step was essential also to confirm the time required to complete the questionnaire and that questions were easy to understand, and instructions easy to follow.

The questionnaire was piloted with a small sample (n=10) of people with enteral tubes and their carers to further test validity and reliability. Piloting is important to ensure consistent, meaningful data that provides a spread of scores to be able to discriminate between respondents (Jackson and Furnham, 2000a). The following was analysed:

- Item facility. This is an index of the number of responses in each category out of the total number of responses for attitudinal questions. This is to ensure this type of question can detect differences.
- Survey reliability. Assessment of the internal consistency of each item.
- Face validity. Assessment of the completion rate and analysis of qualitative comments to ensure the questionnaire is addressing the research question and aims.

Following these small changes, for example free text box size, were made to refine the questionnaire.

Survey dissemination

The survey was administered via Online Surveys (Jisc, 2023). Run by Jisc, Online Surveys is used by over 300 different organisations in the UK and internationally.

A paper and email copy of the survey was also available on request via PINNT. Potential participants could respond to the advertisement on PINNT by emailing or writing to the support group. The group's communications email was used. A member of the PINNT charity monitored mail and identified if the potential participant had requested a copy of the questionnaire to be emailed or sent in the post. The questionnaire was sent to the address provided by the potential participant with a stamped addressed envelope for return if post was used. The email or letter requesting the information contained personal data and so was deleted or shredded following use. PINNT is a registered charity that adheres to a Privacy Policy and is experienced in managing personal data. Two members of PINNT were part of the research team but will not be involved in sending the questionnaire to potential participants. It was considered important to provide an additional route to the questionnaire because some people with tubes may not own a computer or be able to effectively complete a questionnaire online. This approach to the questionnaire dissemination was endorsed by members of the research team who represent patient and public involvement.

Data management

The data was entered into an Excel spreadsheet and quality-checked to ensure accuracy. Each survey response was completely anonymous; the questionnaire explicitly avoided any identification of participants' identities. If any personal information was inadvertently included by a participant, it was deleted by the lead research to ensure all data was anonymised prior to analyses.

Only the research team was able to access the data. Data analyses was undertaken by the research team. Data will be presented as descriptive statistics. Categorical data was presented as both absolute values and proportions.

All information collected was stored in a secure database on a password protected University computer, and will be archived in accordance with Bournemouth University guidelines.

Ethical considerations

Ethics was gained from Bournemouth University Ethics Committee (Ethic ID: 48370).

Participants completed informed consent questions embedded in the survey using the BU template for online surveys. If the participant gave consent, he/she was directed to the survey. Users who answer did not give consent were automatically be directed to an exit page. Participants were informed that they could withdraw at any time whilst they undertake the questionnaire. Participants could leave one or more questions unanswered.

Responses collected were anonymous and confidential. Online Surveys is designed to protect respondent anonymity. It does not use cookies for survey completion and external tracking software such as Google Analytics is not supported. Additionally, information about respondents' IP addresses cannot be accessed. The survey population was wide and diverse enough to maintain the anonymity of individual respondents.

Participants were not required to use a survey password and a respondent list was not used to disseminate the survey. Participants were not required to give their name, date of birth or other identifying characteristics. If participants did identify an individual or their name in the open text questions this was removed when the data was transferred to the spreadsheet for analysis (as indicated above).

Participants were directed to PINNT resources or their own healthcare provider for further information using the statement "If you need any support or information following completing this survey, please contact your healthcare provider or access the website for the PINNT support group". This was placed on the final page of the survey.

Results

The survey opened on 27th March 2023 and closed on 4th July 2023. The survey was completed by 243 respondents who reported that they had a tube that goes in their stomach or small intestine, or cared for someone with this type of tube. Of 242 respondents; 193 (80%) reported that they had a tube, 42 (17%) reported that they were unpaid carers of a person with a tube, and 7 (3%) reported that they were paid carers of a person with a tube.

Quantitative responses

Participant characteristics

All participants reported that they lived in the UK. Table 1 below summarises the country where they reported they lived, the reported age and gender of the person with the tube, the time since the tube was first inserted and the tube type. Where participants reported that they had had the tube for more than two years the time ranged from just over 2 years to 35 years ($\bar{x}$ = 8, SD±6). Some participants reported a mix of tube types, for example a gastrostomy button and a jejunostomy button and a venting gastrostomy and jejunostomy. Some participants reported a range of tubes over several years, for example nasojejunal tube followed by a jejunal tube.

Table 1: Participant characteristics

Participant characteristics	**Number (%) participants**
Reported nationality	
England	218 (90)
Scotland	13 (5)
Wales	9 (4)
Northern Ireland	2 (1)
Reported age of the person with the tube	
Under 18 years old	19 (8)
18 to 20 years old	13 (5)
21 to 39 years old	70 (29)
40 to 59 years old	76 (31)
60 to 79 years old	60 (25)
80 years old or over	5 (2)
Reported gender of the person with the tube	
Male	175 (72%)
Female	57 (24%)
Prefer not to say or self-describe	11 (5%)

Reported time since tube first inserted					
Less than 3 months	3 to 6 months	7 to 12 months	1 to 2 years	More than 2 years	Could not remember
11 (5)	18 (7)	29 (12)	35 (15)	143 (59)	6 (3)
Reported tube type					
Gastrostomy (PEG or RIG)	Jejunostomy	Nasogastric	Nasojejunal	Unsure	More than on tube type
126 (52)	45 (19)	12 (5)	23 (10)	3 (1)	33 (14)

The medical reason for the tube insertion was described variously. Participants were requested to choose from a list of options or self-describe. Most participants chose to self-describe the reason for insertion of the tube (n=115, 47.5%). They described a wide range of medical conditions including intestinal dysmotility, intestinal failure, removal of small bowel, bowel blockage, anorexia, Ehlers Danlos Syndrome, laryngeal dysphagia, fundoplication and cerebral palsy resulting in insertion of the tube. Others selected from a list which included gastroparesis (n=75, 31%), cancer (n=34, 14%) stroke (n=10, 4%), Crohn's Disease (n=10, 4%), Short Bowel Syndrome (n=10, 4.1%), Motor Neurone Disease (n=8, 3%), brain injury (n=6, 3%), Multiple Sclerosis (n=2, 1%) and cystic fibrosis (n=2, 1%). Fourteen (6%) did not know why the tube had been inserted.

Just over half of respondents reported eating and drinking with the tube (n=128, 53%) with the reminder of respondents reporting being unable to eat and drink with the tube (n=114, 47%). Many respondents did not follow a texture modified diet (n=111, 63%) with only 66 (37%) reporting that they did follow such a diet. Participants reported following other types of diet selected from a list (Table 2). Other diet types described included the Foodmap diet, MEWS diet (cow's milk, egg, wheat and soya free), fluid only and a dairy free diet.

Table 2: Diet reported to be followed other than a texture modified diet

Type of diet	**Number (%) participants**
Low residue diet	20 (13)
Gluten free diet	15 (10)
Low fat diet	20 (13)
High fibre diet	3 (2)
Diabetic diet	1 (1)
Small portion sizes	83 (56)
Other diet type	78 (52)

In terms of nutrition given via the tube, 213 respondents (94%) reported the use of ready-made feed, 5 (2%) reported using blended food (liquidised normal food) and 8 (4%) a mix of both ready-made and blended food. Most participants reported using a feeding pump (203, 84%), although 39 (16%) reported that they did not.

