

# The IBD IMPACT survey

---

## Project sponsorship and funding

- EFCCA has selected its own consultants and companies to create the survey, and has directly funded and instructed these companies.
  - Companies were chosen following assessment of written quotations from 3 separate companies.
  - The company that offered best value is: Survey Solutions Ltd, Harlequin House, 7 High Street, Teddington, Middlesex, TW11 8EE. Survey Solutions is an ISO 9001:2008 certified survey provider.
- **The project has been supported by an unrestricted educational grant from Abbott.**
- With Abbott sponsorship, together with central funding from EFCCA, the total investment in the IMPACT survey is £20,750 GBP.
- For more information on the financial arrangements, you can make a 'transparency policy request', by emailing [transparency@efcca.org](mailto:transparency@efcca.org).

## What kind of project is the IMPACT survey?

- Rather than simply an 'EFCCA' project or service which is provided for national IBD associations, this project is a 'joint project' between EFCCA and its national IBD associations. Your guidance and feedback is essential to steer the project.
- It is up to us as a community to get the best from this opportunity and potential. With your help, this could be the largest, highest quality survey ever conducted by EFCCA.
- Each association can opt-in to the project to receive the benefits below.
- For more information, see 'How was the survey developed in consultation with national IBD associations?' below.

## Benefits and outcomes

The benefits and outcomes for both EFCCA, and the 25 EFCCA national IBD associations include:

- A large, up-to-date, high-quality data set, focussed on IBD, collected with a high-quality methodology.
  - A full picture of differing situations, attitudes, and varying equity and equality across 24 European countries, with a unified picture of the commonalities and differences at a European level.
- After analysis, EFCCA will provide:
  - Country-specific reports, to use as you wish.
  - Europe-wide data, and country comparison, to use as you wish.
- The data can be used to:
  - Help define national IBD association strategic priorities.

- Better communicate the needs of people with IBD to the public, health service managers, and politicians.
- Demonstrate unmet needs and priorities for people with IBD.
- Raise awareness of IBD amongst the wider world.
- Involvement in the project demonstrates to your members that we take their everyday perspectives on IBD seriously.
- The project provides an archive of high-quality survey questions, shared from examples of best practice, translated into many languages.
- Awareness leaflets have been provided in key languages to save associations' time and money.
- All materials have been hosted on a download website, to create a central repository of the materials produced – visit [www.efcca-solutions.net/impact](http://www.efcca-solutions.net/impact)

EFCCA will use the data in its strategic and project planning, in awareness raising activities, in European-level lobbying activities, and in media and publicity articles, amongst others.

## Motivation

The motivation for the IMPACT survey is:

- Lack of European-level data on the perspectives of people with IBD, and the diversity of our 25 national IBD associations. Lack of data on common themes and issues across Europe, such as equality across Europe.
- Frequent requests from many national IBD associations to follow-up European or national surveys conducted in the past.
- Frequent requests from many national IBD associations to share and translate examples of best practice in survey and questionnaire design.
- To provide an added-value service for our 25 national association members, at the European level, in response to their requests, encouraging shared best practice, and bridging communications.

## Objectives

The key objective is to provide a pan-European survey that is larger, and of a higher quality, than anything produced before – covering a holistic view of IBD, including both quality of life, and additional aspects such as education, employment, relationships, and others.

Some objectives include:

- True burden of IBD across Europe.
  - Education and career potential of IBD patients
  - Adaptations to everyday life made by IBD patients
  - Relationships and social factors
- Health Care Quality
  - Definition of quality care for IBD patients: access to healthcare professionals, specialist care, provision of holistic care, and discussion of lifestyle factors in the consultation.

- Equity of treatment, availability of treatments.
- Benefits of becoming a member of a national IBD association, or attending national IBD association events.

## Unique points

There are two points that make the survey unique and exciting:

- The last pan-European survey was a long time ago and there have been requests from many associations to follow-up their own survey questions on the European level, in modern times.
- The survey covers not only quality of life, but the social, educational, employment, and holistic aspects of IBD – an IBD survey with this coverage is a first on the European level.

## How was the survey developed in consultation with national IBD associations?

- The project was introduced at the EFCCA General Assembly in April 2010.
- Invitations to become involved in the project were sent to all associations in June and October 2010.
- The full-text of the draft survey was shared with volunteers who responded from 6 associations, in August 2010. Their comments were included in the final version.
- The EFCCA Board then reviewed the finalized survey before approval.
- EFCCA's autumn newsletter featured more details about the project.

## How is independence assured?

- The project has been supported by an unrestricted educational grant from Abbott.
- EFCCA has designed the questionnaire and all questions:
  - Professional health informaticians from a research centre in Newcastle, UK, have reviewed the survey objectives and all questions.
  - Many questions are sourced from validated, published and peer-reviewed academic surveys.
  - Many questions are sourced and translated from national IBD association surveys conducted in the past, which are examples of best practice.
- The name 'IMPACT' and slogan 'discover the true IMPACT' was created by a member of the EFCCA Board.
- EFCCA has selected its own consultants and companies to create the survey, and has directly funded and instructed these companies.

## How can associations promote the survey?

- Encourage all your association members to complete the survey online, at [www.surveysolutions.co.uk/ibd-survey](http://www.surveysolutions.co.uk/ibd-survey).
- Download and use the PDF version of the survey in your language – visit [www.efcca-solutions.net/impact](http://www.efcca-solutions.net/impact)

- Download and use the promotional flyer in your newsletter – visit [www.efcca-solutions.net/impact](http://www.efcca-solutions.net/impact) for a version in your language.
- Create newsletter articles about the project.
- Use the 'IMPACT' logo wherever you wish.
- Add a link from your association website to the survey page.
- Create a news item on your website to promote the survey.

Please feel free to use all the survey resources as you wish – EFCCA has created these materials as resources especially for our 25 national IBD associations to use.