



EFCCA | 2023 STRATEGY PLAN | 2027

Global Collaboration Based
on Shared Knowledge



EFCCA
European Federation of Crohn's
& Ulcerative Colitis Associations

About EFCCA

The European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA) is an umbrella organisation representing 46 national Crohn's and Ulcerative Colitis (collectively known as IBD) patient associations.

We are an organisation of people united in our commitment to improve the life of over 10 million people living with IBD worldwide (3.4 million in Europe alone), to give them a louder voice and more visibility.

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Foreword

*We are very pleased to present the EFCCA Strategy Plan for the period 2023-2027. It sets the ground of where EFCCA is now and where we envision EFCCA in four years by outlining **strategic directions in awareness raising, empowerment, research, and development, while building on networking under the overarching advocacy.***

We are particularly proud of the work done for the development of the new strategy and the results achieved, as this was the first time that the strategy was developed together **with all the EFCCA members in a concerted way.**

The Inflammatory Bowel Disease (IBD) community has grown significantly throughout the years and has gained in capacity and accountability despite the challenges faced during the COVID-19 pandemic.

The work done by EFCCA to develop the future strategy of the IBD community reflects this evolution. In fact, the process was highly participative (Annex 1) and started with an in-person meeting in Barcelona in June 2022 and moved on with three rounds of online consultations through SurveyMonkey:

1. **on the vision, mission, and values.**
2. **on the strategic objectives.**
3. **on the strategic and priority areas.**

Our members had a very active role in the development of the Strategy with an average of **78% participation** in the process.

This Strategy **builds on the achievements and lessons learned** from the previous 2019 – 2022 Strategy Plan and the effort of the Board and the Secretariat to thoroughly analyse what worked best in the past and what we need to focus on to best address the new challenges faced by the global IBD community. This analysis (Annex 2) was presented at the meeting in Barcelona and was the basis to enhance the discussion with the delegates on the

future strategic directions. This is why we highlight in the Strategy Plan where we start from and where EFCCA stands today.

The overall context with which the IBD patients' community interacts also evolved over time. EFCCA is a **recognized partner of the medical and research community** participating in the ECCO guidelines development, EMA consultations, and in several Horizon research projects. EFCCA has consolidated its relationship with European institutions, such as the European Commission and Parliament, and is **ready to actively participate in major policy dialogues.** EFCCA's **capacity to gather data** through surveys and evidence-based information on clinical trials also using artificial intelligence tools has exponentially increased through the **DIVA** (Data Insights for Added therapeutic VAue) methodology.

The strongest asset of EFCCA remains its membership, which has increased, strengthened, and broadened in scope. In fact, now EFCCA can count on at least one member in each continent beyond Europe, including Asia, America, Oceania, and Africa.

We are now ready to embark on a new period to become formally an **international organisation** consolidating what we have built in Europe to share, support, and encourage the development of new associations globally with a **collaborative approach.** The collaborative approach is a well-tested and ascertained characteristic that EFCCA consolidated throughout the years.

EFCCA's Vision, Mission, and Values remain the same. EFCCA's main goal for the next Strategy Plan period is **Global Collaboration based on Shared Knowledge.** And with this in mind, we will gather all our resources and efforts towards building a better world for people living with IBD no matter where they were born or live.

The Objective of the EFCCA Strategy Plan

The 2023-2027 EFCCA Strategy Plan is a comprehensive document outlining the direction for EFCCAs development in the next four years, aiming at:

- Internally, **uniting our members around a common Strategy for the next four years.**
- Externally, **informing all stakeholders on where EFCCA intends to focus its resources in the next four years.**

The document starts with an overview of the increasing worldwide incidence of Inflammatory Bowel Disease (IBD) and EFCCA has a clear role to build a network of collaboration at the global level.