Hospital experience prior to discharge

Table 3 shows participants responses when asked who supported their training to manage the tube and feeding and who they think should provide most of the training.

Table 3: Participant's views on who should provide training

Person providing training to manage the tube	Number (%) participants "Who trained you to manage the tube BEFORE you or the person you care for first went home? (tick all that apply)"	Number (%) participants "Who provided MOST of the training?"	Number (%) participants "Who do you think should provide most of the training?"
Hospital dietitian	86 (36)	31 (13)	25 (10)
Community dietitian	21 (9)	15 (6)	13 (5)
Hospital nurse	90 (38)	53 (22)	13 (5)
Community nurse	22 (9)	18 (8)	12 (5)
Nutrition nurse	84 (35)	49 (21)	61 (25)
Nutrition company representative	60 (25)	54 (23)	11 (5)
I'm not sure	7 (3)	7 (3)	12 (5)
Someone else	15 (6)	12 (5)	1 (1)
I don't think it matters as long as they are good			93 (36)

Most participants reported that the training they received prepared them to manage the tube and feed at home (n=126, 52%). However, 81 (33%) participants felt they were only partly prepared, and 30 (12%) indicated that they did not feel prepared. Four (2%) participants indicated they did not know.

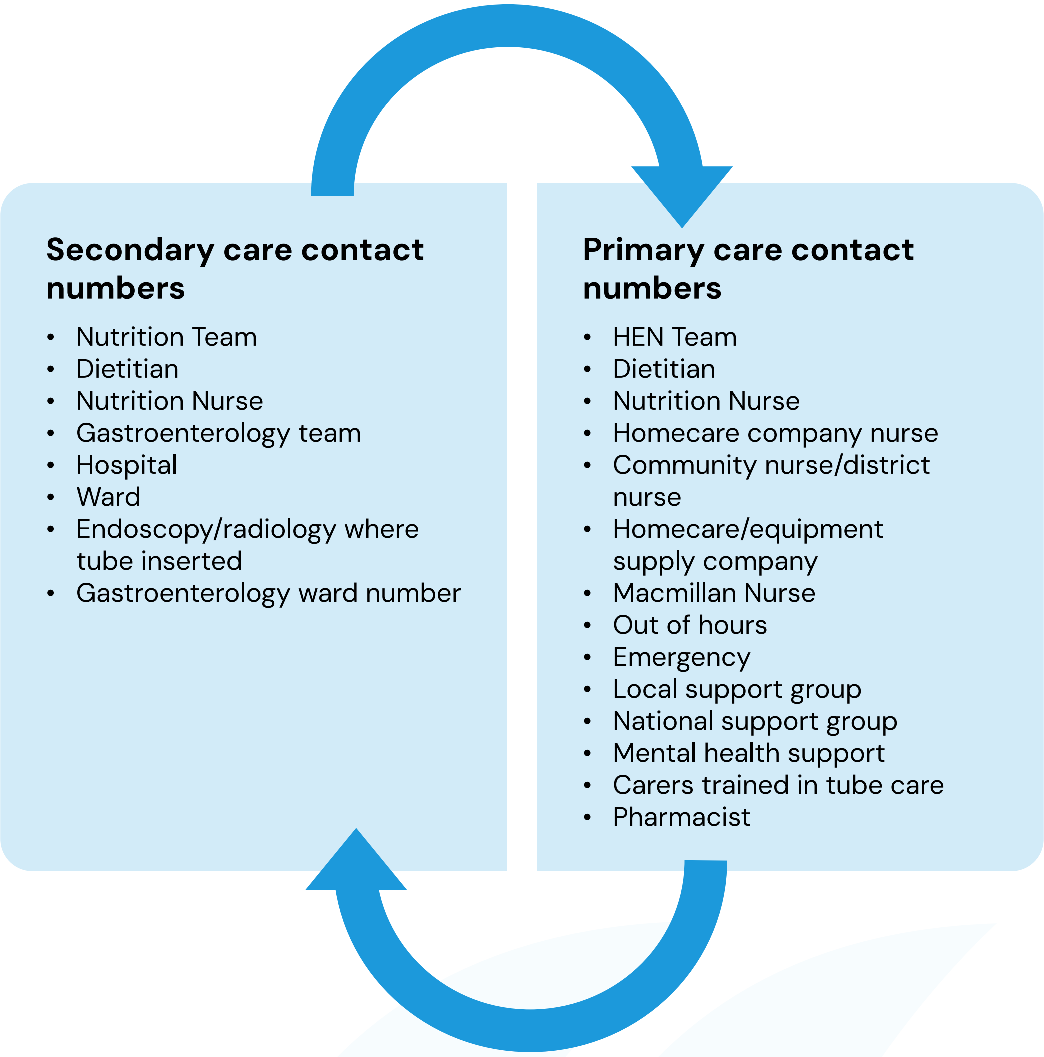
The majority of participants (n=139, 57%) indicated that they were given written information about the tube and associated management before they went home. Some (n=50, 21%) indicated that they needed more written information. However, 47 (19%) participants reported receiving no written information.

When asked what written information they thought people going home with a tube required participants' response are summarised in Table 4.

Table 4: Summary of required written information	
Category	**Components**
Managing the tube and feed	• Tube type and how it works • Current feeding plan which includes medication and flush timing. Option to have laminated plan. Possible feeding regime changes if needed. • Medication • Medical information related to the tube • Pump guidance • How to change the tube • Dos and don’ts • Tube management including fixing the device and sleeping with the tube • How to order feeds and who is responsible for the prescription • How to make sure you have enough stock and get more equipment • What to take to hospital and on holiday • What is not normal and what is an emergency • Stoma management whilst healing when healed • Managing emotions associated with the tube • What to expect at home • How to get more support • How to live with a tube
Problem solving	• What to do when things go wrong • Flow chart of what to do with common problems • Letter or document to give to A&E, doctors, nurses, etc. with tube information
Who to contact	• For issues • For emergency support • For wellbeing support • Out of hours/24-hour support line • Community nurses • Nutrition Team
Role of the carer and acting as an advocate	• Carer support information • How carers can manage their own meals
Patient support groups info	• PINNT • Local support groups • Facebook groups • Peer support
Format of information	• Information tailored to each person • Images and diagrams to break up the text and coloured pictures of sites • Tips included • Clear instructions • Bare minimum of information and as much information as possible with detailed • Descriptions • Tracker • Leaflet, booklets, online format • FAQ • Up to date information

Many participants (n=149, 62%) reported that they were provided with a list of people to contact to support them to manage the tube when they got home, however some reported they did not have all numbers they needed (n=51, 21%). Thirty-nine (16%) participants reported that they were not provided a contact list and nine (4%) participants that they did not know if they were provided with a list. The list of contact participants suggested that they needed are shown in Figure 1.

