What is the most appropriate terminology to be used in diagnosis and management of 'medically unexplained' dysphagia? (MUD)

A systematic exploration of the terminology used in the diagnosis and treatment of oropharyngeal dysphagia

A review of the literature has failed to find evidence of the incidence and prevalence of MUD However, the umbrella diagnosis of functional neurological disorders is described as "among the most common causes of neurological disability" with an incidence of 4 to 12 per 100 000 population per year and a prevalence of 50 per 100 000 population based on a community registry. [1]. MUD reportedly accounted for 12 % of patients per year visiting an outpatient clinic for dysphagia [2].

The literature review revealed that there was a wide range of terms used to define and describe MUD. Terms used include unexplained dysphagia, Medically Unexplained Oropharyngeal Dysphagia (MUNOD), psychogenic dysphagia, hysteria-conversion dysphagia conversion disorder, dissociative disorder, functional dysphagia, functional neurological symptom disorder, non-organic dysphagia, globus hystericus, phagophobia or swallowing phobia. [3, 4, 5, 6, 7, 8, 9, 2, 10]. This lack of consistent terminology makes it difficult to draw any conclusions that can be meaningfully applied to this population. A recent scoping review [11] showed that this is an under-researched area, with no current clinical guidelines available. It highlighted the confusion due to multiple terms in the literature. This is likely to impact on clinical practice, development of positive diagnostic criteria and professional conversations regarding MUD. Sample: Any health professional who has been involved in delivering a swallow diagnosis to an adult patient with MUD. Questionnaire disseminated via UK professional bodies: Royal College of Speech and Language Therapists (RCSLT), Association of British Neurologists (ABN), Royal College of Physicians (RCP), ENT UK (The professional membership body that represents Ear, Nose and Throat and its related specialities). British Society of Gastroenterology (BSG), British Psychological Society (BPS), Association of Clinical Psychologists UK (ACP UK), Royal College of General Practitioners (RCGP) Codes and themes from phase 1 thematic analysis:

# (swallowing difficulty) in the absence of a clear medical explanation.

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#### Introduction

A wide range of terms to describe MUD are used across many specialties. This lack of consistent terminology makes it difficult to draw meaningful conclusion from the literature and optimally manage these patients.

### **Objectives**

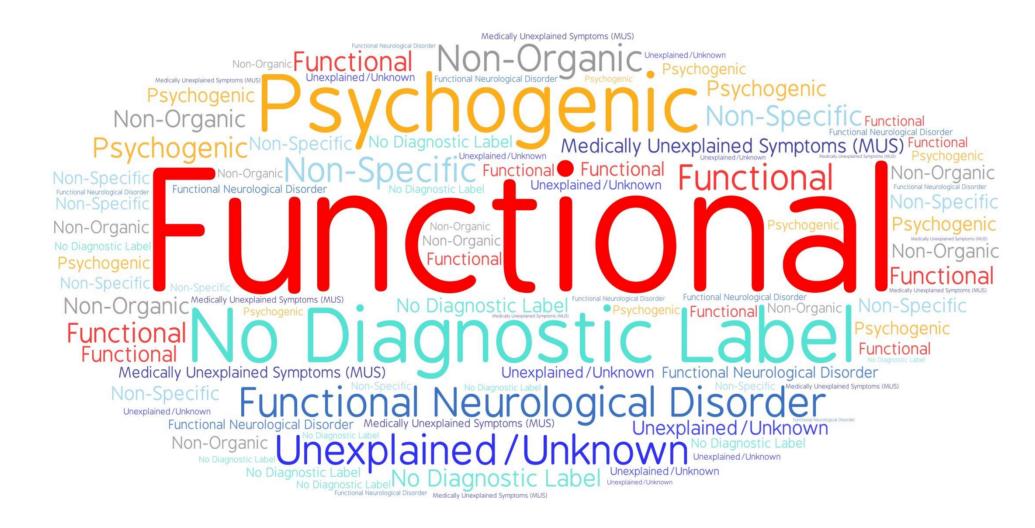
1. To explore consensus across disciplines on appropriate terminology regarding clients with a 'medically unexplained' dysphagia. 2. To investigate health professionals' understanding of the current terminology use and reasoning behind this.

## **Methods**

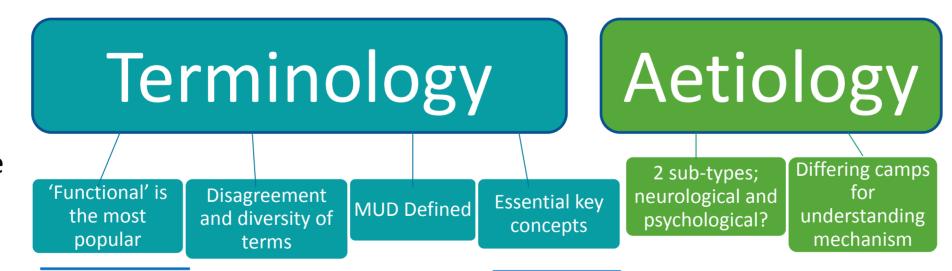
An online survey tool is being used to deliver a 3 round Delphi questionnaire to a range of medical and health professionals. The consensus results will be discussed in patient focus groups. Phase 1 of the Delphi survey is complete and phase 2 is currently in development.