Then, based on an assessment of the previous strategic plan implementation, the document introduces the main EFCCA achievements to date, positioning **EFCCA at the forefront of the IBD Community worldwide and in a leadership role.**

The process established to reach a consensus around the Strategy Plan with the EFCCA members showed how the IBD community is now prepared and demanding a more active role in policy, research & development to guarantee effective patient centrality. To support all this, EFCCA is developing a new and very innovative **tool for building evidence-based knowledge** which is the **DIVA** (Data Insights for Added therapeutic VAalue) approach.

Over the next four years, EFCCA will **enhance global collaboration within the IBD community** and **amplify its voice.** EFCCA will aim to **promote patient-centricity** in **policy and research** using **evidence-based data** facilitated through DIVA, which will ensure the sharing of good practices and benefiting people worldwide living with IBD.

This Strategy Plan identifies the future direction structured in **five strategic areas** including three pillars: **awareness raising, empowerment, and research & development.** These three pillars are rooted in a solid foundation represented by **networking** and are kept together by an overarching roof represented by **advocacy.**

The document defines how the activities of each one of the five strategic areas will support the strategic direction toward a global IBD community based on collaboration and shared knowledge.

Each year the Board and the Secretariat will develop a **Work Plan** identifying specific projects and activities to support the implementation of the Strategy Plan. The Work Plan will identify the priorities and objectives of that specific year also keeping into consideration the suggestions gathered in the discussions and consultations with all the members during the Strategy Plan development process. A dedicated annual budget will be allocated to the implementation of the Work Plan. The Work Plan will be the basis for the EFCCA annual activities.

IBD in the world

Inflammatory Bowel Disease (IBD) affect **10 million people in the world**¹ and **3.4 million people only in Europe**². Men and women are equally likely to be affected, and while the disease can occur at any age, EFCCA will promote and raise awareness of age-specific challenges that people with IBD face from adolescence to adulthood to 60+ and over.

As the incidence of IBD is growing dramatically around the world, EFCCA believes that strengthening links with sister associations that share our overall vision can help build a network of cohesion and visibility at a global level and contribute to creating a louder and more effective critical mass of patients and communities.

1. Centers for Disease Control and Prevention (US) (2015) <https://www.cdc.gov/ibd/data-statistics.htm>; *Emerging Trends of Inflammatory Bowel Disease in Asia, Gastroenterol Hepatol (N Y)*. 2016 Mar; 12(3): 193–196 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4872848/>; *Worldwide incidence and prevalence of inflammatory bowel disease in the 21st century: a systematic review of population-based studies, The Lancet Volume 390, No. 10114, p2769–2778, 23 December 2017* [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(17\)32448-0/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)32448-0/fulltext);
2. *The burden of inflammatory bowel disease in Europe, Journal of Crohn's and Colitis Volume 7, Issue 4, 1 May 2013* <https://academic.oup.com/ecco-jcc/article/7/4/322/386167>;

EFCCA today

*EFCCA counts on **46 national Crohn's and Ulcerative Colitis patient associations** and is representing the interests of over **10 million people living with IBD worldwide**, to give them a louder voice and more visibility.*

EFCCA representatives are actively engaged with international medical societies such as ESPGHAN, UEG, and ECCO and have contributed to **guidelines** revisions, animated working groups, and seminars proposing a more patient-centric approach to clinicians and researchers.

EFCCA is also involved in EMA consultations whenever necessary.

EFCCA is an active member of **seven EU-Funded large research projects** (Innovative Medicine Initiatives and Horizon Europe). (Full list in Annex 3).

In 2010 EFCCA became one of the founding members of World IBD Day which is observed annually on 19 May.

EFCCA plays a crucial role in coordinating and mobilising national IBD patient organisations around the world to globally raise awareness about Crohn's Disease and Ulcerative Colitis and to increase public understanding of these chronic conditions. Today World IBD Day is the most powerful tool to raise awareness around the impact of IBD on the persons and their families. Since 2019 EFCCA developed or backed the development of several surveys to better understand the challenges faced by the IBD patients' community and to support them in overcoming these challenges. The surveys were led by EFCCA or developed together with high-level scientific institutions such as ECCO, Hospital Beatriz Angelo in Portugal, Humanitas University Hospital in Milan (Italy) and the Portuguese Society of Gastroenterology. Most of the surveys were developed at European level and some others also at global level with a significant outreach and high response rate, in several cases of about 4.000 respondents.

