

IMPACT Survey



2010-2011 Crohn's & Colitis Patient Survey

www.surveysolutions.co.uk/IBD-Survey

- Pan-European patient survey (November 2010 – August 2011) developed by the European Federation of Crohn's and ulcerative Colitis Associations to assess the real IMPACT of IBD on patients' lives, relationships and careers
- Self-selection online survey including over 50 questions on patients' quality of life, as well as the social, educational, employment, and holistic aspects of IBD
- Survey intended to generate awareness and improve understanding of IBD
- Over 6000 completed IMPACT questionnaires (63% of patients with Crohn's disease; 33% of patients with ulcerative colitis) from 27 countries
 - More than 13 000 patients with IBD have now taken part in the IMPACT and supporting national patient association surveys (refer to Other Surveys)
- The European Federation of Crohn's and ulcerative Colitis Associations IMPACT survey results are available (www.efcca.org)
- IMPACT project supported by a grant from Abbott



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Damage and Disability

IMPACT – IBD is a progressive disease with significant damage

- 48% of patients with IBD describe their disease as being chronically active or active with periodic flares
- Hospital admission is extremely high: 85% of patients were hospitalised within the last 5 years
- 40% of patients have undergone at least one operation
- IBD are systemic diseases associated with co-morbidities:
 - 49% of patients have joint involvement
 - 34% of patients have skin involvement
- IBD has a significant IMPACT and burden on patients who suffer from these diseases
- IBD are diseases associated with progressive damage

*Hospital admission
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IMPACT – IBD causes cumulative damage and disability (flares and disease manifestations)

- 60% of patients experience cramping abdominal pain due to flares more than 5 days a week
- 55% of patients experience a sudden uncontrollable urge for bowel movement more than 5 days a week
- 49% of patients confirmed that even between flares their life was affected in some way or significantly

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Diagnosis and Health Services

IMPACT on diagnosis and health services

- Most patients received a timely final diagnosis, but 18% waited over 5 years
- An alarming majority (64%) needed emergency care before their diagnosis – a significant clinical risk
- Although 88% of patients have access to a specialist consultant and 45% to a specialist nurse, 24% still feel they do not have adequate access to specialists
- The quality of communication in consultations needs to be vastly improved – 53% of patients felt they were unable to tell the specialist something that was important, and 65% said they wished they were asked more probing questions

The European Federation of Crohn's and ulcerative Colitis Associations recommends:

- Maintain good access to IBD specialists
- Review diagnostic protocols for those who wait over a year to reduce this divergence with otherwise good standards
- Investigate and find methods to prevent patient presentation to emergency care before diagnosis
- Raise awareness with emergency care colleagues that most patients with IBD are treated in this department
- Improve access, as well as provision, of specialist IBD healthcare professionals
- Increase the duration and frequency of specialist consultations, and improve consultation techniques (for both parties) to ensure depth and coverage of issues

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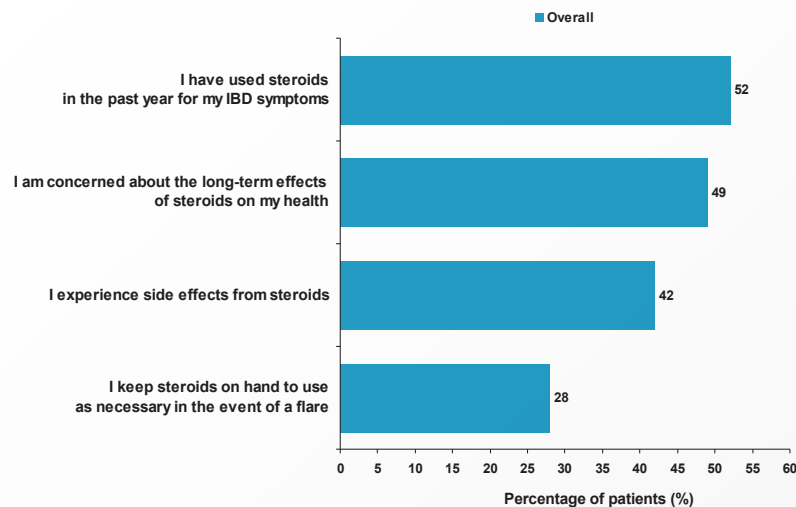
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Treatment

