

# **Development of a multidisciplinary syllabus to support the education and training of roles in cystic fibrosis care: An ECFS Education initiative.**

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## ABSTRACT

**Background:** Clarity and consistency of required knowledge and skills is crucial in supporting the development of members of cystic fibrosis (CF) multidisciplinary teams. Syllabi are effective frameworks for delivering a more uniform and evidence-based approach to high quality holistic care and research.

**Method:** Expert group representatives of the European Cystic Fibrosis Society (ECFS) Education Committee developed multiple speciality focused syllabi to define relevant core knowledge and skills. Contributors from a range of CF disciplines and countries reviewed each syllabus, which were further edited by members of the relevant ECFS speciality / working groups.

**Results:** Nine syllabus frameworks were developed and ratified for medicine, physiotherapy, nursing, pharmacy, psychosocial, exercise, nutrition, clinical trials and fundamental and translational science.

**Discussion:** Multiple challenges exist when developing and applying international syllabi. Examples include disparities in economics, health care infrastructure, available resources, and differing roles and responsibilities. By tapping into a broad international knowledge base, we were able to develop a clear framework for both comprehensive training and ongoing continuous professional development. These syllabi will support the further harmonisation of training and enhance education for both clinical and academic CF health care professionals across Europe.

## INTRODUCTION

The European Cystic Fibrosis Society Education Committee (ECFS-EC) was established in 2016 to concentrate on four key educational aims: (i) to develop a clear cystic fibrosis (CF) curriculum / syllabus which could enhance education across all disciplines and members of the ECFS, (ii) to assess and address unmet educational needs, (iii) to create CF relevant educational material and (iv) to reference all available educational resources.

A key priority and focus in recent years has been the development of clear syllabi, which will encompass the needs of an evolving society membership. On an individual level, a well-defined syllabus helps identify and rectify knowledge gaps to support improvements in quality of care. They also support and promote continuous professional development (CPD) by providing a consistent standardised framework for ongoing education. On a speciality group level (e.g. physiotherapists, psychologists), the presence of a unified framework improves the effectiveness of international collaboration and promotes safer, more consistent, efficient and equitable clinical practice. On a research level they can support consistency and alignment to key principles. At centre or hospital level, syllabi can support evidence-based investment in the multidisciplinary team (MDT) by clearly defining the importance of specific roles. Indeed, achieving investment in MDT care can be challenging especially where there is a lack of framework or culture for MDT collaboration (1). Where current guidelines may define MDT members whole time equivalents in the context of patient numbers (2-4), syllabi provide more textured description of the roles, skills and objectives. Finally, at a European level, such syllabi are essential to support education, training, speciality group events and international conferences by ensuring all relevant topics are comprehensively

covered. The importance of such a framework is reflected by the growing number of syllabi being developed by speciality societies such as the European Society for Paediatric Gastroenterology, Hepatology, and Nutrition (ESPGHAN), the European Respiratory Society (ERS) and the European Society of Endocrinology (ESE) (5-7). Although developed at a European level, such endeavours can certainly apply or be useful more globally.

The development of a unified international educational framework has highlighted the overt disparity and inequality in health care and financial constraints limiting MDT services across Europe (with parallel to the global situation). Despite this inequality, current MDT members (academic and clinical) have a responsibility of ensuring that they maintain, update and enhance their knowledge, skills, effectiveness and expertise through a proactive approach of CPD (3).

A clear and evolving educational framework has become particularly important in the era of CF transmembrane regulator protein modulator therapies (CFTRm), where clinical outcome has been transformed for many people with CF. These changes in health care outcomes are also driving new models of care and evolving both new and established MDT roles (2, 8). We describe the successful development of a set of ECFS syllabi covering the core knowledge required for optimal CF care.

## **METHOD**

The ECFS-EC includes international experts and representatives from each speciality, linked to one of ten ECFS projects, special interest or working groups (Table 1).

Table 1 - Represented contributor groups.

ECFS Clinical Trials Network (CTN)
ECFS Exercise Working Group
ECFS Mental Health Working Group
European Psychosocial Special Interest Group (EPSIG)
ECFS Nursing Special interest Group (NSiG)
European CF Nutrition Group (ECFNG)
European CF Pharmacy Group (ECFPG)
ECFS Physiotherapy Specialist International Interest Group (PhySIIG) *
ECFS Standards of Care Committee
Neonatal Screening Working Group

\*Group created from the merger of 2 historical groups in 2023: International Physiotherapy Group for CF (IPG-CF) and ECFS Physiotherapy Special Interest Group (PhySIG)

The committee includes representatives from 10 countries (Austria, Belgium, Denmark, Germany, Israel, Poland, Portugal, Ireland, Switzerland and UK). Representatives were tasked to coordinate and develop a syllabus for their respective specialist area, and to identify additional authors from within their

speciality if desired. The number of authors and contributing countries are shown in Table 2.

All authors were informed of the aims of the syllabus; (i) to outline the main topics/subjects of knowledge within the speciality and (ii) to define the key principles within these topics that a specialist working in this area would need to have knowledge of.

The purpose was clarified as (i) to provide the specialty with a core education framework and define the remit for training and learning, (ii) to provide the wider ECFS community with understanding of the scope of the speciality, and (iii) to provide a tool for evaluating existing education content, identifying gaps and ensuring comprehensive coverage that supports each speciality.