More information can be found at <https://efcca.org> publications.

This large number of surveys promoted by EFCCA, and large number of respondents proves the unique role that EFCCA plays in gathering patient data for policy and research development and the need to develop a structured way to gather data.

EFCCA is now ready to move a step further and build internal capacity to analyse the data that are gathered in different ways through new and innovative tools.

EFCCA has its own educational platform, the **EFCCA Academy**, which is one of its flagship activities in terms of patient empowerment. The Academy was launched in April 2018 to provide specialised training for people with IBD enabling them to raise awareness on specific topics and to become advocates for their IBD patient community. Academy-qualified patients become then trainers of other patients within their own local community. The training modules are usually split into online and in person sessions and students are requested to defend a thesis at the end of their learning path. One of the most impactful educational

programmes focused on clinical trials, their benefits, challenges, and myths around them.

EFCCA has been a historical member of the European Patients' Forum (EPF) and of the International Alliance of Patients' Organisations (IAPO), a patient organisation that has over 300 member organisations from 71 countries, and it represents 50 disease areas with which EFCCA could broaden its scope beyond Europe.

EFCCA's new working methodology aims to identify and address the real needs of people living with IBD through analysing and interpreting scientific data to improve therapeutic outcomes. DIVA will help us to gather both publicly available data and EFCCA internal data to analyse and interpret the unmet need of the IBD communities.

DIVA will provide **harmonised opinions and recommendations** to stakeholders such as regulators, policy makers, pharmaceutical industries, and healthcare professionals. It will be the strategic tool to implement and exploit during the next four years.

Vision, Mission, and Values

Our Vision, Mission, and Values remain unchanged, as a result of a consultation with all EFCCA's members, but the new Strategy provide EFCCA with better tools based on scientific data and shared knowledge to face current challenges for people living with IBD. It will also help to broaden the work perspectives to support IBD patients worldwide.

The Strategy draws conclusions from the current global health context and assesses opportunities for the field of IBD. The Strategy reflects EFCCA's evolution, reiterating our focus on solidarity among the global IBD Community based on solid and evidence-based knowledge. This will notably be achieved by supporting advocacy, networking, and joint initiatives among the members and external partners, and stakeholders to improve the life of people living with IBD and have an impact on IBD-friendly policymaking and health systems.

Vision

Our vision is to find a cure for IBD. As no cure has yet been found, the members strongly believe that our vision remains to find the cure for IBD.

EFCCA Mission

Our mission is to improve the overall well-being of people affected by Crohn's Disease and Colitis, collectively referred to as Inflammatory Bowel Disease (IBD).

EFCCA Values

Our values are based on our tag line "United We Stand" and are as follows:

PEOPLE: We believe that people are the focus of our efforts. We believe people make EFCCA and people are our greatest resource.

UNITY: We are a community aiming at improving well-being of people with IBD and we believe that together we work better towards our mission and to support, learn and share with each other.

INTEGRITY: We have strong principles of ethics, honesty, and transparency and expect high ethical standards also from our partners. We will always follow through on our commitments and demonstrate the highest standards of personal and organisational behaviour.

COMMITMENT: We are dedicated to making a valuable contribution to the well-being of people affected by IBD by fostering engagement, involvement, and activism and ultimately finding a cure for IBD.

Strategic Objectives of the 2023-2027 EFCCA Strategy Plan

With its membership today EFCCA covers all continents. EFCCA has grown significantly in the last years and is ready now to broaden its scope of work beyond Europe to become an International IBD patient organisation to better:

- Strengthen EFCCA advocacy capacity to advance IBD global policy action toward improving accessibility of diagnostics, treatment, and care for IBD patients.
- Increase IBD Patients' centricity in Research and Development worldwide.
- Empower EFCCA delegates and the global IBD patient community to increase their advocacy capacity.

