



# The true IMPACT of IBD

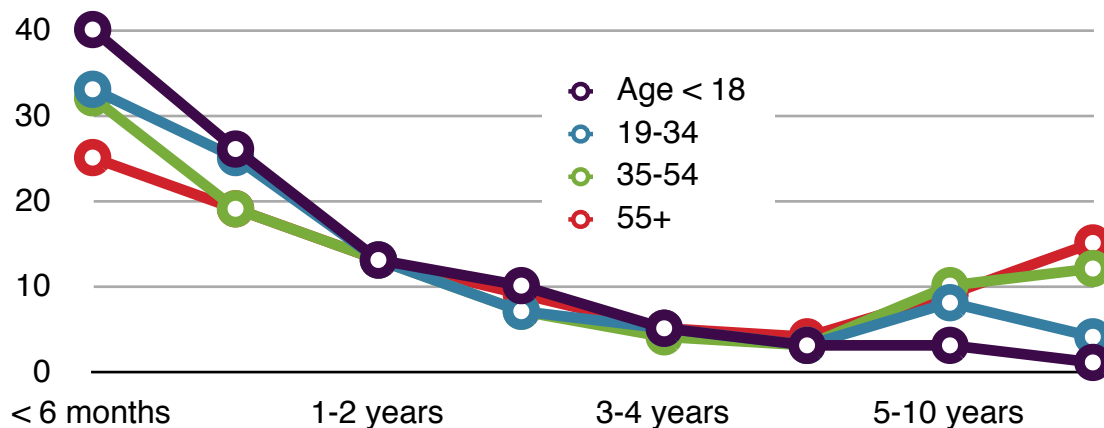
## A European Crohn's and Ulcerative Colitis Patient Life IMPACT Survey



### IMPACT of diagnosis

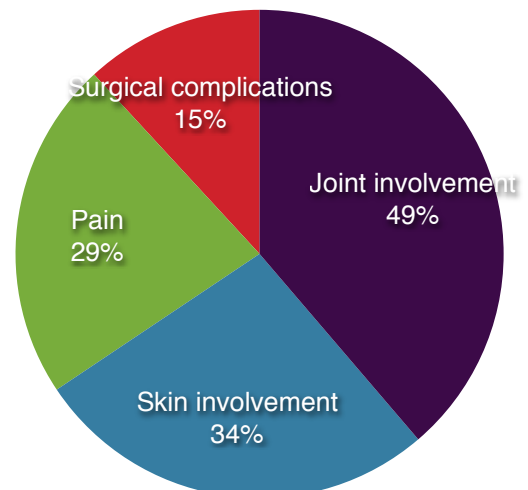
- 70% of all respondents saw a specialist within the first year of their illness
- 32% claimed that they received a final diagnosis within 6 months of recognizing their symptoms as relating to IBD; 54% within a year; 13% of respondents in 1-2 years; but 18% had to wait 5 years or more for a diagnosis.
  - Under-18 respondents were most likely to be diagnosed more quickly (40% within 6 months).
  - Those aged 35 waited longer for a diagnosis (those aged 55 waited the longest).
- 67% of respondents presented their IBD symptoms at an emergency clinic at least once before receiving a definitive diagnosis.

How long after your first noticed your symptoms did it take to receive your final diagnosis?



### IMPACT of complications

- Joint involvement
- Skin involvement
- Pain
- Surgical complications



**IMPACT**

2010-2011 Crohn's & Colitis Patient Survey  
www.surveysolutions.co.uk/IBD-Survey

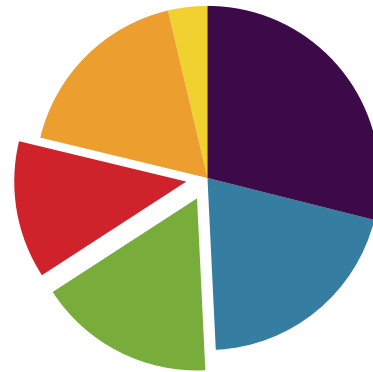


## IMPACT of health care and treatment

- 70% are very or somewhat satisfied with their treatment plan.
- 73% of people who had an operation were satisfied with the outcome.

The medication most likely to be currently taken were:

- Aminosaliclates (5-ASA) 47%
- Immunosuppressives 33%
- Biologicals 27%
- Corticosteroids 21%
- Pain medication 28.5%
- No medication 6%



- 52% had used steroids, 42% experienced side-effects and almost all were concerned about the long-term effects.
- 85% of respondents had been hospitalized due to IBD in the past 5 years (37% <5 days, 48% >5 days). Those with CD were most likely to have been hospitalized (89%), but those with UC were more likely to spend a longer time in hospital.
- 60% of younger patients having spent 6 days or more in hospital