Figure 1: List of contact numbers requested by participants



Secondary care contact numbers

- Nutrition Team
- Dietitian
- Nutrition Nurse
- Gastroenterology team
- Hospital
- Ward
- Endoscopy/radiology where tube inserted
- Gastroenterology ward number

Primary care contact numbers

- HEN Team
- Dietitian
- Nutrition Nurse
- Homecare company nurse
- Community nurse/district nurse
- Homecare/equipment supply company
- Macmillan Nurse
- Out of hours
- Emergency
- Local support group
- National support group
- Mental health support
- Carers trained in tube care
- Pharmacist

Additionally, many participants (n=161, 67%) indicated that they used other ways to learn about the tube. These included the PINNT website, Facebook pages, patient support groups in person and online, carers groups, relatives/friends/other tube users experiences of tube feeding, internet searches, reference books in the library, YouTube, Google search, TikTok, speech and language therapist, general practitioner, manufacturers' website, parent forums, e-Learning, and Instagram. Some participants (n=78, 32%) indicated that they did not use other ways to learn about the tube and a few indicated that they did not know (n=3, 1%).

Participants were asked what they thought was the best way to prepare people to go home with a tube and the results are summarised in Figure 2. However, some participants felt that the experience of living with a tube was difficult or impossible to prepare for because it is an individual experience.

Figure 2: Preparing to go home with a tube

Listen and talk

- Time for questions
- Talk to others with a tube
- Explain clearly
- What to expect

Support sources

- Introduce to PINNT
- Video
- Tube and feed info
- Contact information
- What's normal
- Supplies contact
- Meetings
- Plan in place for problems
- Help to carry on working
- Hotline first few days
- Leaflets
- Social media groups
- Written information
- Buddy system
- Join groups before tube fitted to ask questions

Community support

- Community team
- Visited for first advance and rotate
- Pain control
- Community nutrition nurses visit daily/every other day when first go home
- Accept support from friends and family
- Educare family about improtance
- Informed healthcare professionals
- Rucksack available
- Helpline
- Someone at home when discharged
- Lots of storage space

Preparation in hospital

- Build confidence
- Days of training
- Hands on practice in hospital
- Demonstrations
- Don't wait to discharge to train
- Use equipment in hospital
- Time off ward to prepare
- Time to recover before going home
- Checking they know what they need to
- More indepth
- Don't discharge at the weekend
- Expereinced people training

Emotional support

- Recognise life changing
- Time to adjust in hospital before going home
- Not seeing it as a negative
- Focus on positives – no shopping, food bills, cooking
- Support to accept essential for life
- Normal to be upset
- Compassion, ressurance and understanding
- One day at a time
- Normalise the tube and integreat into daily life
- Psychologcal therapy
- Menal health checks
- Products to hide tubes

Managing the tube at home

Most participants (n=138, 57%) reported that the training about the tube that they were given in hospital was not different to what they were advised to do at home. Some participants (n=76, 32%) reported there were differences and 27 (11%) did not know if the training was different.

At home, most participants reported that they could manage the tube themselves (n=164, 68%), however, 51 (21%) participants needed their family to help them with the tube and 26 (118%) relied on nurses or carers to help them with the tube.

Figure 3 shows the participants responses when asked who helped them to manage the tube at home and the support that they received from each healthcare worker. Most participants reported that they were provided with services from Nutricia Homecare (n=141, 58%). They also report support from Abbott Hospital2Home (74, 31%) and Fresenius Kabi Homecare (n=18, 74%). Six participants (3%) reported that they had no homecare company support and 3 (1%) did not know.

Figure 4 shows participants responses when asked how often a review was done by a healthcare professional and how often they would like a review done.

Many participants (n=138, 57%) indicated that the tube was replaced regularly. Eighty (33%) participants reported the tube was not replaced regularly and (10%) did not know. Figure 5 shows reported routine place of insertion and where participants report they would like their new tubes inserted.

Figure 3: Participant reported support to manage the tube at home

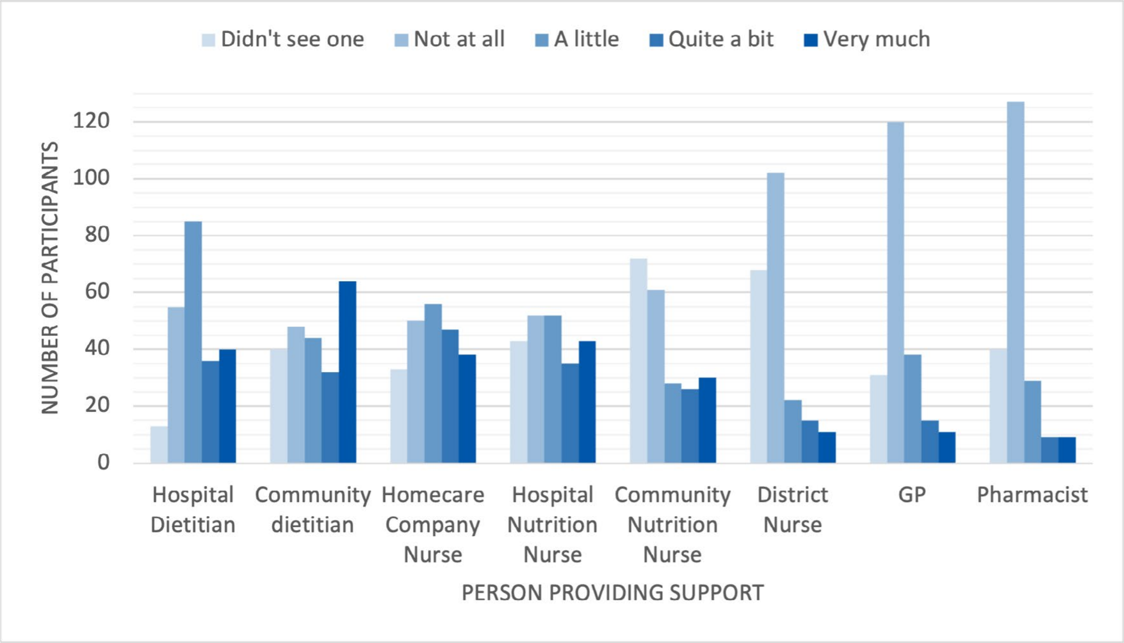


Figure 4: Frequency of review done by a healthcare professional (nurse, dietitian, or doctor)

