



# Public awareness of Crohn's disease and ulcerative colitis: A national survey<sup>☆</sup>

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## KEYWORDS

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## Abstract

**Background and aims:** Crohn's disease (CD) and ulcerative colitis (UC) are lifelong inflammatory bowel diseases (IBD) progressing over time. Lack of public awareness may contribute to tardy consultation of primary care physicians, late diagnosis and development of potentially preventable complications of disease.

A public opinion poll has been performed to assess the awareness of CD and UC in the Austrian population.

**Methods:** In March/April 2006, 122 interviewers of an international polling institute asked 1001 Austrians aged 16 and over about their knowledge of CD and UC. People interviewed were selected using a quota sampling scheme representing the Austrian population.

**Results:** CD and UC were never heard/read in 68% and 79% (group 1), respectively, whereas 23% and 14% had already heard/read these terms (group 2). Only 9% and 7% of participants gained information on or were familiar with CD and UC (group3), respectively. Among provided choices of potentially afflicted organs interviewees of group 3 associated the terms "CD" and "UC" with an intestinal disease in 86% each. Among those of group 2 + 3 the corresponding figures were 53% and 60% for CD and UC, respectively. Overall, 7% and 4% of the participants stated to be aware and/or informed on CD and UC and correctly associated these terms with an intestinal disease.

**Conclusions:** This is the first study on public awareness of the terms "Crohn's disease" and "ulcerative colitis". Poor knowledge in the public is reported which may vastly impact outcome and health economic consequences of IBD.

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## 1. Introduction

Crohn's disease and ulcerative colitis, collectively known as inflammatory bowel disease, are lifelong diseases, which become usually manifest in early adulthood and progress

**Table 1** Characteristics of interviewees.

Interviewees, absolute number, (%)		1001 (100)
SEX	Men	480 (48)
	Women	521 (52)
AGE	16–29 years	210 (21)
	30–49 years	384 (38)
	≥ 50 years	407 (41)
EDUCATION	Primary-, secondary school	327 (33)
	Further (vocational) education	440 (44)
	General qualification for university entrance (Matura), university	234 (23)
INCOME	≤ 1500 Euro/month	274 (27)
	1501–2400 Euro/month	341 (34)
	≥ 2400 Euro/month	254 (25)
RESIDENCE	Rural area (≤ 5000 inhabitants)	427 (43)
	Small town, medium-sized town	267 (27)
	Provincial capital	107 (11)
FEDERAL STATES	Vienna	199 (20)
	Lower Austria, Burgenland	226 (23)
	Styria, Carinthia	218 (22)
	Upper Austria	169 (17)
	Salzburg, Tyrol, Vorarlberg	189 (19)

over time towards complications prompting intestinal surgery.<sup>1</sup> The predominant symptoms are diarrhea, gastrointestinal bleeding, abdominal pain, weight loss and malnutrition, which can greatly impact patients' well-being, quality of life, and working ability.<sup>2</sup> Concerns about loss of bowel control, feeling dirty or smelly, and body image ranked highly for both UC and CD.<sup>3</sup> Altogether, patients at their peak of social and professional orientation are affected by symptoms and concerns which still appear less accepted in our society.

IBD is still facing an essential under-management in our health systems despite an increasing incidence of up to 20 per 100.000 of population and a substantial health economic burden of disease.<sup>4</sup> A collaborative study with the Austrian IBD patient association (ÖMCCV) has recently revealed a median delay of 2.4 and 3.4 years from first symptom to diagnosis of ulcerative colitis and Crohn's disease, respectively.<sup>5</sup> In 30% CD was diagnosed after 5 years. Delay of diagnosis and therapy may result in potentially preventable primary complications.

We assume that lack of public awareness might contribute to tardy consultation of primary care physicians by patients suffering from chronic symptoms socially unacceptable. Thus, we performed a public opinion poll to assess the awareness of CD and UC in the Austrian population, which is after extensive search of literature the first study ever carried out and published.

## 2. Materials and methods

### 2.1. Study design

Within the scope of a nation-wide awareness campaign organized by the Austrian IBD patient association and the IBD working group of the Medical University of Vienna an international polling institute, *IMAS international*, was

commissioned to perform a public opinion poll assessing the awareness of CD and UC in the Austrian population. In March/April 2006, 122 employees of *IMAS international* asked 1001 Austrians aged 16 and over about their knowledge of CD and UC within the scope of a multi-issue survey in form of a personal interview. Interviewees were selected using a quota sampling scheme representing the Austrian population according to sex, age, highest degree of school education, maximum income, residence in federal states, and affiliation to urban/rural population (Table 1).

