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.

Results
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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