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RESEARCH ARTICLE

Development of 'gastrostomy tube – is it for me?', a web-based patient decision aid for people living with motor neurone disease considering having a gastrostomy tube placed

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Abstract

Objective: To develop and pilot a web-based patient decision aid (PDA) to support people living with motor neurone disease (plwMND) considering having a gastrostomy tube placed. *Methods*: In Phase 1, content and design were informed by semi-structured interviews, literature reviews and a prioritization survey. In Phase 2, the prototype PDA was tested with users and developed iteratively with feedback from surveys and 'think-aloud' interviews. Phase 1 and 2 participants were plwMND, carers and healthcare professionals (HCPs). In Phase 3, the PDA was evaluated by plwMND using validated questionnaires and HCPs provided feedback in focus groups. *Results*: Sixteen plwMND, 16 carers and 25 HCPs took part in Phases 1 and 2. Interviews and the literature review informed a prioritization survey with 82 content items. Seventy-seven per cent (63/82) of the content of the PDA was retained. A prototype PDA, which conforms to international standards, was produced and improved during Phase 2. In Phase 3, 17 plwMND completed questionnaires after using the PDA. Most plwMND (94%) found the PDA completely acceptable and would recommend it to others in their position, 88% had no decisional conflict, 82% were well prepared and 100% were satisfied with their decision-making. Seventeen HCPs provided positive feedback and suggestions for use in clinical practice. *Conclusion*: *Gastrostomy Tube: Is it for me?* was co-produced with stakeholders and found to be acceptable, practical and useful. Freely available from the MND Association website, the PDA is a valuable tool to support the shared decision-making process for gastrostomy tube placement.

Keywords: *Motor neurone disease, gastrostomy, patient decision aid*

Introduction

Due to the multisystem effects of motor neurone disease (MND), people living with MND (plwMND) are faced with many complex healthcare decisions, including whether to have a gastrostomy tube placed. Gastrostomy tubes are routinely offered to plwMND to manage the challenges and negative outcomes associated with dysphagia and malnutrition, based on the assumption that the risk of aspiration will be reduced and nutritional status, survival and quality of life (QOL) will be improved. However, the evidence base to support these assumptions is lacking - there are no randomized controlled trials and

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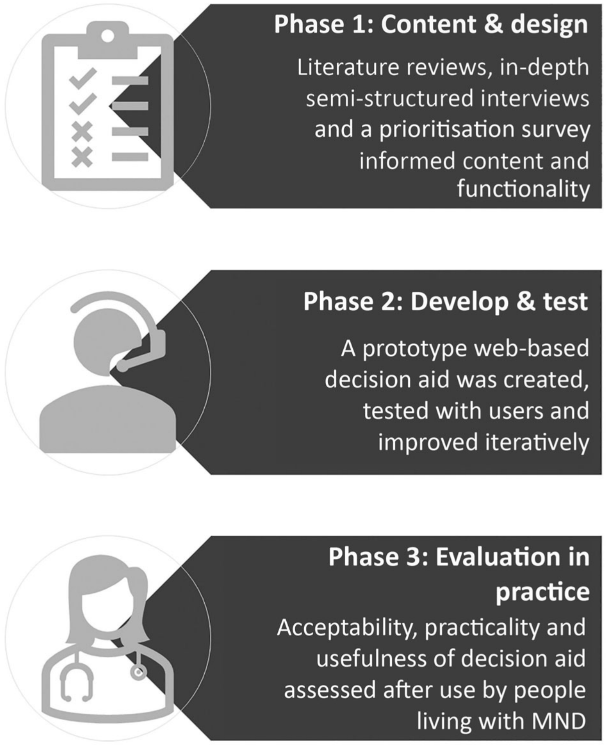
results from observational studies are equivocal (1) – meaning that current guidelines are not evidence-based (2–4). While a recent systematic review concluded that percutaneous endoscopic gastrostomy (PEG) probably prolongs survival in non-malnourished patients, the impact on QOL remains unclear (5).

