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THE TRUE IMPACT OF IBD: A European Crohn's and Ulcerative Colitis Patient Life IMPACT Survey 2010-2011

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1. Development of the survey

The IMPACT survey was a joint project of EFCCA and its national member IBD (Inflammatory Bowel Disease) associations. The survey questionnaire was developed by EFCCA in conjunction with Abbott and Survey Solutions and was made available in 10 languages: English, Dutch, French, German, Hebrew, Italian, Portuguese, Slovenian, Spanish, and Swedish. The survey was divided into six domains:

- **Section A** – Your experience with IBD
- **Section B** – Health care
- **Section C** – The impact that IBD has on your life
- **Section D** – Overall work IMPACT
- **Section E** – Overall Life IMPACT

The survey was launched on 29th November 2010 and closed on 5th August 2011. Individual member organisations of EFCCA in various European countries were responsible for the launch and communication of the survey to their own members. This happened in different ways in different countries. In all countries, however, it was a self-selection survey and participation was optional. It cannot therefore be considered a completely random survey and the respondents may not fully represent the wider population of people with IBD.

The project was carried out in compliance with, and to the Quality Standards required under the Data Protection Act, ISO 9001:2008 (for Quality Management Systems), the MRS (Market Research Society) Code of Conduct, and the MRS Company Partner Quality Commitment. The project was supported by an unrestricted educational grant from Abbott.

2. Aims of the survey

The main aim of the IMPACT survey was to obtain an international perspective of the impact of Inflammatory Bowel Disease (IBD) on patients' lives. Other research objectives included

- Understanding perceptions of the quality of Health Care provided,
- Looking at access to healthcare and support facilities in various countries (from the perspective and perceptions of the patient),
- Understanding more about the differences that exist between countries, age groups, genders and those with different types of IBD.

3. Respondents

Although more responses were received in the end, the 4,990 online responses that had been received by the close were included in the analysis. An important original aim of the project was to achieve at least 100 responses from each of at least 10 countries; this was achieved in 15 countries. Figure 1 shows the response rates in the participating countries.

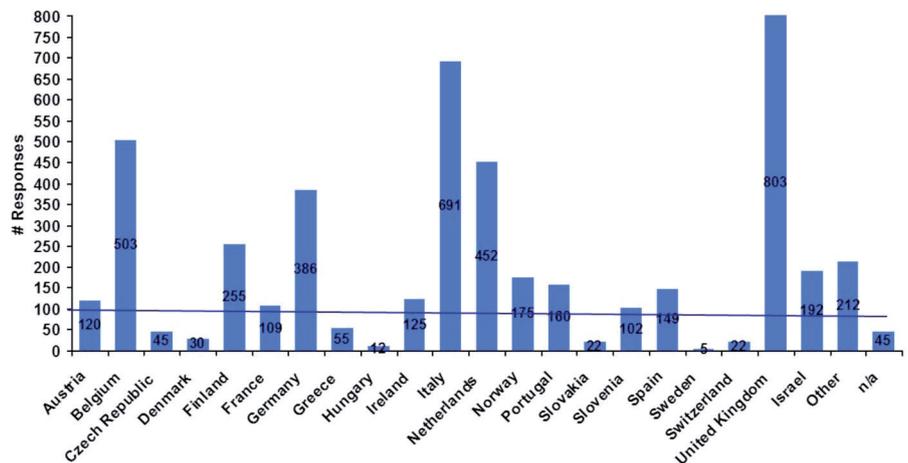


Figure 1. Response rates across the participating countries. The line represents the amount of responses that the survey aimed at.

66% of responses were from women, 33% from men. Most respondents (68%) were from 19 to 44 years old. The diagnoses of the respondents can be seen in Figure 2. It is, however, important to note that this report only reflects the respondents to this survey; the gender ratio and the proportions in diagnoses may not be fully representative of the population of IBD patients as a whole.