IMPACT on treatment

- Evidence for treatment plan (anti-TNF and surgery)
- Access to biological therapy is becoming more established, but the majority of patients have used corticosteroids, experienced side effects, and are concerned about long-term effects (Figure 1)

Figure 1. Prolonged use of steroids raises concerns among 49% of users and 42% experience side effects from steroids



The European Federation of Crohn's and ulcerative Colitis Associations recommends:

- Maintain and develop good IBD health-service standards, in line with published guidelines – www.ibdstandards.org.uk
- 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**
- Ensure that use of corticosteroids is in line with ECCO guidelines, and that the full range of treatment options is considered, according to comparative risk–benefit profiles



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Daily Life

IMPACT on daily life

- Half of patients diagnosed with IBD are fighting active disease today – they are not in remission
- 96% of patients feel tired, weak and worn out in daily life during a flare-up; this only reduces to 83% during remission

The European Federation of Crohn's and ulcerative Colitis Associations recommends:

- Management plans should include assessment and management of the three key symptoms: fatigue, urgency and pain
- Success criteria should focus on effective management of symptoms, as well as IBD as the root cause
- Management plans should include assessment of the wider symptomatic impact of IBD on everyday life, as well as the clinical context

IMPACT on relationships

- IBD affects patients' personal and social interactions
 - 40% were prevented from pursuing an intimate relationship
 - 23% had an intimate relationship end due to their IBD
 - 29% were prevented from making or keeping friends due to their IBD

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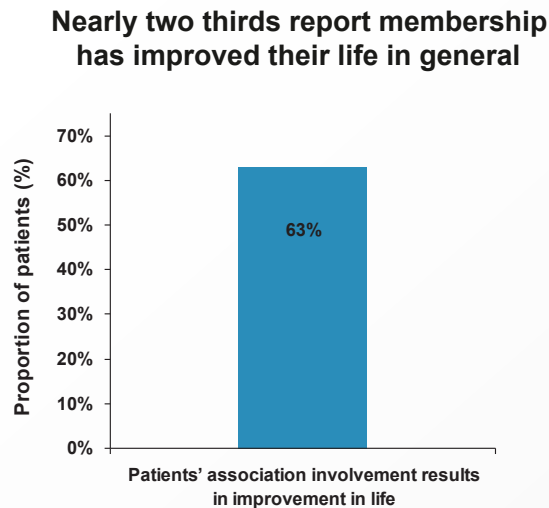


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- However, 39% of patients thought that meeting others with IBD made them more optimistic, and nearly two-thirds of those who joined a patients' association felt it had a beneficial impact on their life (Figure 4)

Figure 4. Benefits of patients' association membership



The European Federation of Crohn's and ulcerative Colitis Associations recommends:

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

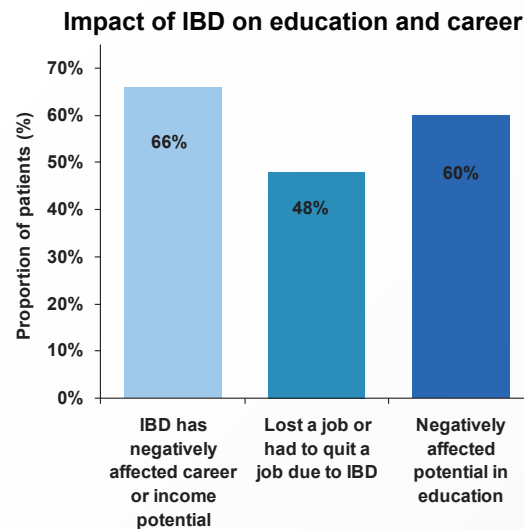
40% *were prevented from pursuing an intimate relationship*