#### Results

Word cloud proportionately represents range of terms from survey



#### Preliminary thematic analysis from Delphi round 1:



Overarchi ng Theme	Terminology	Terminology				Mechanisms/ aetiology	
Sub themes	<ul> <li><sup>4</sup>Functional' is the most popular term</li> <li>Most up to date with modern understandi ng</li> <li>Patient preferenc e</li> <li>Recognis ed as an acknowle dged disorder</li> </ul>	Disagreement and diversity of terms in use 2. Labels are unhelpful 3. Avoiding negative implications	MUD defined	Essential key concepts 1. This is real 2. No malignancy 3. Consistency 4. Treatable	2 sub-types – Neurological and psychological	Differing camps for understanding aetiology 1. Software/ Hardware 2. Interaction of mind and body 3. Sensitivity/ sensation 4. Maladapti on	
Codes	1 Functional' is the/a term in use to describe MUD 6 Functional neurological dysphagia, or dysphagia, or dysphagia	2The preference is to describe the presentation rather than label 3'Functional' is a dismissive term, implies "all in the head" 4'functional overlay/ element' is the terminology in use 5'psychogenic' is the/ a term in use to describe MUD 7'unknown origin/ unexplained' are terms in use to describe MUD 8'non-specific' is a term in use to describe MUD 14 Psychogenic is out of date 15 non-organic dysphagia is a term in use to describe MUD 21 Psychogenic is out of date connection to 21 Psychogenic is appropriate/better when there is a clear connection to psychological trigger 26 'Functional' can be misleading as has multiple meanings 30 Medically unexplained is a misnomer and falsely representative 32 Psychogenic/psychological/ psycholo	36 Functional dysphagia = our definition or similar 38 MUD can present with altered physiology with altered physiology altered physiology altered physiology altered physiology altered physiology altered physiology altered altered physiology altered altered but still be d'anage to brain/ damage to brain/ damage to brain/ definition or similar 41 Non- organic Dysphagia sour definition 42 Blurred distinction between orophx and cesophage al 56 "overlay" is when an organic presentati on does not explain the whole presentati on	9 Consiste ncy across the team/professionals is important 22 It is appropriate to acknowledge that we are uncertain of aetiology 24 Terms need to be patient-centred and tailored to individuals 35 It is important not to be judgemental or imply malingering when discussing diagnosis 37 It is important to reassure that the symptoms are real and will be taken seriously 45 Reassurance that there is nothing malignant and other medical causes have been ruled out is important 47 MUD is not rare and is an acknowledged condition	35 Neurolog ical specialties use FND 36 There may be at least 2 subtypes of MUD, one more allied to psychological trigger and one more allied to FND 17 MUD can be part of a broader spychological or psychological or psychologica	13 MUD is linked to sensory changes 16 MUD is linked to beliefs or perceptions about swallowing 46 MUD is caused by or closely related to mental health issue/ syschological issue/ stress or anxiety 48 It is useful to compare with other physical symptoms e.g. butterflies 49 In MUD there is a breakdown in presence of working musculature. Also can be explained by hardware/ software model 50 MUD can be caused by maladaption 52 MUD is related to globus pharyngeus, muscle tension and/or reflux	

#### Central organising concepts:

'Functional' is the most popular term: Functional is the most used and most well supported term used to talk about MUD

Disagreement and diversity of terms: A range of terms is currently in use and there is disagreement on their appropriacy and meaning

MUD defined: There is general agreement on a definition of MUD "Dysphagia occurring in the absence of demonstrable abnormalities in the swallow anatomy and neurology" which includes an allowance of some abnormal physiology (unexplained) and a blurring of the distinction between oropharyngeal and oesophageal.

Essential key concepts: There are important key concepts within any explanation or diagnosis of MUD, regardless of terminology/ specialism

2 sub-types – Neurological and psychological: There may be 2 sub-types of MUD, with one more aligned to FND and one more aligned to psychological conditions.

Differing camps for understanding aetiology: There are several ways of understanding and

Most up to A range of date with terms in use modern understanding

Labels can Patient be unhelpful preference

Avoiding Recognised as negative an implications acknowledged disorder

This is real

No

malignancy

Consistency of terms

This is treatable

Software/ hardware Interaction of mind and body Sensitivity/ sensation

Maladaption

explaining the mechanism behind a presentation of MUD.

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https://www.nbt.nhs.uk/bristol-speech-language-therapyresearch-unit/bsltru-research/medically-unexplained-<u>dysphagia</u>