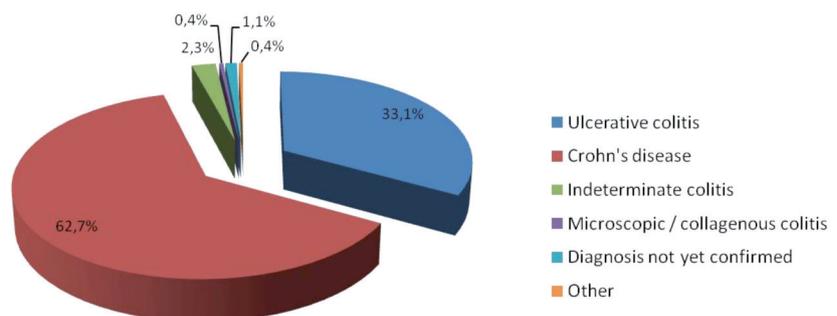


Figure 2. Diagnoses of the respondents.



4. Results of the survey

4.1. Section A: Your experience with IBD

4.1.1. Forms of IBD

Crohn's disease was the most prevalent condition affecting the respondents (63%). There were slightly more female (64%) than male (61%) respondents with Crohn's disease than Ulcerative Colitis, however women outnumbered male respondents by a ratio of 2:1 in the survey as a whole. Conversely, there were slightly more males (36%) than females (32%) with Ulcerative Colitis. Compared to respondents in other age groups, the under 18 age group reported slightly more Crohn's disease (65%) than Ulcerative Colitis (29%).

4.1.2. IBD and work ability

Almost half of the respondents were fully employed (47%), 59% of them having Crohn's disease and 37% Ulcerative Colitis. Although many respondents were able to work full time, 10% of the respondents (67% Crohn's disease, 28% Ulcerative Colitis) were under-employed due to IBD and 8% of the respondents (70% Crohn's disease, 25% Ulcerative Colitis) unemployed due to IBD. 14% of the respondents were students and 5% retired.

4.1.3. Being directed to someone who can help

Being directed to someone who can help seemed to happen reasonable quickly for most respondents: 70% of all respondents saw a specialist within the first year of the first symptoms (49% within 6 months, 21% within six months to a year). There were, however, some differences between genders and age groups; the process tended to take on average slightly longer for women. 74% of male respondents saw a specialist within a year of the first symptoms, as opposed to 68% of female respondents. Respondents in the under 18 age group saw a specialist faster; 63% of the respondents within 6 months and 82% within a year. Respondents aged 35 and above waited longer, and the respondents aged 55 and above seemed to wait the longest.

4.1.4. Getting a diagnosis

67% of the respondents had presented their IBD symptoms at an emergency department or emergency clinic at least once before receiving a definitive diagnosis. 33% of respondents visited emergency services twice or more, and for 8% of the respondents it took five or more emergency visits before a final diagnosis.

54 % of respondents received a final diagnosis within a year of recognizing their symptoms as relating to IBD (32% within six months, 22% in six months to a year). Men (33%) were slightly more often diagnosed within six months than women (31%). Respondents in the under 18 age group received a speedier diagnosis (40% within six months).



For 13% of the respondents it took 1-2 years to receive a final diagnosis. This increased to over 20% in respondents aged 35 years and over. 18% of respondents had to wait 5 years or more. Indeterminate Colitis and microscopic/collagenous colitis took the longest to diagnose, while Ulcerative Colitis was diagnosed the fastest (46% within six months).

