Project title: Development of a grant application to estimate the safety, effectiveness and cost-effectiveness of implementing routine dysphagia screening on care of the older persons wards.

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Plain English Summary

Aims and objectives

- To invite patients and experts on to the team to support research delivery.
- To identify things which make nurses more or less likely to regularly screen for swallowing problems.
- To identify the things that we should measure to show the value of regularly screening for swallowing problems.

Background

Swallowing problems are common in older adults and can cause chest infections (pneumonia). Yet, these problems are not routinely identified when older adults are admitted to hospital. We aim to show the value of regular hospital screening for swallowing problems.

Methods

Step 1. We developed our expert and patient teams to ensure that our approaches to research are likely to work.

Step 2. We carefully looked at what has been published before to find out what helps and hinders nurses to regularly screen for swallowing problems in hospital.

Step 3. We worked with experts to create a long list of things which we should measure when trying to value the screening service.

Key findings

- Nurses struggle to screen for swallowing problems (OD) due to time, workload, and inconsistent methods.
- A standard tool and training improve confidence, especially with complex patients.
- Nurses recognise screening can help patients and their hospital organisation.
- To measure the value of a screening service, researchers should look at its effect on: mortality, aspiration pneumonia, choking, medication intake, patient's experience with the service, swallowing-related quality of life, hospitalisation & proportion of patients referred to speech and language therapy.

Patient & Public Involvement

Patients and the public have been involved in: study design, collection of information, analysis, writing articles and reports and working in partnership with the team to present the results.

Conclusions and future plans

This work will inform further research to develop and test a hospital screening service to identify swallowing problems in older adults.

Description of Research

Background

Oropharyngeal dysphagia (OD) is defined as a physical problem with swallowing and is estimated to be prevalent within a third of adults aged ≥65 years [1]. This is believed to increase to almost half of older adults in hospital [1] and over 80% in hospitalised older adults with dementia [2].

If left unidentified, OD can lead to aspiration pneumonia, with some studies estimating patients with OD are up to 11 times more likely to develop pneumonia than patients without [3]. Furthermore, patients and carers report significant psychological burden from OD, impacting on family dynamics, social life and independence [4,5].

However, it is currently not routinely screened for in care of the older person hospital wards [6]. This is in contrast to stroke wards, where routine screening for OD has been demonstrated to reduce risk of aspiration pneumonia, mortality, patient dependency and length of hospital stay [7].

Aims and objectives

To develop an NIHR Program Grant for Applied Research application to test our hypothesis that routine screening for oropharyngeal dysphagia on 'care of older person' wards will improve patient outcomes.

The objectives were to:

- Identify and recruit research team and patient and public involvement members required to optimise research team effectiveness.
- Identify the barriers and enablers to its routine implementation to inform intervention development.
- Describe the core outcome measures that should be used and tested.

Methods

To address the PDG's aim and objectives, the program was comprised of four phases.

1. **Development of the Expert Advisory Group (EAG) and Patient and Public Involvement (PPI) team.**

Utilising the PDG steering group's networks, we set out to build our program management team such that we have the necessary range of expertise for the final program grant. Working with community groups, we also developed a PPI group to support the delivery of the Program Development Grant (PDG) and eventual program grant for applied research (PGfAR).

2. Systematic review with meta-ethnography.

To holistically understand and address the barriers and enablers to nurses routinely screening for OD in care of the older person wards, we first need to identify all those that have already been reported. Therefore, this meta ethnography aimed to identify and describe the barriers and enablers to nurses routinely screening for OD in hospital. We also mapped identified barriers and enablers to the relevant domains of the Theoretical Domains Framework (TDF) which will inform the development of the nurse behaviour

change intervention [8].

The systematic review protocol was registered on PROSPERO (registration number: CRD42024608080).

Inclusion criteria:

- Population- Healthcare professionals providing oropharyngeal dysphagia screening or assessment. · Outcome- Data relating to factors which are barriers and/or enablers to healthcare professionals routinely screening for oropharyngeal dysphagia. Barriers and/or enablers must be explicitly stated by authors or appear to be an important part of the findings.
- Setting- Patients receiving care on older people's wards or stroke wards.
- Study design- Primary research using qualitative or mixed methods.
- Publication type- Peer-reviewed journal articles and registered trials.

Exclusion criteria:

- Systematic reviews, abstracts or conference presentation.
- Papers with no empirical qualitative data.
- Ongoing trials.
- Studies reporting on patients receiving care on wards other than care for the older people's or stroke wards e.g., cancer wards.
- Studies only reporting on the perspectives and experiences of speech and language therapists.