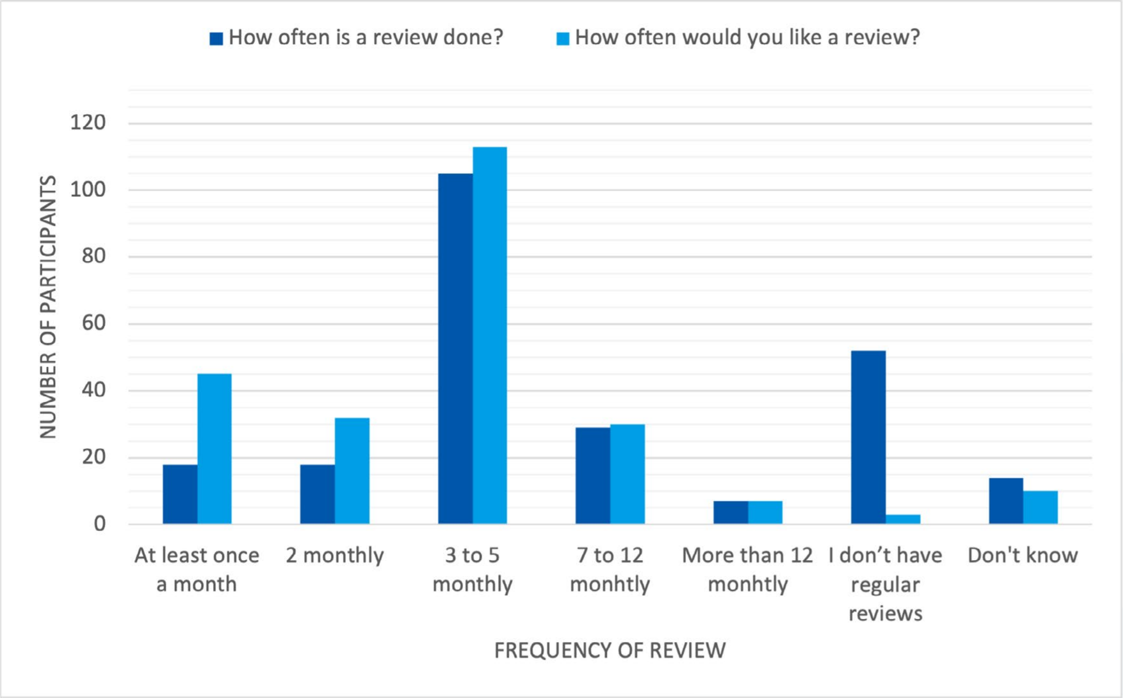
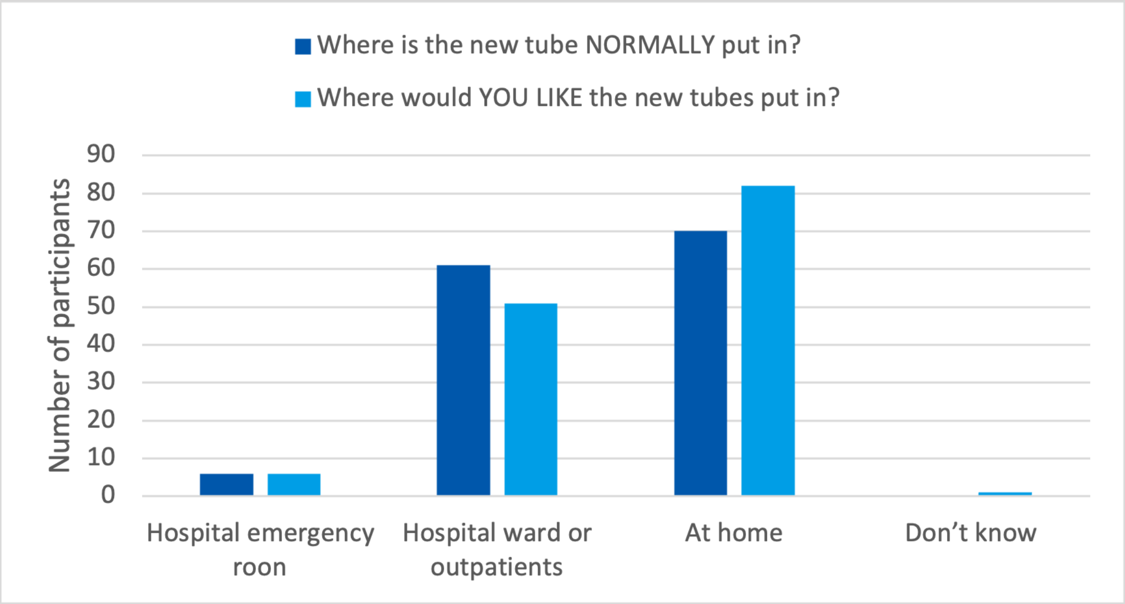


Figure 5: Place of tube insertion



The tube was reported to have fallen out since the person returned home by 105 (44%) people. However, more than half of participants (136, 56%) reported that their tube had not fallen out. When it had fallen out it was replaced in the hospital emergency room (23, 22%), hospital ward or outpatients (42, 40%) and at home (17, 16%). Twenty (19%) participants reported it had been replaced in different places and two (2%) did not know where it had been replaced. If the tube has been replaced only 46 (22%) participants reported it had been replaced once or twice; 30 (14%) had had it replaced three or four times and for 124 (59%) participants, it had replaced more than four times. Twelve (6%) participants did not know how many times it had been replaced.

Participants were asked what they thought would help most when someone's tube fell out. The results are indicated below in Figure 6.

Figure 6 Participants views on what would help if the tube fell out

- Emergency Department to know how to stop the tract closing and how to replace the tube
- Treatment as outpatient while waiting for tube replacement
- Direct referral to radiology or endoscopy by nutrition nurse/dietitian
- Dietitian/hospital nutrition nurse/gastroenterology team/radiologist available 7 days a week

Hospital

- Quick replacement by home service (nutrition nurse/doctor/dietitian)
- Community nurses trained to replace tubes
- Helpline
- Tube that can be placed at home
- Stoma plug
- Training to self place for carers and people with tubes

Community

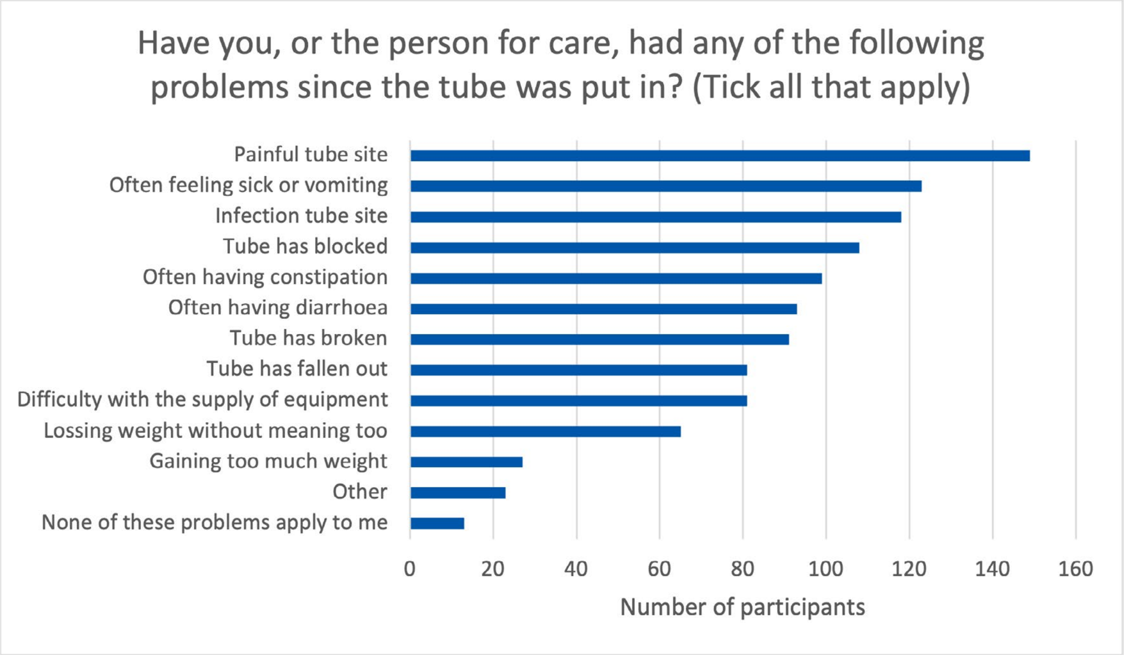
- Plan – clear guidance, who to contact, 24 hour contact, all healthcare workers can access
- Carry card with details of tube
- Replacement kit: spare tube, plugs, adhesive tape, pH strips, lubricant

Person with tube or carer

Participants were asked to indicate from a list if they or the person they cared for had experienced problems. The results are shown in Figure 7.