In the UK, artificial feeding is considered by law to be a medical treatment so informed consent is required for adults with the capacity and the right to refuse treatment is recognized (6) (Separate guidance is available for adults who lack the capacity to consent (7).) Obtaining informed consent is part of shared decision-making, defined as '… a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care' (8). The aim of shared decision-making is to empower people to make decisions about their care which are right for them, based on both the available evidence and the person's individual preferences, beliefs and values (8). A well-constructed patient decision aid (PDA) can be a valuable tool to support shared decision-making. By presenting evidence-based information, communicating the risks and benefits associated with each option, checking understanding and clarifying personal values and preferences, a PDA can help plwMND decide whether a gastrostomy tube is appropriate for them (9). Support for decision-making may be particularly welcome given the complexity of the decision: gastrostomy feeding can have a significant impact on an individual's everyday life, with both positive and negative consequences (10), and prolonging life is not a goal for all plwMND (11–13).

Whilst web-based PDAs have been developed in Australia (https://mnddecisiontools.com/public/1/decision_tool) and the US (https://lesturnerals.org/nutrition/about-this-decision-tool/), this is the first study to document the development and pilot testing of a web-based PDA to support plwMND in the UK considering a gastrostomy.

Materials and methods

This was a mixed methods study, with three phases. There were two phases of PDA development, followed by a third phase of a preliminary evaluation of the PDA in practice (see Figure 1). PDA development observed the Medical Research Council's guidance for the development of complex interventions (14), a published process for developing web-based decision aids (15) and International Patient Decision Aid Standards (IPDAS) (16). A study advisory committee (SAC) including plwMND, their carers, and healthcare professionals and researchers with experience in MND and/or patient decision-making had oversight of both the study and the PDA itself. Ethical approval for Phases 1-2 was provided by the West of Scotland Research Ethics Service, reference 17/WS/0078, and by London - Surrey Borders Research Ethics Committee, reference 18/PR/0571, for Phase 3. All participants provided written informed consent. Reporting follows Standards for UNiversal reporting of patient Decision Aid Evaluation studies (SUNDAE) guidelines (19).



Phase 1: Content & design

Literature reviews, in-depth semi-structured interviews and a prioritisation survey informed content and functionality

Phase 2: Develop & test

A prototype web-based decision aid was created, tested with users and improved iteratively

Phase 3: Evaluation in practice

Acceptability, practicality and usefulness of decision aid assessed after use by people living with MND

Figure 1. Process for the development and evaluation of the Patient Decision Aid.

Participants

In Phases 1 and 2, plwMND and carer participants were recruited from MND and palliative care clinics, hospices, support groups and via adverts on social media. Healthcare professionals were recruited directly by the research team, via a member of the advisory committee, or through adverts on social media and professional groups. In Phase 3, plwMND were recruited through members of their clinical care team at research sites and via social media, the MND Association website, research network, support groups and social media.

Phase 1

Phase 1 consisted of two literature reviews, interviews and a prioritization survey. The first literature review, conducted in July 2019, used search terms related to neurodegenerative disease, decision-making/information need and nutrition support to identify qualitative studies that included data on the information required by people with neurodegenerative conditions considering a gastrostomy. The second literature review, conducted in September 2019, used search terms related to decision-making, patients/carers and digital interventions, to identify web-based PDAs for any condition and studies describing their development and evaluation. For both literature reviews the following databases were searched: Medline, Web of Science, Embase and CINAHL. Two reviewers screened titles and abstracts. Full texts were retrieved if suggested by either reviewer. Both reviewers checked papers for relevant data with any disagreements were resolved through discussion.

Cross-sectional, semi-structured interviews with plwMND, carers and HCP participants explored personal experiences of gastrostomy (plwMND and carers only); key information required for decision-making; what a PDA might contain and look like; when to introduce a PDA; and how to meet carers' needs. The interview guide was sent to participants prior to the interview, providing thinking time and assisting those with communication difficulties. Interviews took place either in person or by telephone at a time and place convenient to the participant. All interviews were audio-recorded and transcribed verbatim.

Suggested PDA content from the first literature review and interviews were extracted to a framework, the main themes of which were based on the interview guide topics (20). A prioritization survey was created in iSurvey (University of Southampton online software) by extracting each suggested piece of content from this framework and asking respondents to indicate whether it must, should, could or should not be included in the PDA (MoSCoW prioritization model (17)). All Phase 1 participants and the SAC were invited to complete the survey. Formal rules for item exclusion and inclusion were not applied, but the results from the survey were discussed in conjunction with PDA standards to determine what content to include and the prominence of the content.