4.1.5. Important attributes of IBD patients

Respondents were asked to tick all aspects that applied to them. The following statistics summarizes the responses:

- **52% have used steroids** for their condition
- **49%** are **concerned about the long-term effects** of steroids on their health
- **49% have joint involvement** associated with IBD
- **42% experience side-effects** from steroids
- **34% experience skin involvement** associated with IBD
- **28.5% regularly use pain pills** to relieve their IBD symptoms
- **28% keep steroids on hand** in case of an IBD flare
- **15%** have **complications of surgery** such as adhesions, wound infections or pain

4.2. Section B: Health Care

4.2.1. Satisfaction with the treatment plan

70% of all respondents reported that they were very or somewhat satisfied with their treatment plan, whilst 14% said that they are either somewhat or very dissatisfied. Men were slightly more satisfied than women (men 72%, women 69%). Least satisfied with the treatment plan were respondents with Indeterminate Colitis (29% dissatisfied), respondents whose diagnosis was still unconfirmed (50% dissatisfied), respondents who were unemployed due to IBD (29% dissatisfied), seeking disability (26% dissatisfied), unable to receive disability status (24% dissatisfied), and under-employed due to IBD (20% dissatisfied).

4.2.2. Medication

Only 6% of the respondents were currently not taking any medication. Of those currently taking medication, most (47%) were taking aminosalicylates (5-ASA), particularly men (51%) and those with Ulcerative Colitis (72%) or Indeterminate Colitis (61%). 33% of the respondents were taking immunosuppressants, 27% biological drugs, and 21% corticosteroids. 1% of the respondents did not know what they were taking.

Of the respondents taking corticosteroids, 42% reported having experienced side effects. Women reported more side effects (45%) than men (38%). 49% of the respondents were worried about the impact of corticosteroids on their long-term health. Women and younger respondents were more concerned than men and the older age groups.



4.2.3. Frequency of hospitalization

The majority (85%) of the respondents had been hospitalized in the past five years because of IBD. Of these respondents, 37% had been hospitalized for 1-5 days and 48% for longer, and almost 60% of the under 18 age group spending six or more days in the hospital.

Respondents with Crohn's disease had been hospitalized the most (89%), however the majority of these (52%) had spend no more than 1-5 days in the hospital during the past 5 years. On the other hand, 22% of respondents with Ulcerative Colitis had not been hospitalized (as opposed to only 11% of respondents with Crohn's disease), but when respondents with Ulcerative Colitis were hospitalized, it tended to be for a longer period of time (65% had been hospitalized for 6 days or more in the past 5 years).

4.2.4. Surgery

Most (60%) of the respondents had not been operated for IBD. However, 16% had had one operation, 8% two operations, and 16% 3 or more. 7% had been operated 5 times or more. Respondents in the under 18 age group had had less operations, whereas 45% of those aged 55 or more had had at least one, and 30% more than one. Respondents whose ability to work had been affected by IBD were more likely to have had at least one operation compared to those who were fully employed. 56% of the respondents with Crohn's disease had been operated at least once and 34% more than once. Of the respondents with Ulcerative Colitis, 87% had had no operations.

The majority (73%) of respondents who had an operation were very or somewhat satisfied with the outcome, however 11% expressed dissatisfaction. These findings were similar for both men and women and across all age ranges. Lowest levels of satisfaction were seen among those with Indeterminate Colitis and, to a lesser extent, respondents whose ability to work had been affected by IBD.

4.2.5. At the clinic

88% of the respondents reported having access to a Specialist Gastroenterologist, and 45% reported having a nurse who understands or specialises in IBD. Younger respondents were more likely than others to report their clinic had a counsellor or psychologist. Most respondents (69%) felt they had adequate access to their IBD professional. 24% of the respondents, however, felt they did not.

53% of the respondents felt that they didn't get to tell the specialist something important at their appointment; of these respondents, 25% said it happened sometimes, and 28% it happened a lot. 65% of the respondents wished that the gastroenterologist had asked more probing questions. Highest levels of satisfaction were seen among younger respondents aged 18 or less.

As for communicating with health care professionals, 63% of the respondents reported that the specialist/gastroenterologist service practitioners provided the best range of options for patients to get in touch. This was followed by family/general physician



clinic/service (35%) and nurse (21%). As for returning calls promptly, specialist/gastroenterologist (53%) and family/general physician clinic/service practitioners (29%) were considered best, followed by nurses (20%). Respondents were allowed to tick all that applied.

