

Development and pilot testing of a web-based decision aid for people with motor neurone disease considering a gastrostomy tube (DiAMoND Study)

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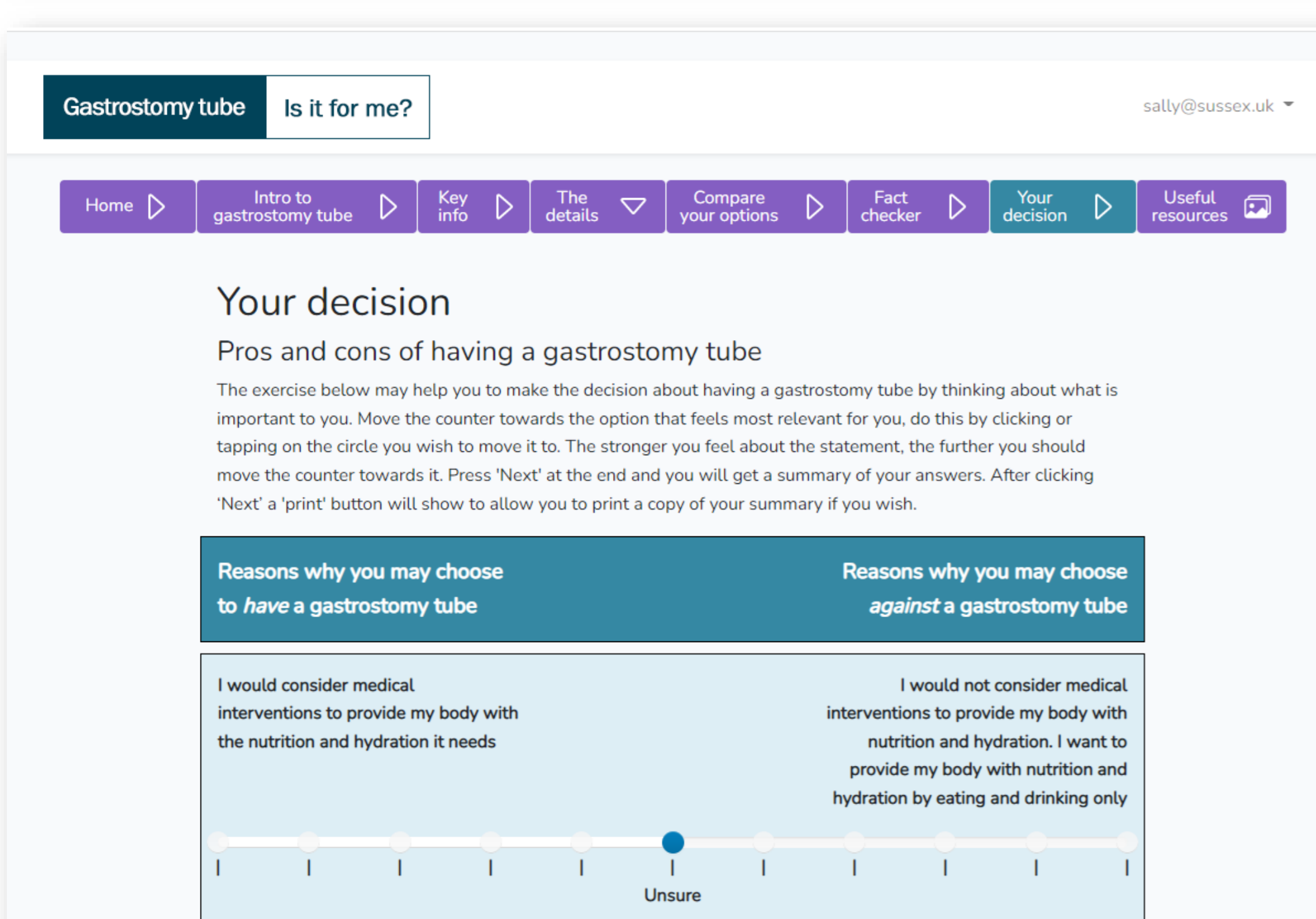
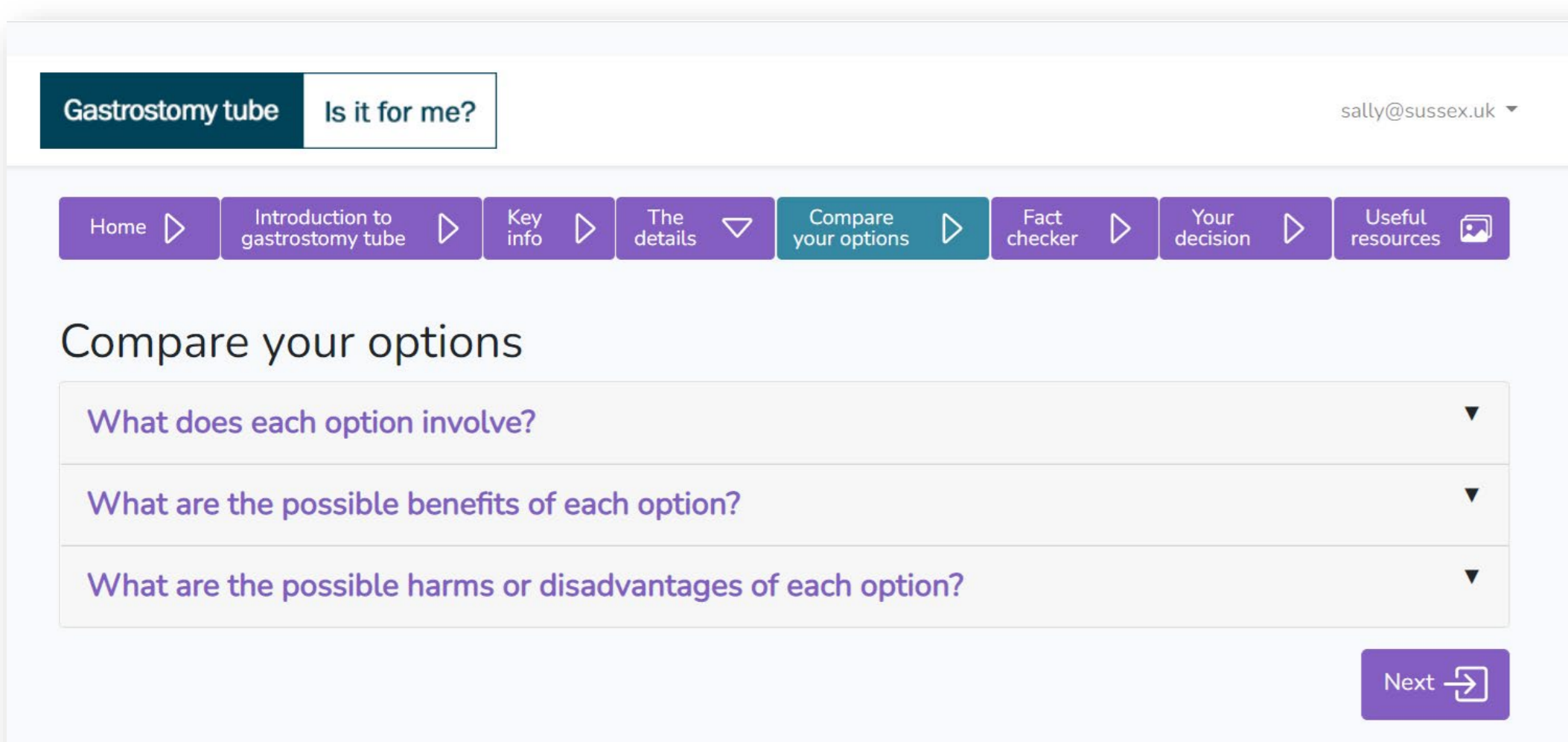
Introduction

