



## Interim results from the IMPACT survey

### Introduction:

Inflammatory bowel diseases (IBD) significantly impacts the lives of patients. The European Federation of ulcerative Colitis and Crohn's Associations (EFCCA) is undertaking a pan-European IMPACT<sup>1</sup> patient survey that is unique in that it not only covers the affect of IBD on quality of life but also on additional aspects such as education, employment, relationships and others. IBD affect over 2.2 million people in Europe (5 million worldwide). In most cases the illness can be kept under control with medication, but despite extensive research there is currently no known cause or cure for IBD.

The survey is still open until 1 July 2011 at:

<http://www.surveysolutions.co.uk/sc/form.aspx?id=eleoct&lang=1>

It is available in 9 European languages (English, French, German, Italian, Spanish, Portuguese, Dutch, Swedish and Slovenian).

### Interim results

This interim report is based on **1,547 responses** up to and including **28<sup>th</sup> January 2011**. 63% of respondents have Crohn's and 32% are Ulcerative Colitis sufferers. In terms of gender 68% of responses are from women and 32% from men. The majority of responses (69%) are from 19-44 year olds. A final analytical report will be issued following the closure of the survey in July 2011

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## **Main issues:**

### **Quality of health care:**

- Just over half (51%) saw a specialist within 6 months of their IBD-related symptoms
- Almost a third (31%) visited at least 3 times or more an emergency department/clinic with IBD symptoms before they were formally diagnosed
- Half (48%) have used steroids in the past year for IBD symptoms and nearly half (46%) report being concerned about the long-term effects of steroids on their health
- Over 40% report experiencing side effects from the use of steroids.

### **Experience with health care professionals**

- 1/3<sup>rd</sup> of respondents (38%) say that they wish their gastroenterologist asked them more probing questions
- 50% feel that at least sometimes after an appointment, they feel they didn't get to tell their doctor something important.
- 20% feel that they do not have adequate access to their IBD professional

### **Effect of IMPACT on work:**

- over 66% feel that their IBD has had a negative effect on their career
- 48% claim to have lost a job, or had to quit a job, because of their IBD
- 56% feel stressed or pressured about taking time off sick from work
- 27% of IBD sufferers have taken more than 25 days' sick leave in the past year
- 26% of respondents claimed to have heard of complaints or unfair comments at work about their performance in relation to their illness

### **Overall impact of IBD on life**

- 33%, or one in three respondents, feel that their IBD has affected their ability to pursue intimate relationships
- 22% agree that their IBD has caused an intimate relationship to end

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- Even on the ability to make new, or keep existing, friends, there appears to be an impact: 28% agree that their IBD has affected them negatively in this way

### **Other effects of IBD**

- 52% (60% of under 18's) feel that their IBD has negatively affected their ability to perform to the full in an educational setting.
- 65% claim to worry about the ready availability of toilets when they are meetings or events
- 60% worry about the availability of toilets when they go somewhere new
- 37% are frequently woken from sleep as a result of IBD-related pain

### **Effects of being a Part of a Patient Association :**

- 53% of respondents claimed to have engaged with one of the EFCCA member organisations
- 61% of those who had engaged with one of the EFCCA member organisations, claimed that this had made an improvement to their life in general.

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