Education and Career

IMPACT on education and career

- 52% of patients were unable to perform to their full potential in an educational setting
- The majority of people with IBD feel it has impacted on their educational performance and negatively affected their income and earnings (Figure 2)

Figure 2. IBD impacts on education and career



IMPACT on work productivity correlates with disease severity

- 75% of patients have cancelled or rescheduled an appointment due to IBD flares
- 61% of patients feel stressed or pressured about taking time off from work due to IBD; 25% have received complaints or unfair comments and 21% have suffered discrimination
- 43% of patients had to make an adjustment to their working life (e.g. home working or flexible hours)
- Disease severity and ability to work seem to correlate

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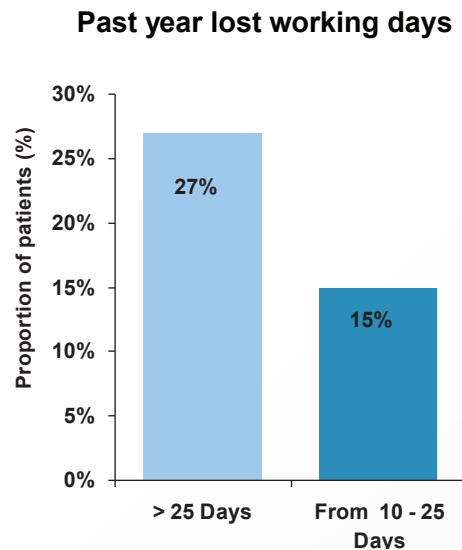
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Education and Career

- Over 40% of patients took 10 or more days off work in the past year due to IBD: 27% took more than 25 days off (Figure 3)

Figure 3. IBD leads to lost working days



The European Federation of Crohn's and ulcerative Colitis Associations recommends:

- 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 consultations 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

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Other Surveys

IMPACT findings are supported by data from national patients' association surveys

Spain (ACCU; GETECCU; GETEII) – 1688 patients

- 25% stated that IBD greatly affected their working lives
- Over 3 hours' working time is lost on average per week
- 20% had received unjustified complaints about their work performance
- Almost half (45.4%) had been hospitalised for an average of 24 days
- 40.2% of patients were experiencing a flare at the time of the survey

Greece (ELIGAST and Crohn's and ulcerative colitis patients' associations of Attica and North Greece) – 1181 patients

- 76% believed that greater access to specialised gastroenterologists would help improve their IBD healthcare
- 60% felt sadness and frustration, or emotional tension (stress) due to their disease
- Approximately half were not satisfied with the information they had in relation to the disease and its impact on their lives
- Most patients expressed the need for more information about the possible complications of the disease, including cancer and side effects of drug therapy
- 57% were absent from work for at least 5 days in the past year due to IBD
- 37% thought that IBD had affected their personal lives

Other Surveys

Crohn's and Colitis UK survey (Gay M et al. Crohn's, Colitis and Employment – from Career Aspirations to Reality. Hertfordshire: Crohn's and Colitis UK, 2011) – 1906 patients

- IBD had a significant impact on the working lives and wider wellbeing of people with the condition
 - 57% had reduced their working hours due to their IBD
 - 79% agreed that IBD had affected their confidence and self esteem
- IBD affects people from career start to end, impacting aspirations and career choice through premature retirement
 - 51% agreed that IBD had impacted on their career progression
 - 50% agreed that IBD had prevented them from reaching their full potential in the workplace

Ireland

A campaign to raise awareness of IBD, which affects nearly 20 000 people in Ireland, was recently launched by Dr Dawn Harper (general practitioner) on behalf of the Irish Society of Colitis and Crohn's disease.