For the second literature review, all accessible web-based PDAs were viewed and features which worked well were noted. In addition, the outcome measures which were used to evaluate the PDAs were tabulated to inform the Phase 3 outcome framework.

Phase 2

The prototype PDA was designed using international PDA standards (supplementary material S1, (21)) alongside data from the prioritization survey, which informed both content and prominence of the content. To ensure the accuracy of the information, all content was carefully checked against the evidence base, including guidelines, best practice documents and published papers, as well as being reviewed by the SAC. The PDA was drafted in PowerPoint, with one slide representing each screen. The website developer used these slides to develop the online version.

Alpha testing involved asking all Phase 1 participants to review the online PDA and complete an online feedback survey on clarity of information, presentation, functionality and perceptions of utility. For each section, participants were invited to highlight any information that was unclear or missing, and if there was anything they would change about the appearance. General feedback and additional comments were also encouraged. Following a review of the feedback with the SAC, a second version of the PDA was produced for beta testing, which used the 'think aloud' method (18). New patients, carers and HCPs talked through their thoughts whilst using the PDA. Beta testing was carried out via video calls due to the COVID pandemic. All interviews were recorded. Text related to changes was transcribed and reviewed. The PDA was revised as necessary after each session until no new changes were suggested (data saturation). The final version of the PDA was checked and approved by the SAC.

Phase 3

Phase 3 was open from May 2021 to June 2022. Participants were invited to use the PDA as they wished and then complete the SURE measure of decisional conflict (22), preparation for decision-making scale (9), satisfaction with the decision scale (23), and a brief survey to evaluate the acceptability of the decision aid. At the end of Phase 3, three online focus groups were held with HCPs to get feedback on the PDA and to discuss implementation. Focus groups were audio-recorded, transcribed, summarized and then analyzed using framework analysis (20).

Results

Phase 1

The first literature review, which aimed to find the information required by people with neurodegenerative conditions considering a gastrostomy, identified 153 records through database searching. After duplicates were removed, 109 titles and abstracts were screened, 25 full-text articles were assessed for eligibility and nine were found to include relevant data (11,12,24–30).

A total of 37 phase 1 interviews were carried out, 10 with plwMND, 12 with carers and 15 with HCPs. See Table 1 for characteristics of the plwMND group. Four individuals already had a gastrostomy when interviewed, three had not yet made the decision, two were awaiting the procedure and one had decided against it. More carers were men (7/12), with a mean age of 67 years (range 52-80 years), and eight had a degree or equivalent. Five were caring for plwMND who had a gastrostomy. HCPs included neurology, neuro-rehabilitation and palliative care consultants, dietitians, specialist nurses, and speech and language therapists, with between 3 and 37 years of experience working with plwMND (mean 14 years).

Relevant data from the literature review and interviews were extracted to the same framework (supplementary material, S2 and S3). The prioritization survey, drawn from this framework, included 82 items of content. It was completed by 5 plwMND, 8 carers and 12 HCPs who had all taken part in the Phase 1 interview and 10 members of the SAC. Most of the items of content (63/82, 77%) were retained.

The second literature review, which aimed to identify studies describing the development and/or evaluation of web-based PDAs, found 1343 records through database searching. After duplicates were removed, 855 titles and abstracts were screened, 95 full-text articles were assessed for eligibility and 25 were relevant. Findings are summarized in supplementary material S4. Most of the decisions are related to cancer ($n = 17$). The majority of studies were conducted in the United States ($n = 14$), with four in the Netherlands, three in Australia and one each in Canada, Germany, Spain and the UK. None of the studies developed a decision aid for MND. The most commonly used outcome measures were the Decisional Conflict Scale ($n = 15$) (31–45), Preparation for Decision Making Scale ($n = 7$) (32,33,39,41,45–47), Decisional Regret Scale ($N = 5$) (36,38,41,45,46) and Control Preferences Scale ($n = 5$) (42–46). Typically, bespoke measures were used to capture the knowledge of a disease or its treatment. It was possible to view 6/25 (24%) PDAs included in the studies.

Phase 2

A total of 20 Phase 2 interviews were carried out with six plwMND, four carers and ten HCPs. See Table 1 for characteristics of the plwMND group. Two individuals already had a gastrostomy when interviewed, two had not yet made the decision, and two were awaiting the procedure. The four carers were all women, with a mean age of 52 years (range 34–61 years), and two had a degree or equivalent. HCPs included a retired hospice medical director, speech and language therapists, dietitians, MND care coordinator, and specialist nurse, each with between 3 and 30 years of experience working with plwMND (mean 13 years).

