

The Cystic Fibrosis Community Advisory Board (CF CAB) -how we measure our successes-



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Background of the CF CAB

Established in 2017 - 6 meetings with 5 companies in 3 years.

An independent pan-European group of trained patients and patient representatives from 13 European countries.

Ensuring the patient perspective is always considered and incorporated, throughout all stages of research and treatment development.

Regular meetings with representatives of CF companies and other CF stakeholders involved in research, development and treatment access discussions.

Methods for evaluation

Meetings with CF companies are followed up with letters.

A survey is sent to both the companies that have participated in CAB meetings and the CAB members.

With each company a “tracker” is established to maintain the interaction and measure achievements. This company tracker is an overarching reference document, used to set goals, capture outcomes and measure progress and success for each company.

CFE CAB Overarching Goals



The below goals apply to all of our CAB meetings. They should be reviewed as a first point of call before all upcoming CABs, prior to setting specific goals for that meeting.

CF CAB Priorities		CF CAB Goals	
Clinical Trials / Research	Closer interaction with companies, facilitating early contact with CT design, to make trials more patient-oriented Get more companies interested in the CF field, to accelerate research; Increase research in organs affected by CF other than the lungs, and most common CF complications. Diminish inequalities across Europe	Clinical Trials / Research	By 2020, we give input about PROM and review informed consents in 50% of CAB meetings. By 2020, 4 additional companies are interested in CAB meetings. By 2020, we address and discuss research into other organs affected by CF in 50% of all CAB meetings.
Access	Improve patient access to new drugs and clinical trials throughout Europe	Access	By 2020, we discuss, get concrete answers and sufficient follow up from companies on access to CFTR modulators in Europe in 50% of all CABs.
Communication / patient support	Empower patient representatives through increased knowledge and knowledge-sharing	Communication / patient support	Meet with 4 companies per year by 2020. Have organized 2 training sessions for CAB Members.
QoL & PROMS	Work on more patient-relevant and patient-friendly measurements of QoL and PROMs. Inequalities.	QoL & PROMS	Give input to XXX QoL and PROM measurements before 2020.



Results

All companies will continue their relationship with the CAB.

Most companies identified distinct patient-relevant outcomes.

All companies say CAB meetings helped them to demonstrate the value of their product to HTA agencies and to regulators.

The meeting helps in making clinical study programmes more aligned with patients' needs, most companies revised parts of studies or research plans.

The tracker is seen as a useful instrument for future collaboration.

Conclusion: *Companies highly value the input from the CF CAB. The most important criteria for a successful liaison are good follow-up and maintaining the tracker active.*

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