A search was conducted on CINAHL, Embase, PubMed and Scopus databases as well as the Clinical Trials and World Health Organisation trials registries (from database/registry inception to November 2024). Reference lists and citations of included papers were also reviewed.

After duplicates were removed, three reviewers (CS, LB and DW) independently screened study titles and abstracts against the inclusion and exclusion criteria in Rayyan. The full text of included papers were then obtained and reviewed independently by two reviewers (CS and DW).

During full text screening, data from included papers were extracted by CS and inputted into a Microsoft® Excel document. Included papers were also appraised using the 10-item Critical Appraisal Skills Programme assessment tool for qualitative research [9].

Included papers were imported into NVivo (R1 2020). CS identified themes and sub-themes from study authors (second order constructs) and coded them with given labels. Participant quotes (first order constructs) and author interpretations of focus group data were coded as barriers (B) or enablers (E) to hospital dysphagia screening, with brief descriptors (e.g., B. Nurses feel unskilled in screening). Codes were grouped under corresponding themes and sub-themes.

Themes across papers were synthesised into higher-level concepts (third order constructs) of barriers and enablers. Participant quotes and author interpretations informed these relationships. DW and LB reviewed the groupings for agreement.

For TDF mapping, a duplicate of the NVivo file from Phase 1 was created. Third (current study team's higher-level interpretations from synthesised data) and second order constructs (author interpretations of focus group data) were removed. The 14 domains of the Theoretical Domains Framework were added into the NVivo file as high-level codes. The remaining barrier and enabler codes of first order constructs (participant quotes) were then mapped to the appropriate Theoretical Domains Framework domain.

To assess confidence in the findings from this systematic review, the Grading of Recommendations Assessment, Development, and Evaluation- Confidence in the Evidence from Reviews of Qualitative research (GRADE-CERQual) was used [10].

3. Development of a Core Outcome Set (COS).

In order to design a definitive trial which will evaluate our OD screening service (to be developed during the PGfAR), key outcome measures that are of value to the NHS and feasible in terms of sample size and data collection need to be established. A 2022 white paper by the European Society for Swallowing Disorders identified the development of a Core Outcome Set (COS) as an urgent need in the field of OD research in order to improve healthcare pathways for people with OD [11]. Core Outcome Sets are an agreed standard set of outcomes which should be recorded and measured, as a minimum, in clinical trials for a specific health condition or area of healthcare. Development and use of a COS enable comparison across similar trials and increases the relevance of results from trials and future research which references this work [12]. Therefore, the aim of this study was to develop a COS for OD screening services in care of the older person hospital wards.

The study objectives were:

1. To identify, from existing literature, previously reported outcomes relevant to oropharyngeal dysphagia screening in care of the older person hospital wards.
2. To prioritise outcomes based on their importance to relevant stakeholders including patients, carers, healthcare professionals, hospital managers and researchers.
3. To achieve consensus on a minimum set of relevant outcomes (i.e., a Core Outcome Set) for oropharyngeal dysphagia screening services in care of the older person hospital wards.

The study was registered on the COMET (Core Outcome Measures in Effectiveness Trials) database (https://www.comet-initiative.org/Studies/Details/3438). Ethical approval was obtained from the University of Leicester General Research Ethics Committee (Project ID: 3236).

The study comprised of three steps:

Step 1. Identifying and reviewing potentially relevant outcomes

In phase 1, a long list of potential outcomes which could comprise the final COS, was developed from three previously developed OD COSs [13–15] and a systematic review of trials evaluating OD screening interventions in stroke wards [16].

Step 2. Two round Delphi questionnaires

The identified outcomes were sent out to key stakeholder groups (nurses, speech and language therapists, pharmacists, senior hospital staff, researchers and patients) in

two-rounds of questionnaires over 3 a month period. In these questionnaires, participants were asked to rate the importance of each outcome using a likert scale. Outcomes which failed to reach consensus in the first questionnaire progressed to the round 2 questionnaire for re rating.

Step 3. Consensus workshop
To finalise the COS, outcomes which achieved consensus to include and outcomes which did not reach consensus to include or exclude were presented and discussed with a select number of stakeholders who participated in the questionnaire rounds.

4. Preparation of the PGfAR application.
Using the findings from Phase 2 and 3 of the PDG, as well as the expertise and experiences of the steering, EAG and PPI groups, we planned to put together a 5-year program grant to develop and test a service to support the routine screening of OD by nurses on care of the older person wards.