Figure 7: Problems since the tube was inserted

Participants also described other problems. These included tube issues including buried bumper, the tube moving out of place and the balloon popping or being stuck in the abdominal wall. Tube site problems were also described with overgranulation, leakage from the tube site, thrush and an abscess in the stomach stated as issues. Feed, pump and delivery problems were also described. These included feeling hungry, stomach cramps, the pump breaking, and deliveries being left on the street.



Feelings about tube management

When asked if they felt confident about managing everything to do with the tube, 132 (55%) participants indicated that they felt very confident, 83 (34%) that they felt quite a bit confidents, 24 (10%) a little confidents and only 3 (1%) not at all confident.

Things that participants indicated would help them feel more confident were: more support, better informed healthcare professionals willing to support, more information and more consistent information, regular reviews, having someone to talk to, getting suitable equipment and tubes that came with covers to hide the tube.

Participants were asked "Have you found everything you have to do with the tube takes a lot of effort?". The results are shown in Figure 8. The impact of managing the tube on daily life is shown in Figure 9. Participants indicated that they thought managing the tube had impacted on daily activities quite a bit (n= 67, 28%) or very much (n–78, 32%). However, 80 (33%) participants reported that the tube impacted on daily activities only a little (n=80, 33%) or not at all (n=16, 7%).

Many (n=124, 51%) reported that close friends and family had reacted very well to everything they had to do to mange the tube. Some reported a mixed reaction (n=88, 36%) and some felt the close friends and family didn't like the tube (n=11, 5%), did not know about it (n=8, 3%) or they did not know (n=11, 5%).

When asked how people they did not know reacted to the tube if they had seen it or been told about it 108 (26%) reported a mixed reaction and 63 (26%) reported they reacted very well. Sixty-nine (29%) indicated that they didn't tell people about the tube and kept it hidden.

Figure 8: Effort involved with the tube

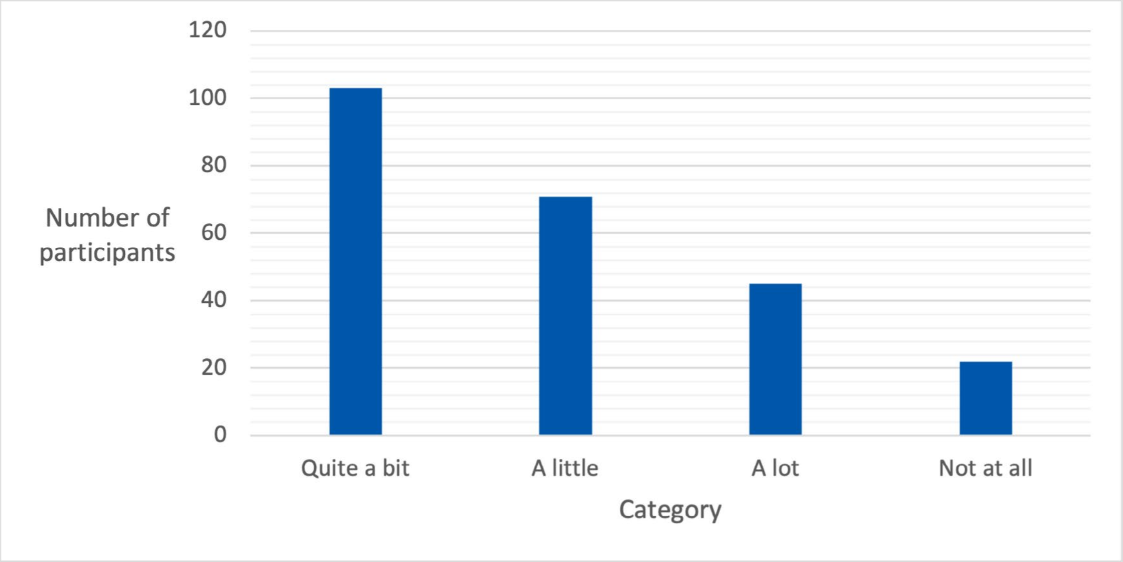
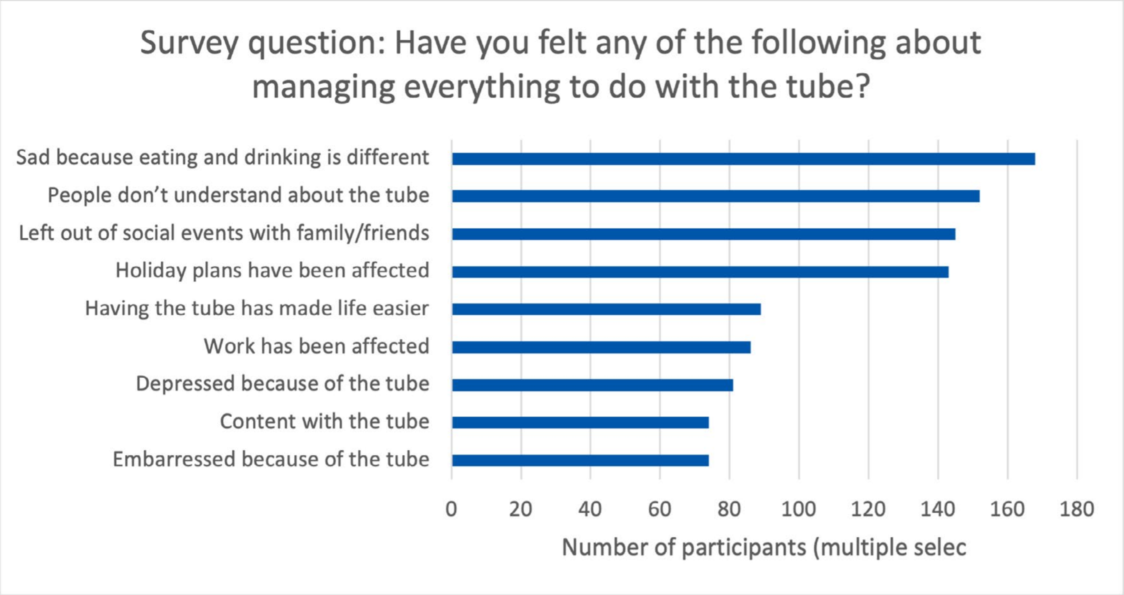


