

Development of mental health quality outcome measures in the Swedish Cystic Fibrosis Registry – pitfalls and possibilities

L. Backström Eriksson, C.Laine, I.deMonestrol, A.Lindblad, E.Bergenmar Ivarsson, S.Järvholm

Objectives: In Sweden a CF Registry is used since 1994, and an active national CF Registry since 2012. In recent years, the need of also including measures addressing mental health has been highlighted. In 2015 the board of the Swedish CF Registry assigned the psychologists at the CF Centres to develop 2–4 quality measures. Herein the scope is to describe this process.

Methods: The work was initiated with discussing quality indicators of addressing mental health in CF care. This resulted in four broad themes; “depression,” “anxiety,” “psychological interventions,” “contact with mental health care.” The operational possibilities of the themes were further discussed with the registry trustee; the measures were directed to be clearly defined, searchable and not dependent on interpretation.

Results: Three measures were created: “attending screening for anxiety and depression,” “self-reported level of anxiety and/or depression” and “contact with psychologist within CF care/elsewhere.” The first version of the mental health registry module was launched in 2016, in 2017 a revised version was finalised. Routines for collecting data were implemented according to local conditions at the CF Centres, and 2017 was the first full year three (out of four) CF Centres consequently reported data in the registry module. In 2018 psychological data were reported with a 48% coverage (3/4 centres) of the entire Swedish CF population (n = 716).

Conclusion: The process from wheat to bread requires a long-term time horizon, continuity, organisational and logistic competence, and increased personnel resources. The benefits are a more standardised way to address mental health minimising risks of leaving patients out, and possibilities to conduct research on a national level in the mental health area. Taking this work to the next level international coordination will be required in deciding on robust measures making it possible to register and use shared data across countries in Europe and worldwide.