

Terms of Reference: Report writer consultant

COPD Standards of Care – Raising the Bar (deadline for applications: 07th April 2023)

EFA is a vibrant alliance of 45 European allergy, asthma and chronic obstructive pulmonary (COPD) patient associations from 26 countries and works for equal access to good quality care, safe, healthy environment and patient participation.

In 2023, EFA plans to evaluate progress on EFA's 2013 COPD minimum standards of care and foster continued progress with new benchmarks and policy recommendations.

To bring greater awareness to the disease, EFA published in 2013 a book on 'Minimum Standards of Care for COPD Patients in Europe' which evaluated existing care for COPD patients to reveal best practices, identify ways to lower healthcare costs and offer recommendations for patient advocacy. The EFA book was a vital piece of evidence that improved the understanding of the number and quality of pulmonary care services in Europe and established minimum standards of care from the patient perspective. Ten years on, EFA aims to investigate if and how these minimum standards have been met and identify areas for future improvement. In essence, EFA seeks to raise the bar, from minimum standards of care to optimal.

EFA is looking for an external consultant to help conducting a desk review on to evaluate status quo against minimum standards of care established in 2013 and drafting the final report of the 'COPD Standards of Care – Raising the Bar' project.

Background and Project Description

COPD is one of the most common long-term respiratory conditions¹ and the third leading cause of death worldwide² yet more than half of COPD patients [surveyed in our research] believe that COPD does not get enough attention compared to other diseases.

Ten years after the publication of the EFA book on "Minimum Standards of Care for COPD Patients in Europe", EFA aims to investigate if and how the minimum standards have been met and identify areas for future improvement. In essence, EFA seeks to raise the bar, from minimum standards of care to optimal.

In this exploration, EFA also seeks to recognise the unprecedented impact of the respiratory pandemic of COVID-19 which increased complications, affected access to care and introduced new digital solutions for COPD patients. The review comes on the heels of EFA's <u>DIG_IT_report</u> that provided a

¹ Xie, Min, Xiansheng Liu, Xiaopei Cao, Mingzhou Guo, and Xiaochen Li. "Trends in Prevalence and Incidence of Chronic Respiratory Diseases from 1990 to 2017." Respiratory Research 21, no. 1 (2020). https://doi.org/10.1186/s12931-020-1291-8.

² Who.int. 2022. Chronic obstructive pulmonary disease (COPD). Available here.



snapshot of the barriers and facilitators to the provision of care in the new digital era. The COPD community can provide further insights on the interaction between the digital healthcare transformation and the minimum standards of care previously outlined.

With the COPD Standards of Care project, EFA will:

- 1. Provide an assessment of the current standards of care for COPD against EFA's 2013 minimum standards of care recommendations, thereby highlighting successes, gaps and best practices.
- 2. Foster better alignment between the burden of COPD and the attention and investment it receives in Europe.
- 3. Empower the COPD community with the evidence and recommendations necessary to pressure health authorities for improved prevention and care.

Scope of work

The consultant will implement a **desk review** to evaluate status quo against minimum standards of care established in 2013, considering also the results of an internal short survey and a Policy Recommendation Workshop conducted by EFA with its members and the global COPD community, with the aim to integrate patients' experience into the report. The consultant will then draft the **final report**.

More in details, the consultant will:

- review the COPD preventative actions and standards of care in countries surveyed for the 2013 study (Austria, Belgium, Bulgaria, the Czech Republic, Finland, France, Germany, Italy, Poland, Portugal, Serbia, Spain, Sweden, Switzerland, the Netherlands and the United Kingdom) and additional EFA represented countries (Iceland, Ireland and Turkey)
- analyse the developments in scientific field on COPD care, guidelines and standards
- study the impact of COVID on COPD prevention and care
- use 2013 data as baseline to evaluate the current situation
- integrate patient experiences and feedback provided by the EFA survey into the desk review report
- draft the final report

The report shall be written in a patient-friendly manner and contain accurate scientific information that will empower the COPD community across Europe, to advocate for better prevention and care.

The work will be developped under the management of EFA and a timeline with deliverables and deadlines is presented in a section below.

Expected Outputs

The work will result into the implementation of a **desk review** and the development of a report on COPD minimum standards of care that will be widely disseminated by EFA through a Communication Campaign highlighting recommendations, targeting and in partnership with EU relevant stakeholders for World COPD Day.



Deliverables and Timeline

The consultant will be responsible for the delivery and quality of the final product. All deliverables shall be submitted to EFA in accordance with the following timeline:

Task/Output	Target due date
Desk review submission	28/04*
Report outline	09/06
Report draft – first review	30/06
Report draft – second review	08/09
Report draft - third review	22/09
Final report submission	29/09

^{*}An interim review is planned on the 20/04

Qualifications of the Consultant

Professional Experience	 Proven experience in the life sciences sectors Track record in drafting and editing materials targeting lay audiences, especially on disease management Proven experience in medical desk research and analysis (desired) Experience working with patients' groups and medical societies (desired)
Language requirement	Native level English

Proposal Submission

Interested applicants should submit a detailed offer, including CV, examples of work and short motivation, to agata.papotto@efanet.org by 7th of April. Short-listed candidates will be invited to a meeting in the week of 11th of April 2023 to present their offer and address questions.