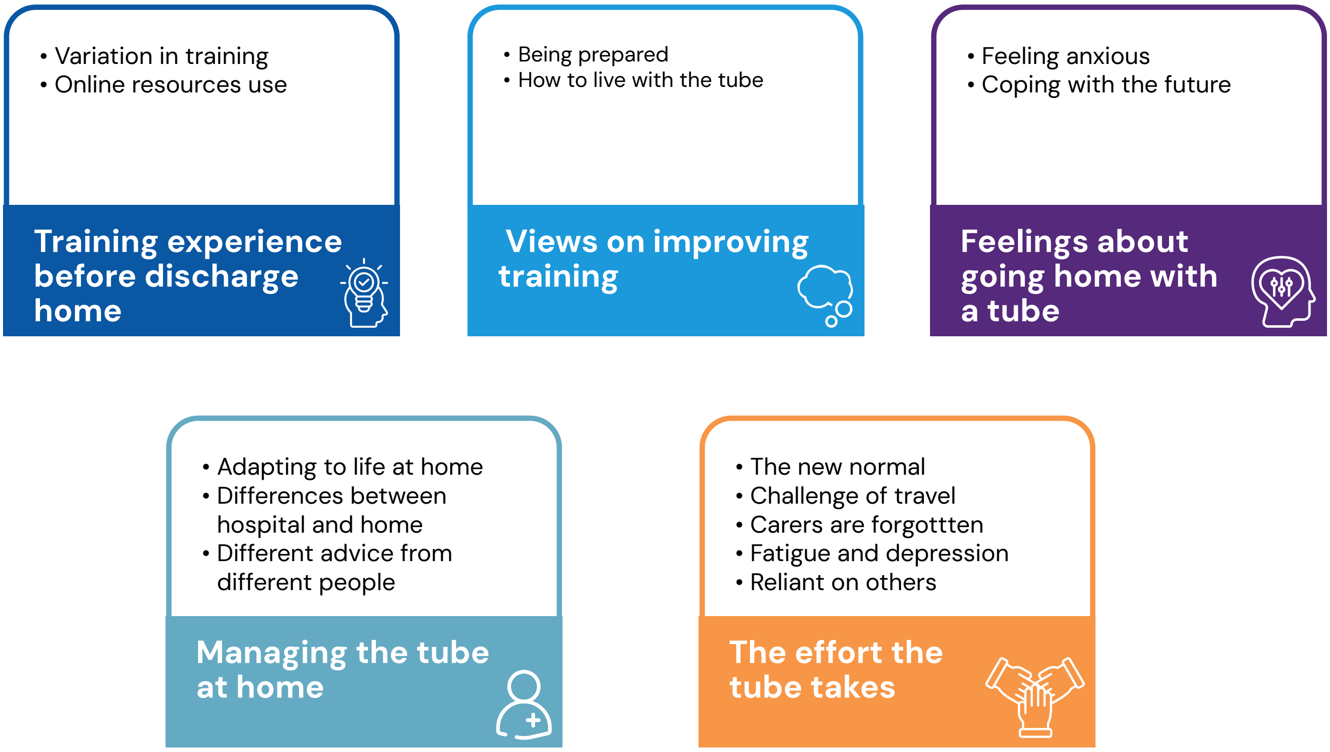
Figure 9: Impact of managing the tube



Qualitative responses

Figure 10 summarise the key themes identified from each of the sections of the questionnaire. These are described in detail below.

Figure 10: Summary of qualitative themes identified from free text in each section of the questionnaire



Training experience before discharge home
- Variation in training
- Online resources use

Views on improving training
- Being prepared
- How to live with the tube

Feelings about going home with a tube
- Feeling anxious
- Coping with the future

Managing the tube at home
- Adapting to life at home
- Differences between hospital and home
- Different advice from different people

The effort the tube takes
- The new normal
- Challenge of travel
- Carers are forgottten
- Fatigue and depression
- Reliant on others

Training experience before discharge home

Participants had the opportunity to describe their experience of training to use the tube before they or the person they cared for with the tube went home. One theme was identified in the participants responses: "variation in training before discharge".

Variation in training

Some participants reported that they had received very little or no training before they were discharged as indicated by the following statements:

> *"PEG nurse in hospital showed me once and got no further training" (ID5690)*

and

> *"I had the tube placed and was sent home without a single ounce of help or compassion" (ID 8393)*

They described that they had trained themselves drawing on previous experience, watching nurses and learning from other people with tubes.

Some participants described an excellent training experience and highlighted the challenges with being prepared:

"I was actually trained once I was at home but the hospital nurses showed me some basics in hospital before I went home" (ID8277)

Several participants described the use of "online resources", particularly YouTube to support their learning:

"Myself, I had to use YouTube videos because nobody showed me what to do." (ID 46).

Views on improving training

When asked to describe how their training could have been improved 149 participants gave their views. The main themes from the responses related to "being prepared" for discharge and managing the tube at home and "how to live with the tube".

Being prepared

Being prepared included the need for thorough training in hospital, what to do when things for wrong and the transition from hospital to home.

The training participants described receiving in hospital varied. Some indicated the training and support received prepared them well and some described being unprepared for going home with a tube. Several participants stated the training in the hospital was too quick for them to absorb all the information was delivered only once. Training which included detailed and repeated sessions at a pace that suited the person was suggested as a way of supporting people to be prepared. This is illustrated in the statement by one participant outlining what would have improved their training:

"More time for questions and to consider the emotional impact of going home with a time and to let it sink it would have been good - I watched a lot of other people on the ward be trained who weren't already familiar with using them and they really struggled to take everything in so quickly, perhaps would be better to do it in smaller chunks or with more guidance (ID3283)".

Many participants outlined that they needed to know what to do when things go wrong and who to contact as exemplified by the statements:

"What to do in hot weather ...Maybe a test of what goes wrong and how to fix it" (ID3393)

Several participants identified the need for more support for the transition from hospital to home. This was described as a need for resources and links to the team supporting them at home. In terms of resources, training booklets, videos, supplies for discharge, helpline information and trouble-shooting advice in printed or email form were described. As one participant stated:

"I felt that it was a challenge to absorb all the information at the time I was told it and would have felt more prepared for going home had I got written instructions so I could read and reread them" (ID7309).

Other participants identified communication between hospital and home settings were key to good training, for example, one participant stated when describing how their training could be improved stated:

> *"I was let down by my dietitian, and no care was organised for me for when I left hospital after fitting, so my husband had to fight for help and support for me" (ID214)*

Whilst others considered the training that they had received supported them in the transition from hospital to home:

> *"I was lucky that my training was excellent (xxx hospital to home nutrition nurse)" (ID6905)*

How to live with a tube

Some participants identified a need to learn about "living with tube feeding" rather than the general management of the tube and associated activities such as feeds, as illustrated by the statements;

> *"How to live, not just survive with tube feeding" (ID1365)*

and

> *"I feel like the practical management of the tube is fine, but there is no mental health or emotional support to help with adjustment in daily living" (ID9688).*

Some considered they had received support that had enabled them to live well with the tube:

> *"I had incredible support throughout enabling me to get my life back" (ID3241)*

Feelings about going home with a tube

Participants were asked what their feelings were about going home with a tube or caring for someone going home with a tube. Most participants responded and key themes that were identified were "feeling anxious" and "coping with the future".

Feeling anxious

Many participants used descriptors such as feeling nervous, overwhelmed, apprehensive, afraid, upset, terrified, worried and daunted to describe their feelings and identified a need for support.

> *"I felt nervous and apprehensive because I'm hospital I was around nurses who knew how to use tubes but coming home it would just be me with no 24 hours support" (ID1765)*

Some participants did not identify that they felt anxious and used descriptors such as fine, OK, alright and no problem. This is exemplified by the statement:

> *"I felt very much at ease going home with it as was giving a booklet containing telephone numbers of people I could ring if need help" (ID1690)*

Coping with the future

Many participants described that they had thought about the future and how they would adapt. Initial feelings were mingled with views of the future and rationalisation of the need for a tube. As one participant stated:

> *"Initially traumatised, but determined to cope. Realising it saves my life" (ID8686)*

Others considered the impact the tube had on their future life:

> *"It's odd. Like suddenly I have this whole new limb that I can't feel but just seems to catch on everything. I always have to be thinking about it in the back of my mind, how I sit, how I lay, What I can wear and what I can physically do without hurting myself. But mostly I miss being able to sit down and eat a plate of food with my family. I never realised how much social interaction is based around food/drink till" (ID5342)*

Managing the tube at home

Training in hospital and home

Participants were asked to provide further information if they wished to describe whether the training that they received in hospital differed from what they were advised to do at home. Eighty-four participants responded to this question and themes arising from the responses are shown in Table 7.