Findings
1. Development of the Expert Advisory Group (EAG) and Patient and Public Involvement (PPI) team.
The is EAG comprised of 7 members: an Executive Director of Community Health Services, a Nurse Consultant for Dementia and Older People, a Consultant Admiral Nurse, a Clinical academic General Practitioner, a Highly Specialist Speech and Language Therapist, an Associate Director of Allied Health Professionals and Quality and a senior research fellow and speech and language therapist.

The EAG members supported the development of the PGfAR application and, if funded, will continue to support the PGfAR with their clinical/professional/academic expertise/experience and, utilising their extensive networks, facilitate the dissemination of the work conducted on the PGfAR to drive real-world impact.

The PPI group is comprised of 6 members who have lived experience of oropharyngeal dysphagia (OD) or have cared for a family member with OD. The group has met on a monthly basis over the course of the PDG to review and advise on; study protocols, study documents and materials, development of the PGfAR application and creation of dissemination materials.

2. Systematic review with meta-ethnography.
From 6,750 studies identified from the primary search, 6 were included in the final meta-ethnography analysis [17– 22].

Four overarching themes were developed to capture the barriers and enablers to routine OD screening in hospital:

I. The surrounding environment- Lack of time, increased workload, inadequate resources and inefficient systems were key environmental barriers to OD screening. This may lead to patients being missed for screening or even screened twice. Support from colleagues and posters of patient's OD screen outcome were identified as helpful environmental factors.
II. Variation in practice- Nurses within hospitals and across different hospitals, may

identify OD in different ways, some more effective than others. Using one, formal screening tool will ensure all nurses follow the same instructions and reduce the risk of missing patients.

III. Influence of knowledge and skills- Training builds nurses' confidence to identify OD. Confidence and competence to screen is important for complex patients e.g., less alert, communication difficulties, difficulty following instructions etc. Yet, some nurses feel training takes time and, therefore, struggle to complete it.

IV. The value of OD screening- Nurses recognised identifying OD early could facilitate early nutritional intake, hydration and medication. Avoiding non-oral feeding methods could also improve patient mood. Nurse-led screening also facilitates speech and language therapists to prioritise patients, based on OD screening outcomes. OD screening also viewed to enhance professional development.

Fifty-seven barrier and enabler codes linked to participant quotes (first order constructs), developed from phase 1, were deductively mapped to relevant domains in the Theoretical Domains Framework. Domains with the highest number of codes mapped to them were: 'Environmental context and resources,' (n=19) 'Knowledge' (n=8), 'Memory attention and decision processes' (n=7), 'Beliefs about capabilities' (n=6) and 'Beliefs about consequences' (n=6).

Of the four key findings developed from the phase 1 synthesis process, one was graded as high confidence (The surrounding environment) and the remaining three as moderate confidence.

3. Development of a Core Outcome Set (COS).

Step 1- 54 outcomes were identified to be sent out to participants in the two rounds of questionnaires.

Step 2- 34 stakeholders responded to the first questionnaire. 29 of the 54 outcomes achieved consensus to include and the remaining 25 did not reach consensus to include or exclude. These 25 outcomes were sent to 28 stakeholders at round two. A further 5 outcomes reached consensus to include. The remaining 20 outcomes did not achieve consensus.

Step 3- 13 participants took part in the consensus workshop in July 2025: three nurses, three pharmacists, three speech and language therapists, three patients and one researcher with an interest/expertise in OD. This group agreed the following outcomes should comprise the final COS: mortality, aspiration pneumonia, choking, medication intake, patient's experience with the service, swallowing-related quality of life, hospitalisation & proportion of patients referred to speech and language therapy.

4. Preparation of the PGfAR application.

Using our developed research team and findings from the PDG, we submitted our 5-year research proposal as a stage 2 application to the February 2025 PGfAR competition (See 'Future research plans' for more detail on the PGfAR proposal).

Conclusions

The systematic review identified critical barriers and enablers, and associated TDF

domains, that nurses encounter during the routine screening of OD in hospital settings. Further investigation with nurses is imperative to deepen understanding of the meta-ethnography findings and to contextualise these barriers and facilitators within the specific environment of older adult hospital wards. Following this and using our mapping of barriers and enablers to TDF domains, a behaviour change intervention can be collaboratively designed with nurses and other key stakeholders to address these determinants to routine OD screening.

The COS modified Delphi study has developed the first COS to evaluate OD screening services in care of the older person hospital wards. The eight outcomes which comprise the Core Outcome Set consider the clinical, patient and resource/process implications of hospital-based OD screening services. Standardised collection and reporting of these outcomes in future trials will enhance the quality and comparability of evidence, support meta-analyses, and facilitate the translation of research into clinical practice. This COS establishes a foundational framework for advancing OD research and improving patient care through consistent and meaningful outcome measurement.