Alpha testing feedback on the initial draft of the PDA included: general changes to formatting to help with navigation through the PDA; adding an explanation of what a PDA is and clarifying who this PDA is for; and recommendations to add extra detail or clarity on some of the technical terms used. In beta testing of the revised prototype, feedback included: changing the order of the content so that the key information section came immediately after the introduction page; formatting changes to the text; amendments to explanations about button tubes and information about the procedure. The outline for the final version of the PDA, named *Gastrostomy tube – Is it for me?*, is

Table 1. Characteristics of people living with MND participants.

	Phase 1 ($n = 10$)	Phase 2 ($n = 6$)	Phase 3 ($n = 17$)
Sex (% male)	70% Male	83% Male	59% Male
Age (years)	70 (56–90)	62 (50–67)	66 (52–76)
Ethnicity	90% White British 10% Indian	100% White British	94% White British 6% White Irish
Level of education	30% degree or equivalent 20% GCSE/O level 50% unknown	33% GCSE/O Level 67% Unknown	47% degree or equivalent 12% A Level 29% GCSE/O level 12% No qualifications
Employment status	80% Retired 10% Self-employed 10% Disabled, unable to work	66% Retired 17% Self-employed 17% Employed	–
Subtype of MND	80% ALS 10% PLS 10% PBP	100% ALS	–
Site of onset	80% Limb 10% Bulbar 10% respiratory	67% Limb 33% Bulbar	–
Stage of disease	80% Symptoms progressing 20% Advanced	83% Symptoms progressing 17% Advanced	–
Gastrostomy tube already placed at the time of the interview	40%	33%	29%

shown in Table 2 and some screenshots are provided in Figure 2.

Phase 3

In Phase 3, 17 plwMND completed the questionnaires after using the PDA (see Table 1 for characteristics). Most (12/17) did not have a gastrostomy when they completed the questionnaires. For the acceptability questions, 16/17 (94%) found the PDA completely acceptable and would recommend it to other people in their position. The participant who would not recommend it did not view 'no intervention' as a viable choice so did not believe there was a decision to be made about gastrostomy tube placement, "If you are losing the ability to swallow, you need a PEG to stay alive. Full stop. It's not a decision". After using the PDA, 15/17 (88%) had no decisional conflict, 14/17 (82%) had a high score on Preparation for Decision Making and 17/17 (100%) had a high score on Satisfaction with Decision Making.