65% of respondents reported that their specialist/gastroenterologist service was best at giving them sufficient time without rushing through the consultation; 35% responded that their family/general physician clinic/service was the best. 60% of respondents felt that specialist/gastroenterologists best understood the impact of IBD on their lives. 28% felt the family/general physician clinic/service practitioner understood best and 19% felt it was the nurses. Men were inclined towards thinking that the specialist/gastroenterologists understood the impact better, whilst women were more inclined to think this of nurses.

4.3. Section C: The impact that IBD has on your life

4.3.1. Current status of disease

50% of the respondents reported to be in remission/not flaring (slightly more men than women), whilst 25% had chronically active conditions, and 23% were suffering periodic active flare-ups. Amongst the respondents who were unemployed due to IBD, 37% claimed to have a chronically active condition (36% for the disabled respondents and 32% for the under-employed due to IBD). By contrast, the fully employed respondents were 10% more likely than average to be in remission. Based on these differences, there does appear to be a correlation between severity of IBD and the effect on the individual's ability to work.

4.3.2. Experience of previous flare

30% of the respondents reported that their last flare had been over 12 months ago. By contrast, 18% had experienced a flare in the previous month, and a further 17% between 1 and 3 months ago; i.e. a total of 35% of respondents had experienced a flare within the last 3 months. The 18 years and under group seemed more likely to have experienced a more recent flare, as well as those who were unemployed due to IBD (28% in the last month), those with microscopic/collagenous colitis (29% in the last month), and those with unconfirmed forms of IBD (40% in the last month).

4.3.3. Number of flare-ups experienced

15% of the respondents reported that their condition was always flaring (17% of women, and 12% of men), whilst another 13% reported having experienced no flares at all in the past two years. A further 10% reported to have experienced at least 7 flares in the past two years, whilst 42% have experienced between 1 and 3 flares.

The respondents claiming that their condition was always flaring were most likely to be in the group that was unemployed (28%) due to IBD. Chronic flaring was also more likely amongst Retired and Disabled groups as well as those who were under-employed;



however, 30% less likely amongst the fully employed. Again, the results seemed to indicate a case-and-effect relationship between severity of the IBD condition and ability to work.

4.3.4. Coping with IBD flare-ups

53% of the respondents reported that during their most recent flare-up, they were somewhat more likely than not to have had to cancel or reschedule an engagement or meeting because of their symptoms. Only 22% felt that their plans were not really disrupted. The participants in the 19-34 age group were most likely to have plans disrupted, along with those who were unemployed, under-employed or disabled, consistent with the conclusion that these are probably the people with the most chronic conditions. Women were slightly more likely than men to have had plans disrupted by IBD.

4.3.5. Frequency of IBD-related symptoms

Frequency of IBD-related symptoms (bleeding, abdominal cramping pains, feeling tired, weak or worn-out, urgency of bowel movements, and episodes of diarrhea) during the most recent flare and in between flares can be seen in Tables 1-5. Somewhat shockingly, all symptoms were experienced also between flares by some respondents; particularly feeling tired, weak or worn-out, which was experienced daily even between flares by 83% of the respondents.

Bleeding	During a flare	Between flares
None	39%	72%
At least daily	61%	28%
5-7 days a week	30%	5%
Most affected	Respondents with indeterminate colitis; 19-54-year-olds	Ulcerative Colitis; Indeterminate Colitis
Least affected	55 years and above	

Table 1. Incidence of bleeding.

Abdominal cramping pain	During a flare	Between flares
None	13%	28%
At least daily	87%	62%
5-7 days a week	51% (37%: 7 days)	14%
Most affected	Women; Unemployed; Underemployed; Disabled; 19-34-year-olds	Women
Least affected	55 years and above	Ulcerative colitis

Table 2. Incidence of abdominal cramping pain.

