IMPACT SURVEY

IMPACT SURVEY

• Pan-European patient survey (November 2010 – August 2011) developed by the European Federation of Crohn's and Ulcerative Colitis Association 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 6,000 completed IMPACT questionnaires (63% of patients with Crohn's disease; 33% of patients with ulcerative colitis) from 27 countries - More than 5,000 patients with IBD have now taken part in the IMPACT and supporting national patient association 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

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 hospitalized within the last five 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 is extremely high:

***85%** of patients were hospitalized within the last five years*

***60%** of patients experience cramping or abdominal pain more than four days a week during a flare*

IMPACT – IBD CAUSES CUMULATIVE DAMAGE AND DISABILITY (FLARES AND DISEASE MANIFESTATIONS)

- 60% of patients experience cramping or abdominal pain more than four days a week during a flare
- 55% of patients experience a sudden, uncontrollable need for bowel movement more than five days a week.
- 49% of patients confirmed that IBD effects their lives in some way even between flares.

DIAGNOSIS AND HEALTH SERVICES

***53%** of patients felt they were unable to tell the specialist something that was important*

IMPACT ON DIAGNOSIS AND HEALTH SERVICES

- Most patients received a timely final diagnosis, but 18% waited more than five years.
- An alarming majority (60%) needed emergency care before their diagnosis – a significant clinical risk.
- Although 88% of patients have access to a specialist physician 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 a specialist something that was important, and 65% said they wished they were asked more probing questions.

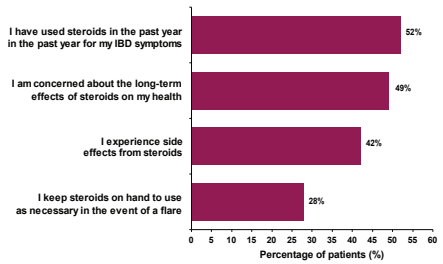
*An alarming majority **(60%)** needed emergency care before their diagnosis*

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.

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



Access to biological therapy is becoming more established

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 reduced to 83% during remission.

***96%** of patients feel tired, weak and worn out in daily life during a flare-up*

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.
- 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.

***40%** were prevented from pursuing an intimate relationship*

EDUCATION AND CAREER

IMPACT ON EDUCATION AND CAREER

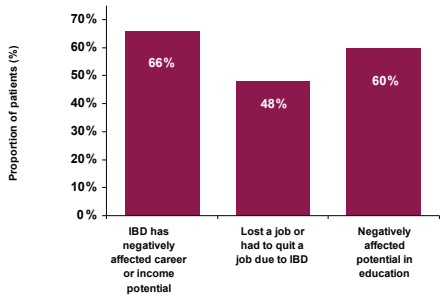
- 52% of patients were unable to perform to their full potential in an educational setting.
- The majority of people with IBD feel it has impacted on their educational performance and negatively affected their income and earnings.

52% *of patients were unable to perform to their full potential in an educational setting*

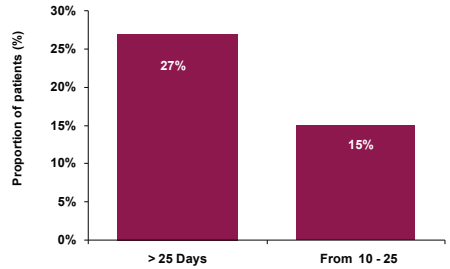
IMPACT ON WORK PRODUCTIVITY CORRELATES WITH DISEASE SEVERITY

- 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., working from home or flexible hours)
- Disease severity and ability to work seem to correlate.
- 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.

Impact of IBD on education and career



Past year lost working days



OTHER IMPACT SURVEYS

OTHER SURVEYS
COUNTRY COMPARISON OF THE IMPACT SURVEY

DISCRIMINATION AT WORK: THE AMSTERDAM TREATY AND THE IMPACT SURVEY

The Amsterdam Treaty (1997) put a great emphasis on the rights of individuals. One of the changes was the inclusion of a non-discrimination article, included in Article 6a of the Treaty (Article 13 in the renumbered Treaty).

The amended article recognizes the issue of disability discrimination, and allows the community to take action against disability discrimination. Results show that one in five respondents in our survey had experienced discrimination at the workplace, which proves this is a serious issue and actions need to be taken, including raising awareness of rare conditions and securing the position of the disabled by producing new legislation.

42% *of respondents had to make work adjustments*

- 42% of respondents had to make work adjustments (such as working from home or part-time); patients had to make the same adjustments for educational programs.
- 52% of the participants – and up to a 69% of patients in the United Kingdom felt they were not able to perform to their full potential in an educational setting due to IBD.
- As most IBD patients are able and willing to work and study, finding flexible solutions and making adjustments in work and educational settings should be supported. Such solutions are inexpensive and will be cost-effective in the long run.