### 2.2. Questionnaire

Interviewees were asked to respond to four questions according to a list of provided answers in a single choice way (Table 2).

### 2.3. Statistical analysis

For the analysis of factors influencing awareness of CD and UC interviewees were grouped according to their knowledge into unaware (= never heard/read about, don't know; group 1), aware (already heard/read about; group 2) and informed

**Table 2** Questions posed to the interviewees.

Have you ever heard or read about Crohn's disease or have you ever been dealing with this disease?	<ol style="list-style-type: none"> <li>1) I have never heard or read about this disease.</li> <li>2) I have somewhere heard or seen this term.</li> <li>3) I have already gained some information about this disease, read up on it.</li> <li>4) I have already dealt with it myself or within family and friends.</li> <li>5) don't know</li> </ol>
Have you ever heard or read about ulcerative colitis or have you ever been dealing with this disease?	<ol style="list-style-type: none"> <li>1) I have never heard or read about this disease.</li> <li>2) I have somewhere heard or seen this term.</li> <li>3) I have already gained some information about this disease, read up on it.</li> <li>4) I have already dealt with it myself or within family and friends.</li> <li>5) don't know</li> </ol>
Do you know or does the disease name (Crohn's disease) suggest which organs are affected or whether it could be contagious?	<ol style="list-style-type: none"> <li>1) ...head</li> <li>2) ...heart</li> <li>3)...liver</li> <li>4)... intestine</li> <li>5)...could be contagious</li> <li>6)... don't know</li> </ol>
Do you know or does the disease name (ulcerative colitis) suggest which organs are affected or whether it could be contagious?	<ol style="list-style-type: none"> <li>1) ...head</li> <li>2) ...heart</li> <li>3)...liver</li> <li>4)... intestine</li> <li>5)...could be contagious</li> <li>6)... don't know</li> </ol>

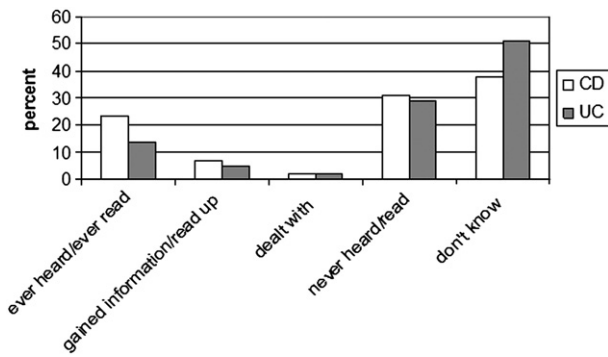


Figure 1 Awareness of Crohn's disease and ulcerative colitis.

(=affected, family and friends, gained information, read up on; group 3).

All results are expressed as absolute numbers and percentages. Chi-square test was used for statistical analysis. All calculations were done by SPSS statistical software (Release 14.0, 2005; SPSS Inc., Chicago, IL).

### 3. Results

#### 3.1. Awareness of Crohn's disease and ulcerative colitis

Being asked about the terms Crohn's disease and ulcerative colitis 69% and 80% of the interviewees chose the answer "never heard/never read" or "don't know" (group 1), respectively, whereas 23% and 14% reported to have already heard/read these terms (group 2, Fig. 1). Within group 3 knowledge of CD and UC due to a case in friends or family was reported in 2% each, another 7% and 5% of interviewees gained information or read up on CD and UC, respectively.

#### 3.2. Association between the terms "CD" and "UC" and type of disease

64% and 73% of all interviewees responded that they did not know which organ "CD" and "UC" were diseases associated with (Fig. 2). Among the provided choices of afflicted organs (intestine, head, heart, liver, or contagious disease) 21% and

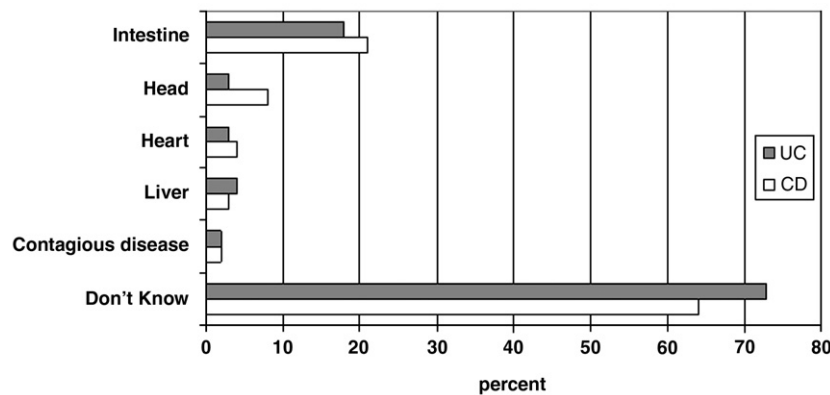


Figure 2 Among all interviewees the terms "CD" and "UC" were associated with disease of intestine, head, heart, liver, contagious disease.