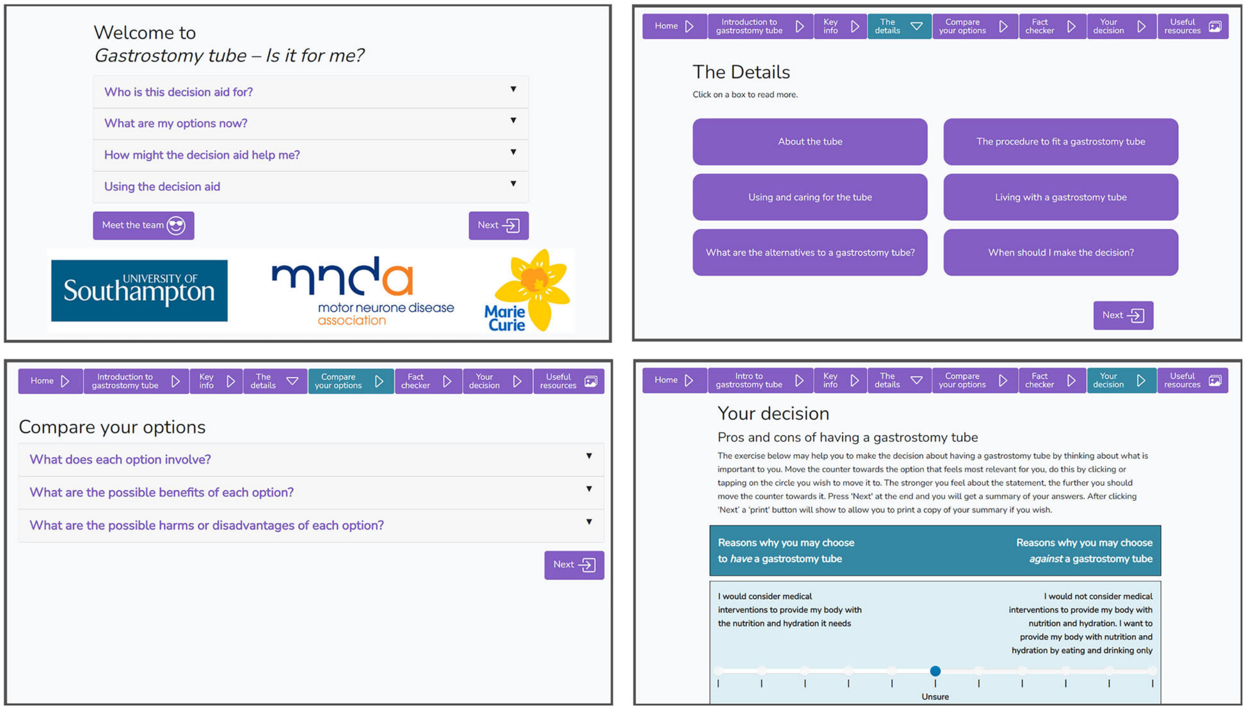
The three HCP focus groups were attended by a total of 17 HCPs who worked with people with MND, including dietitians, specialist nurses, occupational therapists and palliative care doctors. Findings are shown in supplementary material S5. Most of the feedback was positive, with participants commenting that the PDA was straightforward and pooled all the relevant information in one place. However, there were suggestions for further content, some wording changes and the addition of videos. Suggested barriers to PDA use were mainly related to digital exclusion. Participants noted that when resources were publicly available, the need for governance processes was negated, and tools could be integrated into clinical practice at the discretion of the individual, as a team decision or through direction by senior colleagues. Key to implementation was therefore widespread dissemination, and avenues for this were suggested. Whilst there was universal agreement that training was not required for using the PDA itself, it was suggested that some HCPs could benefit from additional training in communication skills, advanced care planning and tube withdrawal.

Discussion

This study describes the development and preliminary evaluation of *Gastrostomy tube – Is it for me?*, the first UK PDA to support plwMND in gastrostomy tube placement decision-making. The PDA was developed to support individuals to make an informed choice about gastrostomy tube placement, consistent with their personal values, and as such facilitates the shared decision-making process. *Gastrostomy tube – Is it for me?* was developed following standard methods, including literature reviews, semi-structured interviews and 'think aloud' interviews, over two phases. In phase 3, plwMND completed validated measures of decisional conflict, decision preparation and satisfaction and an acceptability survey, and feedback from HCPs was acquired through focus groups, along with their thoughts on how *Gastrostomy tube*

Table 2. Content outline of Gastrostomy tube – is it for me*?*

Section of PDA	Content
Welcome	• Who is the decision aid for? • What are my options now? • How might the decision aid help me? • Using the decision aid
Introduction to gastrostomy tube	• Information on what a gastrostomy tube is • Why people with MND are offered a gastrostomy tube
Key information	Answers to frequently asked questions to help decide whether to have a gastrostomy tube. Questions include: • Will I be able to eat and drink with a gastrostomy tube? • How does the tube stay in place?
The details	Contains detailed information on: • The gastrostomy tube • The procedure to fit a gastrostomy tube • Using and caring for the tube • Living with a gastrostomy tube • What are the alternatives to a gastrostomy tube • When should the decision be made
Compare your options	A summary of what each option involves, the benefits of each option, and the possible harms of each option.
Fact Checker	A series of eight questions to check the knowledge of the facts. The answers are displayed below each response after a response has been selected.
Your decision	An exercise to help make a decision about a gastrostomy tube by moving a counter toward a statement that feels most relevant.
Useful resources	Links to relevant resources that provide reliable information.



Welcome to
Gastrostomy tube – Is it for me?

Who is this decision aid for?
What are my options now?
How might the decision aid help me?
Using the decision aid

The Details

Click on a box to read more.

Compare your options

What does each option involve?
What are the possible benefits of each option?
What are the possible harms or disadvantages of each option?

Your decision

Pros and cons of having a gastrostomy tube

The exercise below may help you to make the decision about having a gastrostomy tube by thinking about what is important to you. Move the counter towards the option that feels most relevant for you, do this by clicking or tapping on the circle you wish to move it to. The stronger you feel about the statement, the further you should move the counter towards it. Press 'Next' at the end and you will get a summary of your answers. After clicking 'Next' a 'print' button will show to allow you to print a copy of your summary if you wish.