EFCCA will strengthen its capacity to develop and share new knowledge through:

- the **EFCCA Academy**
- the participation in large **research projects**
- the development and exploitation of a totally new and innovative tool that is **DIVA** (Data Insights for Added therapeutic VALUE), which will be EFCCA's new approach to advocate for patient centricity in policy and research development.

Strategic Areas of the 2023-2027 EFCCA Strategy Plan

EFCCA delivers on its Vision, Mission, and Strategic Objectives of improving the care and the quality of life of people living with IBD globally through five Strategic Areas which can be symbolically assimilated into **three pillars** of a building, **Awareness Raising**, **Empowerment**, **Research & Development** where the **foundations** are represented by the **Networking** activities and the roof is represented by the **Advocacy** work.



Networking

In the past EFCCA invested a lot of its resources in building and strengthening the network among its members. EFCCA is ready now to strengthen its networking capacity toward external global stakeholders. Considering the organisational impact, both on financial and human resources, EFCCA will be focusing more and more on reaching out to new members in the short term, and on more structured international work in the medium-long term.

Internally, EFCCA will encourage and facilitate collaboration, exchange of information, knowledge, and practices, and the promotion of international activities.

Representing a relatively small disease group, it is vital that EFCCA develops and strengthens synergies and partnerships that are beneficial for all. So, externally, EFCCA will strive to collaborate with different stakeholders to establish and reinforce relationships in order to build a stronger worldwide IBD community. Networking is the foundation to sustain all the other pillars and the roots of the EFCCA structure. Networking will be instrumental in continuing the progress toward the internationalisation of EFCCA and it will focus on three areas:

1. Networking between national organisations

EFCCA will continue its work to facilitate networking between the national members. EFCCA is pleased to see that some members, under the umbrella of EFCCA, are now able to meet on their own and collaborate horizontally. Networking between the members helps to develop a sense of belonging. This is why EFCCA will facilitate mentorship programmes among the national associations so that members can support each other. EFCCA will prioritise diversity and inclusion focusing on 60-plus groups, families, and young people, just to mention a few.

2. Strengthening the IBD global community voice

EFCCA will be responding to the natural evolution of the association toward internationalisation. EFCCA already has members from all the continents, others are getting in touch and several members from outside Europe actively engage in several activities, especially World IBD Day. In order to support our members in a more consistent and sustainable way, it is necessary for EFCCA to evolve from an EU organisation into an international organisation.

EFCCA is now mature enough to develop effective relationships with international organisations such as the World Health Organisation (WHO), and the Organisation for the Economic Cooperation and Development (OECD).

EFCCA will work with its members to promote and facilitate more cooperation between regions at the global level, mapping what already exists and organising meetings and, possibly, collaborative events or projects.

For example, EFCCA aims to establish links with the IBD-Emerging Nations' Consortium (IBD-ENC) founded in 2015 and including countries across South Asia, South-East Asia, and the Middle East where IBD is emerging, and other similar regional networks in South and North America, that are promoting the exchange of knowledge and specific interest in IBD.

EFCCA will put a special effort to partner with other organisations working on other chronic conditions - as policy priorities are often the same and the resources are often limited in the patient's community - in order to synergize and increase their impact together.

Advocacy

Patient well-being, proper and timely treatment, and equality are essential elements of health care. Patient advocacy is an element of health care that concerns sharing, expressing, and highlighting the rights, preferences, or desires of a patient or carer. Advocacy also includes ensuring patients have the right to make decisions about their health, promoting patients' equality, preserving human dignity, and speaking on behalf of patients to safeguard the right quality of care.

EFCCA is now highly reputable organisation and is ready to strengthen its advocacy work toward relevant **external stakeholders**, including the European Institutions (Parliament and Commission), Governments, Regulatory Bodies, to advocate for its members on the major European policy dossiers,

Furthermore, as people living with IBD age, they will be more and more affected by comorbidities. So, EFCCA will prioritise the work with organisations dealing with identified IBD comorbidities, such as mental health, cardiovascular diseases, and cancer.