Many participants outlined that management of the tube, feed and medications was adapted as they became more used to the intervention and understood more how they could manage better and learn to live with the tube. For example, flushes were given in a different way, flush volume was reduced, bolus feeding was introduced because of weak hands, skills in managing the site and problem solving were developed.

Others highlighted that there were differences between the care and advice in hospital and at home and there were also differences in advice given by different healthcare professionals at home. Particularly highlighted was that sterile water was used in some settings and tap water in others and the mixing of medications prior to administration in some hospital settings.

Table 5: Differences in training – Key themes with examples of quotes

Theme	Example
Adapting to life at home	"Once I got home and was having issues, the nutrition company nurse gave me different advice to what she had given me in hospital." (ID4181) "I have learned by trial and error the best ways of drawing up the right dosage of meds for my particular meds." (ID5222)
Differences between hospital and home	"The nutrition company used in the hospital was a different one than the one I have at home, due to it being a different hospital trust. This meant changes to my pump and feeds and a new induction. I was also told contradictory information as to whether I needed to finish through the tube with sterilised water or not, Some said yes, others said no need!" (ID7309) "Sterile water advised by hospital and dietitian, feeding tube company said tap water, despite going into intestines!" (ID9115)
Different advice from different people	"Community dietitians and my CNS nutrition nurse give different advice. My GP gives different advice. It's very difficult to navigate and find a team that you trust, but also know whose information 'trumps' the others with regards to a specific issue." (ID7801) "Dietitians and nurses always tell us to check the balloon weekly. Our consultant surgeon told us to never do this as it puts unnecessary strain on the balloon meaning it is more likely to become slack and loose." (ID9885)

The effort the tube takes

Participants were asked to expand on whether they found everything to do with the tube takes a lot of effort. One hundred and one participants responded, and five key themes were identified. These are shown in Table 6.

Table 6: The effort the tube takes – Key themes with examples of quotes

Theme	**Example**
The new normal	"It's changed over time. It's our new normal now." (ID5882) "It's a way of life that just becomes your everyday life." (ID6378) "I feel like a nurse at times. It's overwhelming when things go wrong. But most days it's normal life and we make accommodations very naturally." ID2764
Challenge of travel	"I sometimes think/worry about it being a problem when I travel away from home." (ID6576) "I'm going on holiday and it takes a lot of organising – a trunk is provided but it will be very heavy." (ID9044)
Carers are forgotten	"Carers are forgotten, never asked how I am. I would like a break." (ID1365) "As the carer I feel they don't tend to listen to me as the person I help is an adult, as they say, with capacity, but I know what is happening, I live with it too." (ID7981)
Fatigue and depression	"I suffer badly with fatigue and everything can be a major effort." (ID3797) "Sleep deprivation is an issue that impacts each day and feeling sick. feel neglected at home and remote from seeking medical support and understanding." (ID5909) "When living with a chronic condition you fatigue extremely easily. You have to re-think how you go about daily life, having to carry a backpack (which inflames my shoulders)." (ID6410)
Reliant on others	"I asked xxxx (feed company) for three things, one thing is I just want them to keep me alive by sending my feed, two is to treat me and everyone else with respect, and three to treat me and everyone else with compassion. I have never cried so much as I have recently." (ID3849) "NHS provides no support for emergency tube changes, which is totally unacceptable." (ID9885) "The thing that takes time is arranging supplies and chasing them up." (ID5645)

Comments on survey

Finally participants were asked if they would like to add anything following the final question of the survey. One hundred participants responded and summarised their overall feelings. These included comment on the essential nature of the tube but the fact that it has changed their life. This is exemplified by the statements:

> *“My tube has made a huge difference to my life. While it makes planning holidays and trips out more complex, it has given me the nutritional support to be able to go out and do the things I love” (ID4181)*

> *“I have had an array of emotions about my PEG both good and bad. There have been some wonderful improvements in my quality of life and general care needs but there has also been a lot of sadness surrounding the social aspect I’ve not eating and drinking which has caused depression at times” (ID9631)*

The tube was described as affecting social life, work, home, family life and causing complication. Final comments included health workers lack of knowledge about tube management and the psychological effects.

The need for the study was acknowledged by several participants as illustrated by this statement.

> *“I’m so glad you are doing this study! Thank you! There’s so little awareness in the general public about feeding tubes and even healthcare professionals often don’t have much knowledge about them” (ID6098).*

Discussion

This national survey of 242 respondents has provided a wealth of information about how people with an enteral tube who live at home, and their carers navigated the process of tube insertion and management at home and the support that they consider they needed.

The mixed method approach of open and closed survey questions provided the opportunity to summarise key aspects of people experiences and needs concerning enteral nutrition at home. The voice of participants is heard clearly in the qualitative component of this survey. The approach of providing free text questions within the survey allowed participants to express their own views and contributed to the findings, providing richness, clarification and emphasis.

The findings suggested that some participants felt they lacked the support that they needed both in hospital and following discharge. This was in terms of training, adaptation to living with a feeding tube and co-ordination of care.

This is in accordance with other published findings focussed on the experience of carers supporting people at home with enteral nutrition both in the UK and other countries. Mou et al. (2021) undertook a systematic review of qualitative research focussed on the experiences and needs of caregivers providing enteral nutrition. This review of ten studies identified that carers develop coping strategies to enable them to manage enteral nutrition without standardised training and support services (Mou et al., 2021). A study of 20 caregivers in one area of Iran (Doosti-Irni et al., 2021) identified that carers felt that they lacked knowledge and education about enteral tube feeding and, importantly, highlighted the importance of preparation in the hospital setting as there are regional differences in the availability of resources to support people living at home.

This study identifies what people with tubes and their carer consider “good” and the recommendations below are aimed at supporting local and regional services to meet the needs of people with enteral tubes and their careers and identify areas for improvement. Recommendations for preparation of discharge of people with HEN and services to support people with HEN should include several key components to ensure comprehensive and coordinated care for individuals with enteral feeding tubes and reduce variability between level and quality of care provided.

Recommendations

The purpose of these recommendations arising from the views of people with a tube and their carers on what "good looks like", is to articulate baseline standards and provide a holistic and patient-centred approach to managing enteral nutrition at home, ensuring safety, efficacy and quality of life for people with an enteral feeding tube and their carers.

1. Assesment and planning

Individualised care plans: development of a personalised plan of care with the person with the tube and/or their carer, including the type of feed, method of delivery, and target nutritional intake (https://www.bapen.org.uk/education/nutrition-support/enteralnutrition/home-enteral-nutrition/).

Healthcare professional contact within 24 hours when people first discharged home with an enteral tube.

2. Training and education

People with the tube and their carer training and education: consistent initial and ongoing training, and written information on living at home with an enteral tube. Written information provided when tube inserted via suitable media (https://www.bapen.org.uk/education/nutrition-support/enteralnutrition/home-enteral-nutrition/).

