CORE OUTCOME SET IN OROPHARYNGEAL DYSPHAGIA

International consensus on how to define and assess the severity of oropharyngeal dysphagia

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Description of the initiative

- **Background/context**: Swallowing problems, otherwise known as oropharyngeal dysphagia (OD) can lead to serious complications such as malnutrition, dehydration, aspiration pneumonia and even death. To minimise the serious complications of OD, early identification is essential. However, to date, no international consensus exists on how to define and assess the severity of OD.
- Rationale for the initiative: A recent white paper (European Society for swallowing Disorders [ESSD]) reported on the urgent need for international consensus on the minimum set of outcomes that should be measured and reported in OD clinical practice and trials. Following these ESSD recommendations our group aims to establish such an OD-specific Core Outcome Set (COS).
- **Objectives and scope**: Using the Delphi technique, our present project will develop a multidimensional framework based on expert consensus, representing all relevant aspects related to adult OD. In addition, we will develop and organise educational courses for health professionals to facilitate implementation of the newly developed COS in clinics, research and education.

Planned activities & deliverables

- Outline the steps to be taken: 1) A Delphi study using repeated online surveys will be conducted among international experts and stakeholders (using the ESSD network) to establish a consensus-based COS for adult OD;
 Results of the Delphi study will be incorporated into ESSD educational courses and webinars, presented during conferences and reported on in peer-reviewed publications.
- What are the concrete deliverables of the project? An international consensus-based COS for adult OD to be implemented in clinics, research and education.
- What achievements are possible in the next 12 and 24 months? A Delphi study will be conducted and analysed during the first 12 months. The year thereafter, results will be published in an international peer-reviewed journal and presented at our yearly ESSD conference and webinars. Furthermore, during the second year, findings will be incorporated within a new ESSD course developed to promote best practice in OD assessment for health care professionals.

Resources & enablers

- Describe personnel, financial needs: The ESSD Research Group will provide a team of international experts to support the current project. A total grant budget of €30,000 is requested, to support the design, performance and analysis of the Delphi study (€17,500), and to develop the new ESSD course and disseminate project results (€12,500).
- Specify how the grant will be spent: Funds will be spent on dedicated researchers' time to design, manage, analyse and report on the project.
- What factors will make it successful? The involvement of the European Society for Swallowing Disorders (ESSD), the ESSD Research Group, and the European Dysphagia Council (association established by the ESSD to promote collaboration between national dysphagia societies across Europe).

Results/outcomes & expected impact

- How will the findings be implemented? The findings will be implemented in future clinics, research and education, providing an international consensus on how to define and assess the severity of adult OD.
- How will this project advance patient care / contribute to optimal nutritional care? Based on international consensus, our project will provide the required minimum set of outcomes in OD (COS) that should be measured and reported in clinical practice and trials, promoting transparency and comparability of outcomes. Our project will facilitate early identification of OD, thus minimising its serious complications.
- What makes the project innovative? To date, no international consensus exists on how to define and assess the severity of OD, seriously hindering both clinical and research-based progress in the field. This project will provide an internationally agreed consensus on standards for the evaluation of patients' illness trajectory.
- Will the project be likely to influence national nutrition policy? The publication of our results will influence national and international policies on OD assessment and promote the comparison of treatment efficacy using a standardised consensus-based COS. All project team members are previous and/or current ESSD Board members enabling the dissemination of findings through existing networks.
- Is the project transferable to other settings / countries? The project is highly transferable across settings and internationally.



Please tick to confirm the PEN letter of endorsement is attached. Incomplete submissions will not be considered.

