



Welcome to DIVA

EFCCA's roadmap advocating for the IBD patient community

What is DIVA?

EFCCA's new working methodology aims to identify and address the real needs of patients with Crohn's disease and Ulcerative Colitis, also collectively known as Inflammatory Bowel Disease (IBD).

The working methodology is based on the concept of analysing and interpreting scientific data in order to improve therapeutic outcomes.

EFCCA's approach is called **DIVA (Data Insights for Added therapeutic VA)lue** which will make use of publicly available data as well as internal EFCCA data to analyse and interpret the IBD patient communities' unmet needs.

DIVA will provide harmonised opinions and recommendations to stakeholders such as regulators, policy makers, pharmaceutical industries and healthcare professionals. At EFCCA we believe that the patient should be the starting point in the diagnosis and treatment of IBD.

What is new about DIVA?

DIVA promotes the generation, collection and use of evidence-based patient experience data that allows EFCCA and its members to explore patients' unmet needs based on scientific data and to propose new initiatives and campaigns to find meaningful solutions.

For instance, EFCCA and members are regularly invited to patient councils/advisory boards or similar meetings with stakeholders aimed at identifying unmet needs of the IBD patient community. Through DIVA EFCCA wants to ensure that inputs at such meetings are based on the wealth of scientific data already available and/or - in case of lack of data - EFCCA aims to promote such generation of data.

The potential of DIVA is huge and EFCCA will be working closely with its members to finetune DIVA and its pilot platform to define priority areas of usage for members.

What is included in DIVA?

1. What are the current treatments available for IBD in my country?

2. What are the potential risks and benefits of existing and emerging treatments for IBD?

3. How many IBD clinical trials are there in my country and/or in my neighbouring country?

5. What are the most important unmet needs of the IBD patient community?

4. How can the patient perspective be integrated into the regulatory decision-making process for IBD treatments?

6. What is the safety and efficacy of IBD treatments, and what gaps in the evidence need to be addressed?

7. How accessible and affordable are IBD treatments to patients in my country?



"With DIVA, patient associations have access to valuable data and resources to support their advocacy efforts."

Salvo Leone, EFCCA chairman



"The new platform will be a useful and valuable tool for patient representatives, providing a one-stop shop for information and resources on Inflammatory Bowel Disease."

Roberto Saldaña, EFCCA Coordinator of Innovation and Patient Engagement

DIVA includes a platform with in-depth information on IBD. This information is from publicly available and trusted databases. In particular, it collects information about the general condition of patients and the frequency and impact of symptoms. It will also include information on the various initiatives underway to improve our knowledge of these diseases and their treatment.

An intelligent assistant (DIVA_ai) will help to explore and interpret data from:

1. Internal sources, like those published by EFCCA (journals and congresses) and
2. External sources, like medical guides and official databases.

EFCCA will promote the inclusion of data from work carried out by its members with their close collaboration. All data will have the original source mentioned.

DIVA will also improve the quality of the support EFCCA and its members can provide to researchers, clinicians, pharmaceutical companies and public authorities who need feedback to make better decisions for IBD patients.

What kind of data are included in DIVA?

The platform has qualitative and quantitative publicly (or internally) available information on IBD and updated information on the status of clinical trials and the regulatory status of different molecules. All data will have links to the source to allow patients, health professionals, and researchers to verify the information provided and to enable users to access additional information if needed.

Who has access to DIVA's platform?

DIVA's platform can be accessed by EFCCA members only. A link to the platform will be shared by the EFCCA secretariat to its members.

Other stakeholders can receive reports on request. Since DIVA is still in the pilot phase, EFCCA and its members can discuss further criteria for partial access to include, for example, researchers.

Next steps

EFCCA together with its members will expand the data available on DIVA's platform. EFCCA will also use this knowledge to improve its educational resources, training, and media campaigns to increase awareness of IBD, its impact on patients, and the need for more research and better treatments.

How does it work in practice?

DIVA will be available free of charge to all EFCCA members. It is a useful and valuable tool providing a one-stop shop for information and resources on IBD and will allow EFCCA and its members to find concrete solutions to patients' real needs, preferences, and priorities.

Let's take a look at 3 different examples of how DIVA can support our members:

■ Validation of a Campaign/Initiative

A national research institute has approached a patient association to join forces in a study concerning IBD and fistulas. The patient association has the opportunity, through the use of DIVA, to determine if this is a genuine concern for the IBD patient population in their own country for example, or at a EU level, to review all the published research on the subject, and to pinpoint specific areas of interest, such as for example potential risk factors, treatment options etc...

■ Support meetings with national stakeholders

A patient association is preparing a meeting with government officials from the Health Ministry with the goal of promoting increased clinical trials in their country. The patient association can rely on the information available on the DIVA platform to make informed decisions, including:

- The number of current clinical trials in the country.
- Comparison of the number of clinical trials in their country with neighbouring nations.
- The trend of clinical trials (whether they are increasing or decreasing).
- The type of clinical trials available, such as trials on biosimilars, other innovative medicines etc.
- The phase of the clinical trials (e.g. early stage, late stage).

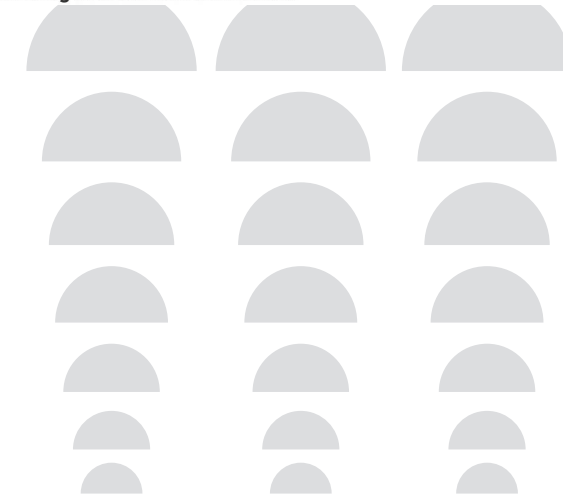
By utilising the resources provided by DIVA, the patient association can strengthen their arguments and effectively communicate the importance of increased clinical trials to government officials.

■ Breaking News

The European Medicines Agency (EMA) has granted approval for a new drug to treat Ulcerative Colitis. As soon as this news is received, the DIVA platform is promptly notified and sends an alert to all members of EFCCA (who have been previously registered upon request by the EFCCA Secretariat). This ensures that they are kept up-to-date on the latest developments and can take action to promote the approval of the drug in their respective countries. By staying informed, the patient associations can work towards accelerating the availability of this new treatment option for those affected by IBD.



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¹ DIVA_ai (artificial intelligence) is a chat function within our platform similar to ChatGTP

For more information please contact the EFCCA office at info@efcca.org