Reasons why you may choose to *have* a gastrostomy tube	Reasons why you may choose *against* a gastrostomy tube
I would consider medical interventions to provide my body with the nutrition and hydration it needs	I would not consider medical interventions to provide my body with nutrition and hydration. I want to provide my body with nutrition and hydration by eating and drinking only

Figure 2. Screenshots of 'Gastrostomy tube – is it for me?'.

– *Is it for me?* could be integrated into clinical practice.

At the start of the PDA, it is made clear that the choice being made is whether to have a gastrostomy tube or not and deciding not to have a gastrostomy tube could have one of three meanings: the individual never wants a tube, they do not want a tube now but will reconsider in the future or they are currently unsure. This recognizes that making the decision about having a gastrostomy is a process and as long as the physical condition allows, the decision can be revisited. This is necessary because, for those people who do not have dysphagia and are not currently losing weight, the decision can seem very abstract and not relevant (48,49). In addition, whilst some people may resist the idea of a gastrostomy tube when first discussed, viewing it as a symbol of deterioration, later on in the disease trajectory, they may come to view it as offering symptomatic relief and easing of concerns (30).

The issue around the timing of when the topic of gastrostomy tubes should be raised with plwMND is distinct but clearly related. We consider this in detail in a separate paper, which draws on both the interviews carried out for the development of *Gastrostomy tube – Is it for me?* and a systematic search of the literature (50). *Gastrostomy tube – Is it for me?* does not provide any guidance on when to introduce the topic of gastrostomy tubes to plwMND or when to go ahead with the procedure - it focuses on the decision about whether to have a gastrostomy tube placed.

How and when HCPs use the PDA will depend on their own clinical practice and the needs of individual patients. *Gastrostomy tube – Is it for me?* can be introduced as soon as the topic of gastrostomy is first introduced, to complement rather than replace clinical conversations. In discussions with HCPs throughout this project, suggested uses for the PDA have included setting it as 'homework' for patients after first introducing the topic, signposting carers to it and going through the PDA with the patient during a clinic session or home visit. It has also been suggested that *Gastrostomy tube – Is it for me?* could be formally incorporated into clinical pathways.

Whichever way HCPs choose to use *Gastrostomy tube – Is it for me?* it is important to recognize that it is just one tool in the decision-making process. It is intended to be used in conjunction with clinical conversations and other resources, such as the education website myTube (mytube.mymnd.org.uk) (51), which uses short films and written information to provide insight into living with a gastrostomy tube. As local MND services and gastrostomy resources and practices vary so much, both nationally and internationally, HCPs may need to localize some of the information in the PDA for their patients.

A related important decision plwMND are faced with is whether to stop using the gastrostomy tube for feeding at the end of life. This is a challenging decision to make, involving ethical and legal considerations. Moreover, the evidence on withdrawal and guidance around the practicalities, such as optimal symptom control, are lacking (52). Whilst *Gastrostomy tube – Is it for me?* mentions the need to discuss stopping feeding at the end of life with the healthcare team, it was not developed to support this decision.

Limitations

Fewer participants were recruited in Phase 3 than planned due to challenges associated with the COVID-19 pandemic. However, evaluation scores in the sample were very high and all those who recognized that there was a decision to be made around accepting a gastrostomy tube would recommend the PDA to others. As most participants in Phase 3 were recruited via the online routes, we did not collect data on a subtype of MND, site of onset and stage of disease (and employment status in error). User feedback and satisfaction will continue to be monitored to check that the PDA meets the needs of all those diagnosed with MND. In addition, the evidence base for the tool will be reviewed every three years.

Conclusion

This study has described the development of *Gastrostomy tube – Is it for me?*, the first UK PDA to support plwMND in gastrostomy tube decision making. It will improve care by supporting plwMND, carers and HCPs through the shared decision-making process to make the complex decision about whether to have a gastrostomy tube fitted. The PDA was co-produced with stakeholders and conforms to international standards. Evaluation by plwMND indicates they found it acceptable, practical and useful. The PDA is hosted by the MND Association on its website, is freely available and will be reviewed and revised, if necessary, every three years.

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Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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