3. Sharing inspiring practices

An effective way to foster networking among members is through the sharing of inspiring practices that can encourage other EFCCA members to overcome common challenges. EFCCA recognises the importance of this and is committed to facilitating the exchange of inspiring practices among its members. By doing so, our members can benefit from shared experiences and learn from others. This enables them to take the most efficient and fruitful route to solving problems, reducing the time and monetary costs associated with trial and error. The EFCCA annual meeting or General Assembly together with all the other occasions, such as training, events, and meetings provides an ideal opportunity for members to come together and share practices: dedicated time will be allocated for this purpose.

such as the Health Technology Assessment (HTA), the European Health Data Space (EHDS) and the Pharmaceutical Strategy. Global stakeholders with whom to build and consolidate a relationship include World Health Organisation (WHO) and Organisation for Economic Co-operation and Development (OECD). Whenever necessary and in strict collaboration with the national members, EFCCA can support advocacy activities at the country level dealing with governments or regional and national Parliaments.

EFCCA patient advocacy is **based on building and strengthening its members' knowledge through the EFCCA Academy and DIVA**, the EFCCA's new methodological approach.

EFCCA will improve the advocacy capacity of its membership in the following areas:

1. **Availability and accessibility** to diagnosis, treatment, and care – EFCCA will support equal and fair access to innovation for early and accurate diagnosis, the best treatment for people leaving with IBD, and equitable care.
2. **Increased patient engagement** in the decision-making process – EFCCA will support and promote patients’ engagement in clinical trials from the design phase through implementation, monitoring, and evaluation.
3. **IBD as “Invisible disability”** about the stigma, isolation, and social impact of IBD and the European Disability Strategy, inclusion strategy, quality of life, discrimination, human rights, employment, and social benefits (EMA engagement framework).
4. **Ownership of data**, as data gathered from or provided by patients should remain under the patient’s control from gathering to management, use, and storage.

Awareness-raising

By awareness raising EFCCA intends making people living with IBD, policy makers, carers, scientific societies, media, health care providers (HCPs), and the general public conscious about a problem or issue impacting the diagnosis, treatment, and quality of life of people living with IBD. EFCCA will raise awareness about any identified and relevant IBD topic or unmet need to make it more visible within its community and any other relevant stakeholder. The goal is to make people living with IBD, policy makers, Health Care Providers, and the wider public **understand** the importance of specific unmet needs such as IBD and 60-plus, IBD and Work, IBD and family, IBD and intimate life, that are relevant for people living with IBD and find support to address them.

Awareness raising is a tool for advocacy, to induce policymakers or any other relevant stakeholder of the urgency to address the unmet needs of people

living with IBD. EFCCA will identify in the Annual Work Plan specific issues relevant to people living with IBD EFCCA wants to raise awareness on. All these EFCCA activities will be based on evidence gathered first hand through **DIVA**, which will give us the scientific evidence on the knowledge gap EFCCA needs to fill in our community.

Awareness raising is the basis for developing a **unified EFCCA voice** and ensuring a **unified message** on IBD at the global level. In this sense, awareness-raising is not only linked to advocacy but also very much to networking and networking is crucial to develop a sense of belonging.

At the international level, EFCCA will identify **new areas of concern** and will **pioneer topics** that are not already discussed at the country level, **exploring new avenues** from which people living with IBD can benefit.

Empowerment

Empowerment means for EFCCA equipping its members with the knowledge, skills, resources, and support they need to actively participate in their own care, make informed decisions, and conducting fulfilling lives despite the challenges posed by IBD.

EFCCA believes that people living with IBD need to be empowered to advocate for themselves, to be the spokesperson for the needs of the community represented, and to speak with a united voice so that they can support each other.

Collaboration among the members is crucial to strengthen the sense of belonging and create a **peer support network**. This will facilitate active participation in the political debate at the country or the international level and will make them feel like equal partners in the process.

Empowerment is the basis for advocacy. Only when empowered, people living with IBD can advocate for themselves. Capacity building is a fundamental aspect of this process. To empower its members, EFCCA will continue implementing the **EFCCA Academy** to provide them with targeted education, training, competence, and information.

