



## **COHESION Study Consensus Meeting**

### **What is a core outcome set?**

Core outcomes sets (COS) are the minimum set of outcomes that should be measured and reported in studies evaluating a health intervention. An intervention is anything that aims to make a change to someone's health. For example, providing a counselling service, giving a drug, or giving people information and training are all described as interventions. Researchers may wish to explore other outcomes relevant to their research, but the COS should always be included. Agreeing the set of outcomes that must be reported in all studies allows us to pool the evidence from different studies, which helps inform health care decisions and also reduces research waste.

### **What is the purpose of the meeting(s)?**

The meeting will help refine the list of outcomes from the online surveys we have conducted and agree on the most important outcomes for inclusion in the COS.

### **What is involved in participating in the COHESION consensus meeting(s)?**

We will host two different consensus meetings to accommodate stakeholders from different countries and time zones. You can attend any one of these meetings.

During the meeting, we will discuss neonatal encephalopathy outcomes that were generated from the online surveys. We will go through these in more detail on the day. You will be asked to rate these outcomes as to whether you think they are essential for inclusion in the COS. The discussion will be chaired by an experienced facilitator who will ensure that everybody gets equal opportunity to be involved in the discussions.

Everyone at the meeting will have different views and ideas, and they are all valid and important. Everyone will be encouraged to share their views, but also to listen to each other. The aim of this meeting is to identify and prioritise 'what' to measure, not 'how' or 'when' to measure the outcomes. Your input and expertise is very important in helping us achieve this. The unique outcomes from these consensus meetings will be pooled and used to populate an online forum. Using this online forum, stakeholders who attended the consensus meetings can discuss outcomes and cast their final vote for an outcome to be included in the final COS. The outcomes emerging from this online voting will make up the final COS for neonatal encephalopathy.

## **How will information from this meeting be used?**

Information and data you contribute during the meeting will help us to inform which outcomes are important for inclusion in the COS for treating neonatal encephalopathy. Once these meetings have taken place, we will ask you to join us in an online discussion forum to vote for the last time, on unique outcomes emerging from these meetings. This final vote will decide which outcomes will be included in the final COS. Only those who have been present at the consensus meetings can partake in the online discussion forum. Full details of the final COS, decided by consensus in the online forum, will be circulated to all delegates. The finalised COS will be disseminated nationally and internationally and submitted for publication. Attendees at the COS meetings and online forum will be acknowledged in any published materials.

## **Additional information**

The COHESION Study is kindly supported by the Health Research Board (Ireland). The COHESION Consensus meeting will be recorded to ensure all important issues raised are captured. This recording will be transcribed following the meeting and will then be destroyed. We may also take some still photographs (screen capture) during the meeting for use in the dissemination of the findings of this project (e.g. website, Twitter). If you do not wish to be photographed, please let us know. You are free to withdraw your participation at any time and this will not impact on your rights.

*If you have any issues or queries about the data protection for this project, please find the contact email address of the NUI Galway Data Protection Officer at [dataprotection@nuigalway.ie](mailto:dataprotection@nuigalway.ie)*

*Please note that you have the right to request from the data controller for COHESION, access to your data, to rectify or erase your data, or to object to the processing of your data.*

*Please note that you have the right to lodge a complaint with the Data Protection Commissioner, see [www.dataprotection.ie](http://www.dataprotection.ie) for contact details*

## **Meeting Details**

The consensus meetings will take place via Zoom video conferencing.

The two dates the consensus meeting will be held on are:

- 17th of January 2022, 2p.m- 7p.m Greenwich Mean Time (GMT)
- 20th of January 2022, 6p.m- 11p.m Greenwich Mean Time (GMT)

## **The COHESION Project Team**

The COHESION Project Team members are: Fiona Quirke, Patricia Healy, Elaine Ní Bhraoináin, Linda Biesty, Tim Hurley, Karen Walker, Shireen Meher, David Haas, Frank Bloomfield, Jamie Kirkham, Eleanor Molloy, Declan Devane.

## **Any Questions/Queries**

If you have any questions or comments in related to this research please do not hesitate to contact us.

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