Authors were advised to be concise and structured, selecting and organising knowledge around key central themes rather than attempting to cover all possible areas. A first draft was initially circulated within the respective speciality or interest group, and edits were made. Each syllabus was then finally circulated for review to all 22 members of the ECFS-EC to provide cross speciality review (Table 2).

Table 2 – Contributor and review process for each syllabus.

Syllabus	First draft (Authors and countries)	First review (specialty group / working group)	Second review
Clinical research	2 (UK, Denmark)	ECFS Clinical Trial Network (CTN)	ECFS-EC **
Exercise	3 (UK, Switzerland)	ECFS Exercise Working Group	ECFS-EC **
Fundamental and translational science	2 (Portugal, Italy)	Selected experts by author	ECFS-EC **
Medicine	1 (UK)	Selected experts by author	ECFS-EC **
Nursing	3 (UK, Netherlands, France)	ECFS Nursing Special interest Group (NSiG)	ECFS-EC **
Nutrition	2 (UK, Belgium)	European CF Nutrition Group (ECFNG)	ECFS-EC **
Pharmacy	2 (UK)	European CF Pharmacy Group (ECFPG)	ECFS-EC **
Physiotherapy	2 (UK, Austria)	ECFS Physiotherapy Specialist International Interest Group (PhySIIG)*	ECFS-EC **
Psychosocial	5 (Czech Republic, Isreal, Poland, UK, Belgium)	ECFS Mental Health Working Group European Psychosocial Special Interest Group (EPSIG)	ECFS-EC **

\*Group created from the merger of 2 historical groups in 2023: International Physiotherapy Group for CF (IPG-CF) and ECFS Physiotherapy Special Interest Group (PhySIG).

\*\*22 members. Countries represented: Austria, Belgium, Denmark, Germany, Israel, Poland, Portugal, Ireland, Switzerland and UK.

As the syllabi developed at different rates from different groups, all syllabi underwent author review in June/July 2025 to ensure continued alignment with current standards and clinical care.

## RESULTS

Nine syllabus frameworks were developed and ratified for medicine, physiotherapy, nursing, pharmacy, psychosocial, exercise, nutrition, clinical trials and fundamental and translational science. Variation in structure, detail and layout were employed by

each group reflecting the unique needs, roles and guiding principles of each specialty. All syllabi are provided in supplementary information.

## **DISCUSSION**

Developing a clear syllabus for each speciality within the CF MDT (including researchers) is an important practical exercise. It helps define essential core knowledge and skills needed to ensure high quality of care and support education at individual, local, national and international level. Supporting centres with good resources remains essential for the delivery of optimal care (1).

The strengths of the development process included the involvement of a broad range of clinically active experts from across Europe. In addition, the inclusion of well-established specialties (e.g. psychology), with both emerging specialities (e.g. exercise) and increasing presence specialties (e.g. pharmacy) provide an element of future proofing and ongoing alterations in care delivery. Sharing this knowledge to all disciplines is particularly important as some may be unaware of ongoing evolving changes, especially if these fall outside their area of expertise.

It is however important to recognise the challenges and limitations of such syllabi. Firstly, it is well recognised that a range of different health infrastructures, economics, legal frameworks and resources exist between countries. This in turn determines the availability of MDT members and may affect the application and adoption of such frameworks. However, the syllabi provide universal principles of optimal care for each specialty, while allowing flexibility in implementation.

There are also significant discrepancies in access to therapies such as CFTRm, which in turn will affect both patient management as well as the configuration of the required MDT. This disparity is particularly evident between eastern and western European health care services (9). However, setting standards for all units will in time support harmonisation of care. Furthermore, there is a lack of homogeneity in both training and education for many specialists across Europe (10). As language remains an important barrier for syllabi that have been designed for international use, translation into appropriate languages will remain essential to ensure appropriate access for all (11). Finally, and perhaps most importantly it is crucial to recognise the challenge of providing and delivering the education required to address the gaps revealed in applying the syllabi. A novel 1 day course to directly address this will be piloted at the ECFS conference 2026.

The management of CF is rapidly evolving, and each syllabus will need to be reviewed on a regularly basis to ensure information remains up to date. This needs to be dynamic, agile and flexible and reflect evolving changes in treatments, MDT roles and clinical practice. Work will continue by the ECFS-EC to include regular, flexible reviews (including input from representatives of countries with limited resources and treatment access) and to begin translation and adaption to optimise use and understanding. Despite the many limitations and challenges outlined, robust initiatives such as the ECFS Standards of Care publications illustrate how comprehensive guidance and frameworks such as these can support practice across regions with differing resources.

## **CONCLUSION**

The ECFS syllabi provide a promising framework for the delivery of knowledge to a diverse group of health care professionals with differing experiences and backgrounds. They are designed to complement rather than supersede national guidelines and to nurture collaboration, equity, and work both nationally and internationally. They represent a step towards harmonisation of care and will aid in education planning and support our diverse and geographically varied community.

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CS: Has received advisory fees from Vertex Pharmaceuticals and Nordic Pharma and speaker fees from Vertex Pharmaceuticals

DP: Has received speaker/board honoraria from Vertex Pharmaceuticals

All other authors report no conflicts of interest

## **CONTRIBUTION**

CS: Conceptualization; Methodology; Project administration; Visualization; Roles/Writing - original draft; and Writing - review & editing.

DP: Conceptualization; Methodology; Project administration; Visualization; Roles/Writing - original draft; and Writing - review & editing.

HKC: Conceptualization; Methodology; Project administration; Visualization; Roles/Writing - original draft; and Writing - review & editing.

All other authors: Conceptualization; Writing - review & editing

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