52% *of the participants were not able to perform to their full potential in an educational setting*

HEALTH INEQUALITIES WITHIN THE EU

Striking differences could be seen in terms of access to specialist care.

For example:

- 86% of respondents from The Czech Republic and 82% of respondents from Spain and Germany felt they had adequate, timely access to IBD professionals, whereas 59% of the Slovenians, 58% of the Greeks, 57% of the British, 54% of the respondents from Israel and 53% of the Norwegian respondents felt the same way.
- The Czech Republic was the only country in the survey where 100% of the respondents reported having access to a gastroenterologist at the clinic they visit.

Striking differences could be seen in terms of access to specialist care.

- 30% of the respondents to this survey did not get to see a specialist in the first year after starting to experience IBD symptoms.
- Just over half (54%) of all respondents received a final diagnosis within a year.

67% *of the respondents had to visit an emergency department or clinic at least once before receiving a definitive diagnosis*

- 67% of the respondents had to visit an emergency department or clinic at least once before receiving a definitive diagnosis (93% in Spain, 89% in Slovenia, 86% in Austria; but only 47% in Germany and 55% in Israel and the United Kingdom)

The variations could be due to different health care systems and policies of referring patients to specialists; but in order to avoid extensive costs of emergency care and shorten the time of living without a diagnosis and corresponding treatment, early access to specialist care should be facilitated.

Access within the first year seemed to be the easiest for respondents from Slovenia and Israel (83%, respectively) and Spain (80%).

However, many respondents in Spain and Slovenia may have been referred to specialist care after visiting the emergency department.

These findings should be revisited in further detail to see if a connection exists.

TREATMENT REGIMENS WITHIN THE EU

In addition to access to care, treatment regimens used for participants from different countries seemed to vary greatly. For example, the use of biological therapies.
These therapies are known to be rather costly, and according to a Canadian study, low income may be associated with increased surgery risk in pediatric IBD patients. This can be due to patients not being able to afford costly therapies.

It is important to ensure all Europeans have adequate access to all necessary medication.

Without looking into different health insurance policies in the European countries and the socio-economic status of the respondents, it is impossible to make such conclusions; nevertheless, it is important to ensure all Europeans have adequate access to all necessary medication. Ensuring access to treatment and therapy is also important to reduce hospital stays: the majority (85%) of the respondents (90% in Ireland, 88% in The Netherlands) have been hospitalized in the past five years because of IBD, 48% for longer than five days.

85% of the respondents (90% in Ireland, 88% in The Netherlands) have been hospitalized in the past five years

EFCCA RECOMMENDACTIONS

FOR DIAGNOSING IBD:

- **Maintain good relationships with IBD specialists,** especially during health financial cuts.
- **Review diagnostic protocols for patients who wait over a year for diagnosis,** in order to reduce discrepancies.
- **Investigate and research methods** to prevent emergency care, which is experienced by a majority before diagnosis.
- **Raise awareness among emergency care physicians** and explain that the majority of people with IBD are treated in emergency care departments.

FOR HEALTHCARE AND TREATMENT:

- **Maintain and develop IBD health service standards** that follow published guidelines.
- A high hospital admission rate represents a poor patient experience, which should be improved. **Reducing this burden may counterbalance the cost of new IBD treatments.**
- **Ensure that use of corticosteroids are in line with ECCO guidelines,** and treatment options are according to comparative risk-benefit profiles.

FOR HEALTH SERVICES:

- **Improve IBD healthcare professionals' availability.**
- **Increase the duration and frequency of specialist consultations.**
- **Improve consultation techniques** (for both parties), to ensure no important information is omitted, there is depth to the conversation and both parties discuss every issue.

FOR RELATIONSHIPS:

- **The impact IBD has on relationships should be considered** by healthcare professionals.
- **Healthcare professionals should actively guide patients** to national IBD associations.

FOR DAILY LIFE:

- **Management plans should include assessments and management** of key symptoms, including: fatigue, urgency, and pain.
- **Criteria should focus on management of symptoms and the root cause of IBD.**
- **Management plans should include assessment** of the wider symptomatic impact of IBD on everyday life, in addition to the clinical context.

FOR WORK AND EDUCATION:

- **Management of IBD should allow patients to remain employed.** The cost of new innovative treatments for IBD may be counterbalanced by improved employment rates and reduced social costs.
- **Effective medical consultations** should address the patient's day-to-day activities, including work.
- **A patient's employment and educational aspirations** should be regarded as goals and future successes.
- **Flexible, supportive and non-discriminatory work practices are required.** Those who face discrimination must be supported by the IBD community.