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1. Context

- Cystic Fibrosis Europe (CFE): federation of national cystic fibrosis (CF) patient organisations in Europe.
⇒ **Defend interests of people with CF, engage with key stakeholders** (EU, industry, etc.).
- CF Round Table of Companies (CFRToC): collaboration between CFE and companies (5) active in CF.
⇒ **long-term educational collaboration.**
- New European regulation regarding clinical trials (CTs) (536/2014).
⇒ **lay summaries of CT results.**
⇒ need for improved communication tools.

Overarching aim:

Collaboration between CFE, the Cystic Fibrosis Trust (CFT), the European Cystic Fibrosis Society-Clinical Trials Network (ECFS-CTN) and CFRToC to establish a **standardised glossary of CF terms**, for systematic use in patient-friendly CT summaries

5. Perspectives

- ⇒ Importance of the targeted audience: definitions for **lay audience without prior knowledge of the illness or related-terms.**
- ⇒ Agreement of stakeholders on utilisation of terms and glossary.

2. Objectives of the study

- **Select ~10 terms**, CF-specific and commonly used in CT to be defined in a **pilot study of the glossary.**
- **Define a workflow with all stakeholders** leading to a glossary approved by the participating companies.

3. Methods

- CFE, CFT and CTN preselected 27 CF-terms.
NB: Generic CT terms, not specific to CF, defined elsewhere were excluded.
- Patients representatives from *Sweden, Finland, Belgium, Moldova, France, The Netherlands, Israel, Turkey and United Kingdom* were asked to rank the 10-top terms to be defined as a priority in a glossary.
 - The top-ranked terms were validated by industrial partners as a kick-off set

4. Results

- ⇒ Shortlist of **11 terms with the highest ranking by CF patients representatives** (see table 1.).
- ⇒ Ranking reflects the fact that **the voters are familiar with CF vocabulary.**
- ⇒ Terms with highest ranks show **good variety of terms between clinical research and basic science specific to CF.**



Table 1. Ranking of terms proposed for the glossary. Terms with the highest ranking were selected for the pilot study (in red)

CF-specific terms	Ranking
Minimal function mutation	1
Nasal transepithelial potential difference	2
Nonsense mutation	3
Gating mutation	4
Minimal clinically important difference (MCID)	5
Residual function mutation	5
Forced expiratory volume (%ppFEV1)	6
Pulmonary exacerbation rate (PeX)	7
Medicine washout period	8
Mucolytic	8
Mucociliary clearance	8
Corrector	9
Potentiator	10
Lung clearance index	
CFTR modulator	
Forced vital capacity (FVC)	
Genotype	
Amplifier	
Protein CFTR	
Anti-inflammatory	
(Compound) Heterozygous	
Multiple Breath Washout	
Sweat chloride	
CF questionnaire-revised (CFQR)	
Spirometry	
Homozygous	
Six minute walk test (6MWT)	



- ⇒ Approval by participating companies.
- ⇒ Creation and publicity of an online glossary.
- ⇒ Translation into national languages.