Motor neurone disease (MND) is a degenerative disease, characterised by deterioration of the nerves in the brain and spinal cord. Due to the multisystem effects of the disease, patients are faced with many complex healthcare decisions, one of which is whether to have a gastrostomy tube fitted. Ethical challenges to research mean the evidence base for gastrostomy tube benefit is lacking¹. Patient decision aids (PDAs) contribute to the shared decision making process² and support individuals to make informed choices which are consistent with their values by:

- Providing evidence-based information
- Communicating the risks and benefits associated with each option
- Helping to clarify personal values and preferences
- Checking understanding

The aim of this study was to develop and pilot a web-based PDA to support people living with MND considering a gastrostomy.

Screenshots from *Gastrostomy Tube: Is it for me?*



Conclusion

The DiAMoND decision aid is the first in the UK to support people living with motor neurone disease in gastrostomy tube decision making. It was co-produced with stakeholders and conforms to international standards. Evaluation of the decision aid with people living with motor neurone disease indicates they found it acceptable, practical and useful. The decision aid is hosted by the Motor Neurone Disease Association on its website and is freely available.

References

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Methods

- The development process, shown below, was consistent with International Patient Decision Aid Standards³, and Medical Research Council's guidance for the development of complex interventions⁴.
- plwMND, carers and health care professional (HCPs) contributed throughout, either as research participants or as study advisory committee members.
- Due to the COVID-19 pandemic, most interviews were carried out using Zoom or Teams. Surveys and questionnaires were carried out using Microsoft Forms.



Phase 1: Content & design

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

Interview and literature review findings were synthesised using a framework approach. Content was prioritised using the MoSCoW approach (must have, should have, could have, would not have).



Phase 2: Develop & test

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

Alpha testing comprised a survey on clarity, presentation and functionality. Beta testing used the "think aloud" method⁵.



Phase 3: Evaluation in practice

Acceptability, practicality and usefulness of decision aid assessed after use by plwMND

After using the PDA, plwMND, recruited via 4 sites or social media, completed an acceptability survey and validated questionnaires assessing decisional conflict⁶, preparation for decision making⁷ and satisfaction⁸.

Results

Phase 1

The prioritisation survey comprised 82 items of content, drawn from the literature review and 37 interviews, and was completed by 25 participants. 63/82 (77%) content items were retained and results were used to inform prominence of each piece of content.

Phase 2

23 participants completed the alpha testing survey and 20 participants took part in the "think aloud" interviews (beta testing). Several iterations of the prototype PDA were produced during Phase 2. Most changes were language-related but in addition, the frequently asked questions were moved earlier in the PDA and embedded videos were removed due to navigation challenges.

Phase 3

17 patients completed the questionnaires after using the PDA. For the acceptability questions, 16/17(94%) found the PDA completely acceptable and would recommend it to other people in their position. One person saw no need for a PDA because he assumed anyone in his position would agree to have a gastrostomy tube fitted. 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.

References

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