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Feeling tired, weak, worn out	During a flare	Between flares
None	4%	17%
At least daily	96%	83%
5-7 days a week	74% (58%: 7 days)	35% (22%: 7 days)
Most affected	Women; 19-34-year-olds	Women; Unemployed; Underemployed; Disabled
Least affected	55 years and above	

Table 3. Incidence of feeling tired, weak and worn-out.

Urgency of bowel movements	During a flare	Between flares
None	11%	34%
At least daily	89%	66%
5-7 days a week	55% (40%: 7 days)	43%
Most affected	Ulcerative Colitis; Indeterminate Colitis	Disabled; Unemployed; Indeterminate Colitis; Crohn's disease; Aged 34 and above
Least affected	Students; Retired	

Table 4. Urgency of bowel movements.

Frequency of runny stool	During a flare	Between flares
None	7%	39%
At least 1 a day	93%	61%
1-2 a day	12%	29%
5-10 a day	56%	10%
More than 10 a day	20%	3%
Most affected	Women; Disabled; Microscopic/collagenous Colitis	34 years and above; particularly 55 years and above
Least affected	18 years and under	Employed

Table 5. Frequency of runny stools / episodes of diarrhea.

51% of the respondents reported that their life was only slightly (or not at all) impacted by their IBD symptoms, compared to people without IBD. However, 49% responded that their life was significantly affected. Respondents who were fully employed as well as students tended to report fewer such incidences. More numerous incidences were reported by respondents who were unemployed or disabled. Over half of respondents (56%) reported they hardly ever have to cancel or reschedule an engagement or





meeting because of IBD, however 37%, particularly the unemployed respondents, reported that that this may be necessary.

4.4. Section D: Overall work impact

4.4.1. Being absent from work

61% of the respondents felt stressed or pressured about taking time off work due to IBD. 26% had not taken time off in the past year due to IBD; 74% had. Of these, 26% had had more than 25 days of absence due to IBD (especially under- or unemployed respondents as well as those with disability). 58% of the respondents had not made adjustments to their working life to avoid having to take time off, however 42% responded they had done this. It should be noted that 56% of underemployed respondents had opted to go part-time.

The primary reasons for being absent due to IBD were fatigue and/or not enough energy to get through the day (51% - rising to 75% among respondents who were under-employed and 67% among the unemployed); doctor's appointment (49%); cramping or painful abdomen (46%); and hospital/emergency department visit (44%).

75% of the respondents reported not having received complaints or unfair comments about their performance. For 25% of the respondents, however, this had happened. Unemployed respondents were most likely to report such incidents. 79% of the respondents denied having suffered discrimination in the workplace; 21%, however, had experienced it.

4.4.2. How IBD affects behavior at work and career path

Only 28% of the respondents reported that their IBD does not affect their behaviour at work (with those in full employment being the least affected). For the rest (72%) the most prevalent effects of IBD seemed to be being less motivated (29%), not participating in social activities at work (25%), being quiet or quieter during meetings (23%), and being irritable at work (22%).

51% of the respondents agreed that their prospects at work had, to a greater or lesser degree, been affected negatively by IBD; 36% of respondents felt this very strongly. Unsurprisingly, those most likely to say they had been disadvantaged were those unemployed due to IBD (96% agreed that prospects have been affected); those unable to receive disability status (92%); those under-employed due to IBD (88%); those seeking disability (84%); disabled respondents (82%); and retired respondents (76%). In addition, 44% of respondents said that they had lost or had had to quit a job because of IBD (rising to 93% among those who were unemployed).



4.5. Section E: Overall life impact

4.5.1. Friends and intimate relationships

40% of the respondents reported that IBD had prevented them from pursuing intimate relationships, rising to 64% among those with microscopic/collagenous colitis (a very small group) and 51-58% among those who were disabled and/or under- or unemployed. The respondents in these groups were also more likely to say that their IBD had caused an intimate relationship to end. 45% of the respondents, on the other hand, had not experienced IBD as an impediment in the pursuit of intimate relationships, and 66% denied that IBD had caused an intimate relationship to end.