New areas of training have been discussed to specifically address the young IBD community generations. The objective is to provide them with the knowledge, skills, and support necessary to manage their condition and play a proactive role in their national associations and in EFCCA.

EFCCA will continue to invest in the leaders of tomorrow with ad hoc activities.

IBD youngsters will be fully involved in designing tailor-made projects and initiatives that can help ensure that the activities meet their specific needs and interests. We will establish a youth advisory group consisting of young people with IBD. This group will serve as a platform for them to provide input, share ideas, and actively participate in designing activities. New educational areas have been discussed during the consultations with the EFCCA members and they will be specifically addressed during the definition of each yearly Work Plan process.

During the next Strategy Plan period, EFCCA will exploit and develop **DIVA**, as a fundamental tool to increase the knowledge and be the basis of any evidence-based argumentation with key stakeholders. Furthermore, DIVA will increase the ability of people living with IBD to share-decision making with HCPs and medical societies.

Research and Development

EFCCA has grown and increased its research and networking capacity in the last few years and today is an equal partner of several large EU research projects. EFCCA is an effective partner of ECCO in designing new scientific guidelines.

EFCCA believes that Research and Development is an essential pillar of its future strategy and IBD patients need to strengthen their involvement in Research and Development. EFCCA will continue and expand its involvement in EU research-funded projects and will explore research opportunities at the global level.

EFCCA's strategic priorities in research and development will include the following:

- Identification of **research priorities** to benefit people living with IBD exploiting the outcomes of **DIVA**.
- **Patient centricity** in research, design and develop the protocol, disseminate the results; conduct the study design, informed consent, study logistics (location, frequency of the consultations, etc.), monitoring of the implementation of the study, analyses of the data, being part of the steering committee and the safety committee, ethical committee, and communication to the patients of the research outcomes.
- **Map of unmet needs** which can be done only with a deep knowledge of the current situation through data, a strong network, and an empowered membership.

Main Strategic Directions

The main strategic directions identified include:

IBD has no border toward the global community of people living with IBD

This strategic direction emphasises the importance of fostering a global community for individuals living with IBD. It recognizes that IBD affects people across different countries and cultures and aims to break down geographical barriers by promoting collaboration, information sharing, and support networks on an international scale. By connecting associations and people with IBD worldwide, the approach enables the EFCCA network to learn from each other's experiences, share knowledge about treatments and management strategies, and provide other support. The ultimate goal is to create a unified global community that transcends borders and empowers people living with IBD to navigate their condition more effectively.

Increase patients' voice in research and development for people living with IBD to empower them

There is a need to elevate the role of people living with IBD in research and development efforts related to the disease. Historically, patient perspectives and experiences have often been overlooked or undervalued in the medical field. By actively involving patients in research and development processes, their unique insights, challenges, and preferences can be integrated into the design and evaluation of treatments, interventions, and healthcare services. This approach not only empowers people living with IBD to actively participate in decisions affecting

their own health but also ensures that their voices contribute to the development of more patient-centred and effective solutions. It promotes a shift towards a more collaborative and inclusive approach to healthcare and research, where patients are recognized as valuable stakeholders and partners.

The voice of the future generation of people living with IBD, including young people but not exclusively them

This strategic direction recognizes the importance of giving voice and representation to the next generation of individuals living with IBD. It acknowledges that the needs, experiences, and perspectives of young people living with IBD may differ from those of older generations, and thus, their unique voices must be heard and valued. By actively engaging and empowering young individuals with IBD, organisations and communities can ensure that future healthcare services, policies, and research endeavours are tailored to meet their specific requirements. This approach also acknowledges that the impact of IBD extends beyond the immediate experience of the disease and encompasses long-term considerations, such as transitioning to adulthood, education, career choices, and family planning. By amplifying the voice of the future generation, this strategic direction aims to shape a more inclusive and supportive environment for individuals living with IBD throughout their lives.

The EFCCA Board thanks all the members for their contribution throughout the Strategy Plan consultations.

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