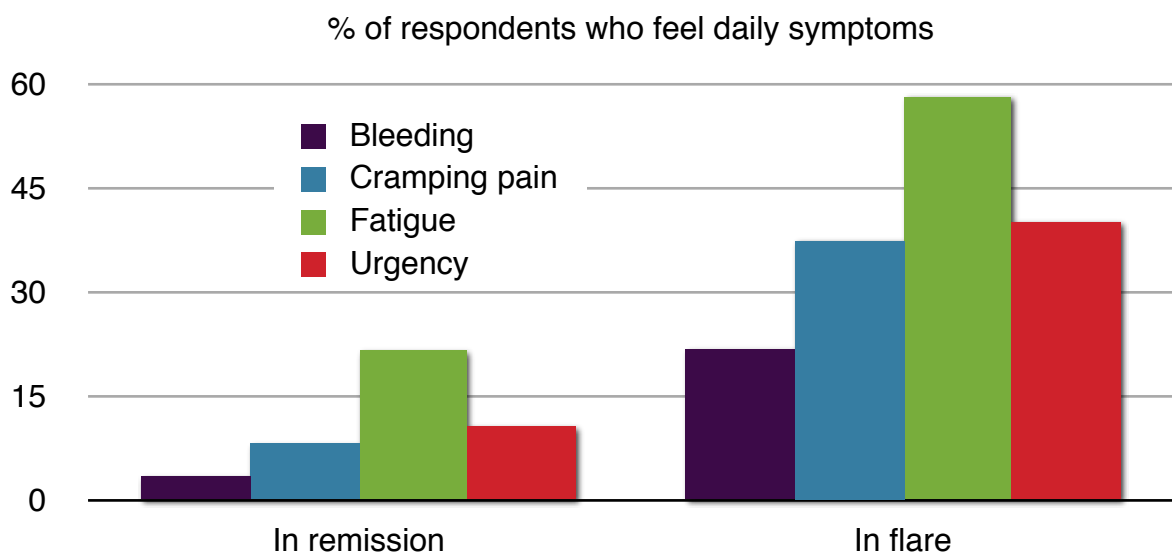
## IMPACT of health services

- 88% say that their clinic has a Specialist Gastroenterologist and 45% say they have a Nurse who understands or specializes in IBD.
- However, 24% say they do not have adequate access to their IBD professional.
- 53% feel that at their appointment they didn't get to tell the specialist something that was important.
- 65% say they wish that the gastroenterologist had asked more probing questions.
- Interestingly, men (more than women) are inclined towards thinking that the Specialist/Gastroenterologists understand the impact better, whilst women are more inclined to think this of Nurses.



## IMPACT on daily life

- Half of respondents were in remission (slightly more men than women), one out of four had a chronically active condition, and 23% were suffering periodic flare-ups. 35% had experienced a flare within the last 3 months.
- Most (96%) felt tired, weak or worn out daily during a flare and also between flares (83%). During a flare, 89% had daily urgent bowel movements and 93% diarrhea (between flares 66% and 61%, respectively).
- 40% reported to frequently wake from sleeping due to IBD-related pain. This problem affects women even more than men (43% compared to 33%).
- 49% felt their life was significantly affected.



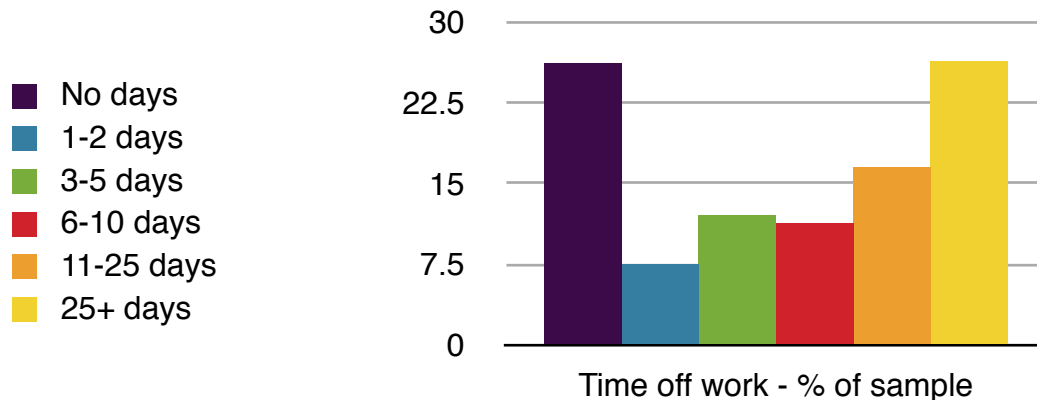
## IMPACT on work and education

- There seems to be a correlation between disease severity and ability to work: amongst the unemployed, 37% had a chronically active condition, whereas the fully employed were 10% more likely than average to be in remission.



74% had had time off in the past year due to IBD. Reasons included fatigue (51%), appointment (49%), cramping or painful abdomen (46%), and hospital/emergency visit (44%).

- 26% have had more than 25 days absence



- 61% felt stressed about taking time off work due to IBD.
- 25% had received complaints or unfair comments at work.
- 21% had suffered discrimination.
- 72% felt that IBD affects their behavior at work.
- Half of the respondents felt that their prospects had been affected negatively by IBD. 36% felt this very strongly.
- IBD had a negative effect on performance in an educational setting (52%).



## IMPACT on relationships

- IBD prevented from pursuing intimate relationships (40%; 51 – 58% among disabled and/or under- or unemployed) and affected the ability to make or keep friends (29%).
- 34% say IBD has caused an intimate relationship to end.
- 39% felt that meeting others with a similar condition made them more optimistic (43% among those aged under 35 and 46% among students).
- 44% of respondents had engaged in some way with EFCCA member associations.
- 63% of those who had joined a patients' association felt it had a beneficial impact on their life.