The majority of respondents (57%) said that IBD had not gotten in the way of their ability to make or keep friends; a significant proportion (29%), however, said that it had. Under-employed respondents and those with a disability were more inclined to say this.

4.5.2. Education

52% of the respondents felt that IBD had negatively affected their ability to perform to their full potential in an educational setting, rising to 61% among younger respondents aged 18 or under. This was an even more prevalent issue for disabled respondents and those who were under- or unemployed.

4.5.3. Availability of toilets

Availability of toilets is a very personal and significant problem for people with IBD. Concerns tend to increase with age. 27% of respondents reported that other people sometimes joke about their frequent need to go to the toilet. This, however, probably reflects a lack of understanding of IBD rather than insensitivity. 66% of the respondents worried about the ready availability of toilets whenever they went somewhere new, and frequently considered the availability of toilets when they planned to attend something. 27% kept a list (in memory or written) of clean, accessible toilets and considered this when they left home; this approach was used by disabled respondents, in particular. 20% of respondents said they had had to be rude to people at times in order gain access to a toilet.

4.5.4. Effects on sleep

40% of the respondents said that they frequently woke from sleeping as a result of IBD-related pain. This problem affected women (43%) more than men (33%), and under- or unemployed respondents more than those who were working full time. Respondents with Ulcerative colitis were slightly less affected (35%) than those with Crohn's disease (42%).



4.5.5. Contact with other people with IBD

The first time the respondents met someone else with IBD, it seemed to have little effect on many of them. 39%, however, said that it made them more optimistic, rising to 43% among those aged 35 and under, and 46% among students.

44% of respondents had engaged in some way with EFCCA member associations (with those aged 35 and above and retired and/or disabled respondents being most inclined to do so). Least likely to be engaged were those aged 19-34; awareness should be raised within this age group. Importantly, 63% of those who had joined a relevant patients' association said that doing so had had a beneficial impact on their life as someone with IBD.

The most likely ways to be associated with an EFCCA member association were signing up as a member of a national IBD association (37%); receiving patient information leaflets from a national IBD association (34%); and subscribing to newsletters or magazines from a national IBD association (27%). Only few respondents had become EFCCA delegates or worked within an EFCCA project team (1%); had become a leader, or joined a committee within a national IBD association (3%); or helped their national IBD association in fundraising (4%).

5. EFCCA recommendations

For diagnosing IBD:

- Maintain good access to IBD specialists, especially in the face of financial cuts to health services.
- Review diagnostic protocols for those who wait over a year for diagnosis, to reduce this divergence with otherwise good standards.
- Investigate and find methods to prevent presentation to emergency care, experienced by a majority, before diagnosis.
- Work with emergency care colleagues to raise awareness that the majority of people with IBD are treated in this department.

For health care and treatment:

- Maintain and develop good IBD health service standards, in line with published guidelines.
- High hospital admission represents a poor patient experience, an urgent opportunity for improvement, and significant morbidity. Reducing this burden may somewhat counterbalance the cost of new IBD treatments – it may pay to treat with innovative therapies.

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- Ensure that use of corticosteroids is in line with ECCO guidelines, and that the full range of treatment options are considered, according to comparative risk-benefit profiles.

For health services:

- Improve access as well as provision, of specialist IBD healthcare professionals.
- Increase the duration and frequency of specialist consultations.
- Improve consultation techniques (for both parties), to ensure depth and coverage of issues, so that no important information is omitted.

For relationships:

- The impact of IBD on relationships should be considered by healthcare professionals.
- Healthcare professionals should actively sign-post patients to national IBD associations.

For work and education:

- Good management of IBD supports employment. The cost of new innovative treatments for IBD may be counterbalanced by improved employment and reduced social costs.
- Effective medical consultation should address the patient's full life context – including work.
- A patient's employment and educational aspirations should be regarded as goals and success criteria.
- Flexible, supportive, and non-discriminatory work practices are required. Those who face discrimination must be supported in challenging this.

