

ECFS Standards of Care Project meeting, Brussels , January 24th 2019, 8.30 – 10.30 am

Present; Carlo Castellani, Hilde Dekeyser, Pavel Drevinek, Alistair Duff, Isabelle Fajac, Silvia Gartner, Nataliya Kashirskaya, Jacqueliën Noordhoek, Dominique Pougheon, Kevin Southern, Kors vanderEnt

Adult quality monitoring project

- The first 2 phases have been concluded and were presented. Plan is now to move to phase 3 and circulate the statements among adult and mixed European centers and collect their data
- Step 3 may pose a considerable challenge, due to the EU privacy legislation. An updated and law compliant list of who does what and where in CF is not available yet. This will be fundamental not just for SoC quality programmes, but also for other ECFS activities. During a preliminary conversation with ECFS Board, CC expressed the opinion that the SoC project should be involved in the making of this list
- Some concerns were expressed about the workload needed to answer the questions as well as some data not being potentially retrievable by centres. It was suggested that some of questions could be reformulated to make answering more feasible.

Framework for writing ECFS guidelines

- This 3 years project will create a roadmap and will be coordinated by Kevin Southern
- The first year is being used to create an expert group and survey similar sources from other learned Societies and Institutions. In the second year an ECFS guideline document which will take into account European CF peculiarities and the possible need of alternative approaches will be produced. In the third year the plan is to put theory in action by producing guidelines for CFTR related disorders
- Members so far recruited for the expert group are Carlo Castellani, Karen Robinson, Ian Sinha and Sarah Mayell. A limited number of other experts can still be enrolled
- The original name of the project, i.e. Guidelines on Guidelines, has been changed to “Framework for writing ECFS guidelines”.

Pharma book

An ECFS book on CF medicines will be produced, and similarly to previous Society's books, distributed at the 2020 annual conference. The ECFS Pharmacy working group is actively involved. CC will coordinate this together with coeditors Daniel Peckham, Nicola Shaw and Sian Bentley. Preliminary contents and authors list was presented and discussed.

Membership expansion

At the last SoC meeting in Belgrade 2018, there was a need expressed to expand SoC members and involve CF professionals according to their expertise and needs. AD has recruited representatives of the ECFS AHP and nursing assemblies. The intention is to attract as many people as possible and collect different perspectives on needs related to the SoC mission.

Accreditation project

- The possible implementation of an ECFS accreditation system was discussed. This would be based on questionnaires evaluating the centre framework, with no site visits and with involvement of local patients
- Usefulness and feasibility of such initiative were discussed, and the majority found the project not attractive and at high risk of failure. A twinning initiative where major and well settled centres are involved in the training of staff from less established ones was put forward for consideration and will be further discussed in the June meeting. Dominique Pougheon and Gilled Rault later expressed their interest in actively participating in this project.

Website, executive and steering committee

- It has been proposed and accepted that those in charge of specific projects will compose the SoC Executive Committee. Contacts will be through phone meetings. Other members may be invited to join the TCs according to needs
- The Executive Committee and the Steering Committee (presently the Core Committee) members will attend the face-to-face meetings in January during the CTN days and at the annual ECFS June conference. In June AHP members will also be asked to be present

- The website will be updated according to this new framework. Ongoing SoC projects will be posted on the website.

Registry, ERNLUNG

- SoC and the ECFS Registry share some critical topics (quality benchmarking being a good example of some of these). It is vital to cooperate and avoid wasting resources by duplicating what has already been or is being done. It is also important to find common grounds for working together. In order to achieve that Lutz Naehrlich has been invited to join the SoC executive committee
- The SoC project should also be closely connected with ERN-LUNG. Although it is not completely clear yet how we can work together, there may be a great potential of cooperation with ERN-LUNG. Kors van der Ent will liaise with CF ERN-LUNG.

Preliminary time and date for next SoC meeting

Liverpool, 6 June 2019, 12:30-14:30