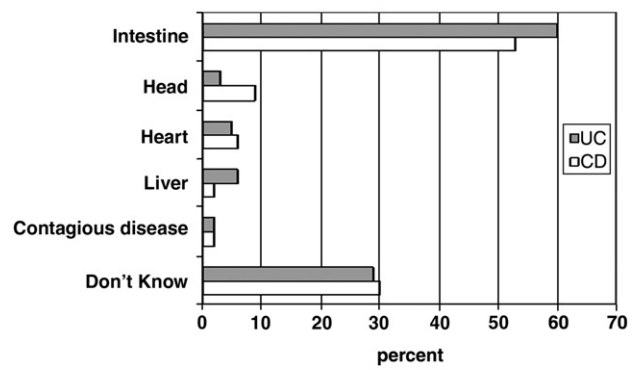


Figure 3 Among group 2+3 the terms "CD" and "UC" were associated with disease of intestine, head, heart, liver, contagious disease.

18% matched "CD" and "UC" with a disease of the intestine, respectively. Within groups 2+3 the corresponding figures increased to 53% and 60% for CD and UC, respectively (Fig. 3) and in group 3 alone the terms "CD" and "UC" were associated with an intestinal disease in 86% each (Fig. 4).

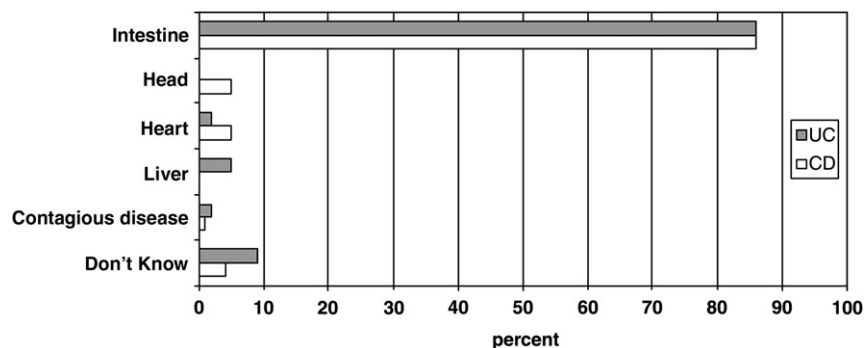
Overall, 7% and 4% of all participants stated to be aware and/or informed on CD and UC and correctly associated these terms with an intestinal disease.

#### 3.3. Factors influencing the knowledge of Crohn's disease and ulcerative colitis

An analysis of the awareness of the terms "CD" and "UC" in subgroups of the Austrian population showed that women, interviewees ≥ 30 years, people with higher school education and urbanites were more knowledgeable about IBD. Among the choices of the afflicted organs interviewees of these subgroups associated more often the terms "CD" and "UC" with an intestinal disease (Table 3).

### 4. Discussion

Although IBD has to be considered as one of the major diseases the awareness of CD and UC in the Austrian population is poor.<sup>6</sup> In our study on 1001 interviewees representing the Austrian population about three quarters



**Figure 4** Among group 3 the terms “CD” and “UC” were associated with disease of intestine, head, heart, liver, contagious disease.

were unaware of the terms “Crohn’s disease” and “ulcerative colitis” and only 7% and 4%, respectively, who stated to be familiar with the terms, associated them with an intestinal disease.

IBD is one of the complex human diseases of major public health importance like rheumatoid arthritis or type 2 diabetes.<sup>6</sup> Early onset of disease and the chronic progressive incurable course of the disease, which is associated with regular outpatient consultations in hospital care, admissions to hospital, bowel surgeries and long-term use of medication cause high direct medical costs within the healthcare system. However, indirect costs such as early retirement and sick leaves even surpass direct costs as the most important economic factor.<sup>7</sup>