Findings from this work have laid the foundations by which we can develop and test a screening service to improve patient outcomes and reduce healthcare resource use.

Patient and Public Involvement

Aim

For project team PPI members to be actively engaged in the oversight of the project and in all decision making regarding its overall delivery.

Methods

PPI were involved across all phases of the PDG.

Our PPI co-applicants (VB and PG) were invited to all monthly project steering group meetings and PPI related feedback/topics was added to the standing agenda. The core PPI group also met on a monthly basis, chaired by CS and VB.

Phase 2- For the systematic review, PPI members: reviewed the study protocol, review search strategy and review findings.

Phase 3- For the Core Outcome Set study, PPI members: reviewed participant-facing study documents (e.g., the participant information sheet), reviewed and amended outcome definitions and participated in the consensus workshop.

Phase 4 (dissemination and program grant application)- Our PPI group also reviewed both study manuscripts and developed a poster presentation of the systematic review findings for the Institute in Excellence in Healthcare conference.

Our PPI members were involved in the development of the PGfAR application. They developed the plain English summary and 'Working with people and communities' summary. The team also reviewed the plans for each work package in the PGfAR to determine where and how patients and the public could be involved. Additionally, they generated a plan for disseminating PGfAR work to patients and the public.

Study results

Phase 2- PPI comments on the systematic review findings were as follows:

- *Finding 1- Influence of knowledge and skills*
    - Nurses should have protected learning for dysphagia training.
    - A dysphagia training module could be included in the NHS training modules given to new employees and a 12-month refresher.
    - Managers are responsible for ensuring nurses have enough time to complete training and should ringfence enough time for nurses to complete this.
    - Training should be given to a wide variety of healthcare professionals, not just nurses, such as healthcare assistants.
- *Finding 2- The surrounding environment*
    - The screening checklist can be printed and placed at the end of every bed on the ward along with the results of the screen e.g., diet recommendations.
- *Finding 4- Variation in practice*
    - Integrated Care Boards are key to ensuring all hospitals are using the same tools and following the same procedures to identify dysphagia.

During this meeting, PPI members suggested the identification and invite of a senior NHS professional to be invited on to the PDG's EAG. Two senior NHS staff have joined the EAG (an executive director of community health services and associate director of Allied Health Professionals and Quality).

Phase 3- As a result of PPI and patient involvement to develop the Core Outcome Set, two patient reported outcomes are included in the PDG's COS; patient's experience with the service and swallowing-related quality of life.

Phase 4- From PPI member suggestions, we have developed research plans to support patient and public involvement in the PGfAR, for example, patient participants recruited from hospitals will have the opportunity to discuss the project with a PPI member, patients can request a PPI member to sit in on their interviews, translated versions of all study documents will be offered to patients etc. PPI members also agreed the following dissemination plans to support patient and public engagement with the PGfAR, for example:

- Collaboration with key patient groups/organisations such as Dementia UK, Age UK, All Party Parliamentary Groups such as 'Aging and older people' and local and national carer groups, such as the Leicestershire Support for Carers.
- ·A newsletter for patients recruited on to the PGfAR.
- Study posters in hospital sites.
- Sessions delivered by the research and PPI team to medical and healthcare students about dysphagia.

Discussion and conclusions

PPI input had a substantial and multi-faceted influence on the PDG: from shaping training recommendations, to ensuring patient-centred outcomes, to designing inclusive recruitment and dissemination strategies. Their involvement provided practical adjustments but also in structural contributions, such as strengthening the research team with senior NHS voices. The breadth and depth of influence demonstrate that PPI was not tokenistic but integral to the study's design, conduct, and potential impact.

Reflective/critical perspective

- The breadth of PPI team members' experiences and knowledge has enabled varied and valuable discussion and review of study materials, processes, ens.
- PPI members feel they have learnt from other members' experiences and knowledge. · The monthly meetings were not too onerous.
- Meetings were led well, with clear active listening which led to actioned outputs, e.g., changes made to the systematic review poster.
- Meetings were scheduled and organised well, with reminders and clear agendas leading to effective use of time.

Data Sharing

All data from the systematic review will be available within the results manuscript and supplementary files.

Anonymised results from the Core Outcome Set study will be included in the study manuscript. For information on all outcomes initially identified to generate the list of potential outcomes to include in the Core Outcome Set, individuals can contact the research associate, Caroline Smith at caroline.smith@leicester.ac.uk.

Both manuscripts will be published in open access journals.

Disclaimer

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