



## **RDEB Clinical Severity Score**

Create an severity score for dystrophic EB easy to use in clinical practice and in clinical trials

**ERN EB group meeting** 

24 February 2023

Complex existing scores **EBDASI** 

iscorEB

# **Delphi Method**

**Literature review:** 

on going bibliography studies / estimated delay: April 2023

**Selection of experts** 

Development of the first questionnaire

estimated delay: Summer 2023

Questionnaire administration and analysis

Adaptation and analysis of successive questionnaires (3 runs)

estimated delay: Autumn-Winter 2023

Synthesis of the results and validation of the severity score

estimated delay: End of 2023

#### **Literature review: ongoing**

European Reference Networks

2 independent reviewers Pauline Bataille (Fellowship) Ines Gannar (Resident)

## **Selection of Experts**

C Has, C Bodemer

**ERN Skin EB members** 

Researchers

**Patients** 

Industry representatives

**The experts** who will be consulted throughout the DELPHI® method process.

The choice of experts must take into account their:

- Knowledge of the issue
- Legitimacy in relation to the group
- Availability throughout the DELPHI® method process.
- Independence from any form of pressure.

The final number of experts is not less than 25.

The recruitment of experts will be done through a network.

The experts will be contacted by e-mail, in order to:

- Explain the purpose of the project and how it will be carried out.
- Tell them what is expected of them and their investment.
- Solicit their participation.

#### **Conducting the questionnaires**

- Three successive questionnaires will be offered to the experts, corresponding to the three rounds of the Delphi® method
- These will be available on a dedicated platform via an invitation to respond by e-mail Two reminders will be sent at 10 and 20 days, and if no response is received at 30 days, the experts will be automatically excluded

**First questionnaire:** guideline throughout the project: it will just be enriched, at each round, with the results and comments generated by the previous round

**Second round of questionnaires**: experts receive the results of the first round and have to give their opinion on the questionnaire again, now having the opinion of the group consulted. If their new answer deviates significantly from the average of the group, they must justify it.

- **Third round:** experts will be informed of the results of the second round and the comments justifying the deviating opinions.
- **This last round will give the final answers**: the median consensus opinions and the dispersion of opinions around this median, which can be interpreted with the help of the justifications and comments collected from the experts.

#### **Literature review: ongoing**

2 independent reviewers Pauline Bataille Ines

#### **Selection of Experts**

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#### **Development of IT support**

Vanesa Delique

Quote

13 250 euros

#### **Data hosting**

Project hosted on a server with "Health Data Hosting (HDS)" accreditation, which attests to ISO 2 certification respecting all the confidentiality rules required for the management of personal health

#### **Data anonymity**

The project does not require a prior request to the Commission Nationale de l'Informatique et des (CNIL), nor to the Comité de Protection des Personnes (CPP), as the data collected will be anoi

#### **Dedicated development**

A dedicated platform will be developed to specifically meet the needs of the project by computeris the DELPHI® method:

- Questionnaires (integration).
- Comments.
- Results (export and analysis).

The development will be carried out under PHP DevShell 3.5 (LGPL 3 license), whose source code will be made available at the end of the project.

# To Summarize Practical EB score of severity Chrisine Bodemer and Cristina Has



#### ✓ Where We are

-Literature review:

-Recruitment of a specialized

-Registration on PROSPERO

-Registration on COMET

ongoing

webmaster with validated quote

web site (Literature review)

web site (Outcomes consortium)

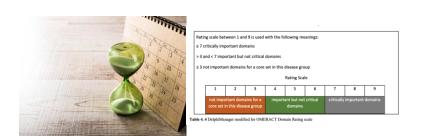


#### ✓ TO DO

-Enlarged List of experts



-Retroplanning meetings qualitative analyses



-Runs e-mail votes



-Final score