After an extensive search of literature about surveys on awareness of common chronic diseases, such as rheumatoid arthritis, diabetes mellitus, psoriasis, and multiple sclerosis we succeeded to find only a few papers on diabetes mellitus. In 1992 a cross-sectional survey by standard questionnaire (street interviews) was conducted to determine public knowledge of diabetes and its symptoms in London’s population.<sup>8</sup> At that time the prevalence of diagnosed diabetes was between 1% and 2%.<sup>9</sup> Although interviewees, who had diabetes mellitus, were excluded from the study the awareness of this disease was impressively high. Diabetes mellitus was heard about in 96% of the people interviewed,

significantly related to older age and female sex. Even almost 73% defined diabetes correctly within the limits set by the investigators. In our study awareness on IBD was disproportionately poor, and may not simply be explained by the 2 to 4 fold lower prevalence compared to diabetes mellitus at time of the above mentioned study. Only 32% and 21% of the interviewees stated to be aware of the terms or informed on CD and UC, respectively. In total only a minority of the participants were able to associate the terms with an intestinal disease. Similar to the diabetes study women, the older generation, people with higher school education and urbanites were more knowledgeable about IBD.

Poor public knowledge of IBD might impact the outcome of patients in various ways. First of all it might contribute to taboo and/or belittle symptoms of IBD which deal with a socially less acceptable part of the body. Late medical consultation could be a consequence. Furthermore, symptoms at first presentation of IBD are non-specific and difficult to interpret by patients and general practitioners. Data on the awareness of IBD symptoms in the latter are not available. However, results of the European Federation of Crohn’s and Ulcerative Colitis Association (EFCCA) patient survey indicated that about three quarters of the patients were diagnosed by a gastroenterologist after symptoms for more than five years.<sup>2</sup> This might be taken as indirect evidence of unawareness of IBD symptoms among general

**Table 3** Association of the terms “CD” and “UC” and kind of disease.

		CD			UC		
		Disease of the intestine	No disease of the intestine	<i>p</i>	Disease of the intestine	No disease of the intestine	<i>p</i>
SEX	Men	82 (17)	398 (83)	0.0009	72 (15)	408 (85)	0.0188
	Women	135 (26)	386 (74)		109 (21)	412 (79)	
AGE	16–29 years	29 (14)	181 (86)	0.009	27 (13)	183 (87)	0.0004
	30–49 years	88 (23)	296 (77)		58 (15)	326 (85)	
	≥ 50 years	98 (24)	309 (76)		98 (24)	309 (76)	
EDUCATION	Primary-, secondary school	59 (18)	268 (82)	<0.0001	46 (14)	281 (86)	<0.0001
	Further (vocational) education	79 (18)	361 (82)		70 (16)	370 (84)	
	General qualification for university entrance (Matura), university	75 (32)	159 (68)		68 (29)	166 (71)	
RESIDENCE	Rural area (≤5000 inhabitants)	90 (21)	337 (79)	0.0005	60 (14)	367 (86)	0.0003
	Small town, medium-sized town	40 (15)	227 (85)		45 (17)	222 (83)	
	Provincial capital, Vienna	87 (28)	219 (72)		78 (25)	228 (75)	

Data are given in absolute numbers and percentages.

practitioners contributing to tardy referral to a gastroenterologist. Increasing awareness of IBD in the public and among family physicians may lead to increased self-referral of patients to their primary care physicians and a more rapid referral to gastroenterologists. A city-wide mass media campaign utilizing local radio and newspapers on diabetes mellitus significantly increased public knowledge after 1-week only, which is supportive to foster similar activities for IBD.<sup>9</sup>

Crohn's disease is a lifelong progressive disease leading to stricturing or penetrating complications with a cumulative risk for intestinal surgery of 70% during the first 15 years after diagnosis.<sup>10,11</sup> A more intensive treatment approach in patients with newly diagnosed Crohn's disease has been suggested to improve outcome. Recently, it has been shown that early combined immunosuppression with infliximab and azathioprine/methotrexate is more effective for induction of remission and mucosal healing than a conventional management, which steps up from corticosteroides to azathioprine and finally to infliximab in case of non-response.<sup>12</sup> Further evidence suggests that mucosal healing is a predictor for a reduced rate in admissions to hospital and surgeries.<sup>13,14</sup> Thus, we speculate that early diagnosis due to enhanced public awareness allows more rapid access to efficacious therapy which could result both in an improved prognosis of IBD and reduced health care costs.

In conclusion, public awareness of CD and UC in the Austrian population, which could be extrapolated to other western countries, is poor. Increasing common knowledge of IBD may initiate more self-referral to general practitioners and could result in early diagnosis and rapid initiation of efficacious treatment. Public awareness of IBD should be of major interest in health policy and nation-wide education campaigns are warranted to become a priority in health promotion.

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Author's contribution to the paper

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S. Angelberger: statistical analysis, data interpretation, manuscript writing

H. Vogelsang: conception and design of the study, data interpretation

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W. Reinisch: conception and design of the study, statistical analysis, data interpretation, manuscript writing

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