Healthcare professional contact within 24 hours when people first discharged home with an enteral tube (https://www.nice.org.uk/Guidance/CG32).

3. Coordination of care

Multidisciplinary team approach: regular coordination among dietitians, nurses, and other healthcare workers to monitor with adjustment of the plan of care as needed (https://www.bapen.org.uk/education/nutritionsupport/enteral-nutrition/home-enteral-nutrition/).

Seamless transition from hospital to home: clear pathways for discharging people with a tube from hospital to home, including provision of necessary supplies and contact details for support services (https://www.bapen.org.uk/education/nutrition-support/enteralnutrition/home-enteral-nutrition/).

4. Monitoring and support

Regular monitoring: ongoing monitoring with the person with a tube and/or carer with adjustment of the feeding regimen as required, and review of tube and ancillaries and lifestyle needs (https://www.bapen.org.uk/education/nutrition-support/enteralnutrition/home-enteral-nutrition/).

Support services: list of contacts with availability provided via suitable media.

Access to out-of-hours support, home care delivery services for supplies, and regular follow-up visits from appropriately educated healthcare professionals (https://www.bapen.org.uk/education/nutritionsupport/enteral-nutrition/home-enteral-nutrition/).

Recommendations

5. Guidelines and standards

National guidance adherence: compliance with NICE guidance (National Institute for Health and Care Excellence) for the administration and monitoring of enteral nutrition (https://www.nice.org.uk/Guidance/CG32).

Infection prevention: adherence to infection prevention protocols to minimise risks associated with enteral feeding, including minimising infection risk from feed, tube flushing and stoma aftercare, in line with local infection control policy (https://www.bapen.org.uk/education/nutritionsupport/enteral-nutrition/home-enteral-nutrition/).

6. Person-centred care

Quality of life considerations: ensuring that the feeding regimen fits into the person's daily routine and minimises the impact on their life. Includes the provision of socio-emotional/psychological support and advice, where required/requested (https://www.bapen.org.uk/education/nutritionsupport/enteral-nutrition/home-enteral-nutrition/).

Feedback mechanisms: systems for people with a tube and their carers to provide timely feedback on the services and care they receive (https://www.bapen.org.uk/education/nutrition-support/enteralnutrition/home-enteral-nutrition/).

Contributions

Carolyn Wheatley has extensive experience of representing the group at a national level and **Lorna Leaston** has extensive experience of HEN. Both are members of the research team and involved in the development of the protocol and the study conduct from the start. **Sue Green** designed, conducted and analysed the survey results. **Liz Anderson** and **Michelle Sutcliffe** provided input on the questionnaire design and findings.

References

Boland, K., Maher, N., O'Hanlon, C., O'Sullivan, M., Rice, N., Smyth, M. & Reynolds, J. V. (2017) Home enteral nutrition recipients: patient perspectives on training, complications and satisfaction. Frontline Gastroenterol, 8 (1), 79-84.

British Artificial Nutrition Survey Committee (2018) Home Enteral Tube Feeding (HETF) in Adults (2010-2015).

Byrnes, C., Mockler, D., Lyons, L., Loane, D., Russell, E. & Bennett, A. E. (2022) A scoping review of best practices in home enteral tube feeding. Prim Health Care Res Dev, 23, e43.

Dinenage, S., Gower, M., Van Wyk, J., Blamey, A., Ashbolt, K., Sutcliffe, M. & Green, S. M. (2015) Development and evaluation of a home enteral nutrition team. Nutrients, 7 (3), 1607-1617.

Doosti-Irani, M., Goojani, F.H., Vardanjani, L.R, & Noorian, K. (2021) Care without sufficient knowledge of people with home enteral tube feeding: a qualitative study. Gastrointestinal Nursing, 19 (10), 26-34.

Flood, C., Parker, E. K., Kaul, N., Deftereos, I., Breik, L., Asrani, V., Talbot, P., Burgell, R. & Nyulasi, I. (2021) A benchmarking study of home enteral nutrition services. Clin Nutr ESPEN, 44, 387-396.

Green, S., Dinenage, S., Gower, M. & Van Wyk, J. (2013) Home enteral nutrition: organisation of services. Nurs Older People, 25 (4), 14-18.

Green, S. M., Townsend, K., Jarrett, N. & Fader, M. (2019) The experiences and support needs of people living at home with an enteral tube: a qualitative interview study. J Hum Nutr Diet, 32 (5), 646-658.

Jackson, C. J. & Furnham, A. (2000a) Designing and analysing questionnaires and surveys: a manual for health professionals and administrators. Whurr Publishers Ltd., London.

Jackson, J. C. & Furnham, A. (2000b) Designing and analysing quesitonnaires and surveys: a manual for health professionals and administrators. Whurr Publishers Ltd., London.

Jisc. (2023) Improving lives through digital transformation. Available https://www.jisc.ac.uk/. (accessed 21/02/23 2023).

Klek, S., Szybinski, P., Sierzega, M., Szczepanek, K., Sumlet, M., Kupiec, M., Koczur-Szozda, E., Steinhoff-Nowak, M., Figula, K., Kowalczyk, T. & Kulig, J. (2011) Commercial enteral formulas and nutrition support teams improve the outcome of home enteral tube feeding. J Parenter Enteral Nutr, 35 (3), 380-385.

Majka, A. J., Wang, Z., Schmitz, K. R., Niesen, C. R., Larsen, R. A., Kinsey, G. C., Murad, A. L., Prokop, L. J. & Murad, M. H. (2014) Care Coordination to Enhance Management of Long-Term Enteral Tube Feeding. Journal of Parenteral and Enteral Nutrition, 38 (1), 40-52.

Mou, J., Sun, J., Zhang, R., Yang, Y., Yang, W. & Zhao, X. (2022) Experiences and needs of home caregivers for enteral nutrition: A systematic review of qualitative research. Nursing Open, 9, 11021.

National Collaborating Centre for Acute Care (2006) Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition.

National Specialised Commissioning Group (2008) A Strategic Framework for Intestinal Failure and Home Parenteral Nutrition Services for Adults in England. England, National Health Service.

Ojo, O. (2015) The challenges of home enteral tube feeding: a global perspective. Nutrients, 7 (4), 2524-2538.

PINNT. (2023) All about PINNT. Available https://pinnt.com/About-Us/All-About-PINNT.aspx. (accessed 23rd January 2023).

Wong, A., Banks, M. D. & Bauer, J. D. (2018) A Survey of Home Enteral Nutrition Practices and Reimbursement in the Asia Pacific Region. Nutrients, 10 (2).

Appendix 1

Advertisement for patient group website and social media (Version 1 22/02/2023).

Do you have a tube into your stomach or small intestine (a PEG, RIG, nasogastric or other type of tube) that you use for water, feed or medication, or do you care for someone with a tube like this?

Do you live at home in the UK and are you over 18 years of age?

We are undertaking a research study to help to develop recommendations about what services should be provided for people with a tube living at home.

We are asking people to take part in an online survey. We want to find out about people's experiences of managing a tube at home and their views on what services should be provided for people with tubes.

If you would like to know more about the research study and survey, please click on the following link:

If you would prefer a paper copy please email PINNT who will be able to provide you with one.

Bournemouth University Research Ethics Committee ID 48379.

Appendix 2

Link to Whole Survey PDF: https://www.bapen.org.uk/pdfs/appendix-2-hen-survey.pdf

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