Setting collaborative research priorities in dysphagia for the speech and language therapy profession

Background

- Dysphagia was identified as a key clinical area needing more research by speech and language therapists in a Royal College of Speech and Language Therapy (RCSLT) member survey 2015.
- The RCSLT liaised with James Lind Alliance and established a process based upon their recommendations (James Lind Alliance, 2018). The RCSLT then partnered with the National Institute of Health Research (NIHR) to identify research questions that were relevant to stakeholders.
- A collaborative approach was chosen as dysphagia is an area that benefits from multi-disciplinary management. Service users are the experts of their own conditions and therefore should be involved (INVOLVE, 2010)
- Stakeholders were engaged at all points in the project. It was hoped this would improve the relevance, quality and impact of research questions and subsequent research.

Process

Oversee overall project

1. • Established the priority setting working group and workstream
   • A group of mixed specialism SLTs oversee the project . A group of dysphagia experts formed a dedicated workstream to guide the dysphagia phase of work.
2. • Identified treatment uncertainties and mapped to existing research
   • uncertainties identified through a member survey and mapped to systematic reviews and guidelines
3. • Prioritisation workshop to develop research questions
   • including a range of stakeholders. Groups were facilitated and 77 questions generated
4. • Prioritsation questionnaire
   • stakeholders chose their top 10 from 77 research questions
5. • Analysis of data
   • identifying questions that were a priority to stakeholders
6. • Publishing top 10 lists for adults, paediatric and general, non age-group specific dysphagia

Results

These are the Top 10 priorities for general, non-age group specific dysphagia.

1. Do people with dysphagia and/or their families/carers carry out recommendations to improve the safety/effectiveness of swallowing at meal times? What strategies are effective to improve compliance with recommendations for postural changes?
2. What is the impact of thickening fluids on the physiology and wellbeing of (a) children and (b) adults with dysphagia?
3. What is the impact of reflux on swallowing function and health outcomes (including pneumonia) for children and adults who have dysphagia?
4. Are caregivers aware of how to identify eating/drinking difficulties and the potential risks and consequences of dysphagia?
5. Does oral sensory stimulation improve health and wellbeing outcomes of children and adults with dysphagia?
6. Are postural changes (e.g. different positions) effective in improving swallowing function and safety in (a) adults and (b) children with dysphagia?
7. What is the impact of shared-decision making (patient, carer and health professionals) for the modification of food textures and fluids on health and wellbeing outcomes when compared with decisions made by health professionals alone?
8. Does the use of (a) Fibreoptic endoscopic evaluation of swallowing (FEES) and (b) videofluoroscopy improve health and wellbeing outcomes for children and adults with dysphagia?
9. What is the clinical and cost effectiveness of nasogastric feeding compared to usual care in people with dysphagia to improve swallowing and quality of life?
10. What are the reported psychosocial effects of (a) nasogastric and (b) gastrostomy feeding in children and adults who are tube fed?

Top 10 lists were also developed for paediatric and adult specific dysphagia. These can be found here: https://tinyurl.com/ho7tvte

Successes

- ☑ Selection by NIHR to test National Patient and Public Involvement Standards
- ☑ Questions taken into NIHR prioritisation rounds
- ☑ Potential research studies are being considered by SLTs

Next steps

- To promote the priorities widely amongst the SLT profession and beyond
- To develop and establish relationships with research funding bodies
- This work is part of a larger project and research priorities for learning disabilities, developmental language disorder, aphasia and autism will also be developed.

References

INVOLVE (2010). Turning the pyramid upside down: examples of public involvement in social care research. Available at: https://tinyurl.com/ybmuhe9c

James Lind Alliance (2018). The James Lind Alliance Guidebook. Available at: https://tinyurl.com/ydc7r42z

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