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Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d'Expertise des Soins de Santé
Belgian Health Care Knowledge Centre

NEEDS EXAMINATION, EVALUATION AND DISSEMINATION (NEED): IDENTIFICATION OF UNMET HEALTH-RELATED NEEDS ASSOCIATED WITH CROHN'S DISEASE

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HEALTH SERVICES RESEARCH

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LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
CD	Crohn's Disease
CHU	Centre Hospitalier Universitaire
COVID	Coronavirus Disease
DALY	Disability-Adjusted Life Years
EC	Ethical Committee
EIM	Extraintestinal Manifestations
EQ-5D-5L	EuroQoL 5 Dimensions 5 Levels questionnaire
GP	General Practitioner
HRQoL	Health Related Quality of Life
IBD	Inflammatory Bowel Disease
IBS	Irritable Bowel Syndrome
IQR	Interquartile Range
KCE	Health Care Knowledge Centre
LUSS	Ligue des Usagers des Services de Santé
MRI	Magnetic Resonance Imaging
NSAID	Non-Steroidal Anti-Inflammatory Drugs
QoL	Quality of Life
SD	Standard Deviation
TNF	Tumor Necrosis Factor
UC	Ulcerative Colitis
UZ	Universitair Ziekenhuis
VAS	Visual Analogue Scale
VPP	Vlaams Patienten Platform

SCIENTIFIC REPORT

1 INTRODUCTION

The current healthcare ecosystem is predominantly supply-driven, leading to a lack of innovation in financially less attractive health areas, inefficient use of public resources for healthcare and unmet patient and societal needs. The NEED (Needs Examination, Evaluation and Dissemination) assessment framework was developed with the aim of serving as a major tool for changing this situation and moving towards a more needs-oriented healthcare system. It allows to identify health-related unmet patient and societal needs in various diseases, highlighting gaps for intervention.[1]

The ultimate goal of this report is to assess whether the NEED framework is effective in evaluating, through a standardised and transparent approach, the current and future unmet health-related needs of patients and society related to Crohn's disease. This is a crucial step that will enable the involvement of other national and international partners and the political support essential to the sustainability of the NEED project.

To achieve this goal, the NEED assessment framework will be implemented in the Belgian context to answer the following research questions:

1. What are the current and future unmet health needs of patients and society related to Crohn's disease?
2. What are the current and future unmet healthcare needs of patients and society related to Crohn's disease?
3. What are the current and future unmet social needs of patients and society related to Crohn's disease?
4. Does the NEED assessment framework require certain adaptations to better assess the unmet health-related needs?

The definitions of the various concepts related to unmet needs as well as the rationale and scope of the NEED approach can be consulted in the KCE report. [1]

2 DISEASE DESCRIPTION

The aim of this chapter is to provide a brief overview of Crohn's disease by presenting a description of the disease, epidemiological data (incidence, risk factors, mortality rates), diagnostic methods and available treatments.

Key points

- **Crohn's disease (CD) is a life-long, chronic disease with symptoms that typically start between the ages of 15 and 25 years.**
- **There exists no curative or disease-haltering treatment for CD. Consequently, more than a third of patients progress to a more complicated disease during their lifetime.**
- **Almost 50% of patients require surgery due to poor efficacy of pharmacological treatment of severe or complicated CD.**
- **The mortality rate of CD is considered low. However, it can result in complications or predispose individuals to certain diseases (e.g. colorectal cancer) which have impact on life expectancy**
- **Over the last century, the incidence of CD has increased significantly, with an incidence ranging from 0.4 to 22.8 cases per 100 000 people in Europe.**
- **The pathophysiology of CD is not yet fully understood. It is believed to be the result of an inappropriate gut mucosal immune response, triggered by dysbiosis in genetically susceptible individuals.**

2.1 Epidemiology

Approximately 0.2% (2.5-3 million people) of the European population suffers from inflammatory bowel disease (IBD), with a European prevalence of up to 396 people per 100 000.[2] Inflammatory bowel diseases are chronic immune-mediated disorders that cause inflammation of the gastrointestinal tract of which Crohn's disease (CD) and ulcerative colitis (UC) are the most common.[3, 4] Although both diseases are classified as IBD, UC only affects the colon, whereas CD can affect all parts of the gastrointestinal tract. This report focuses on CD.

The incidence and prevalence of CD varies significantly between different countries and regions, with the highest occurrence in industrialised regions, such as Northern Europe (France, the United Kingdom, Sweden and Germany) and North America.[5, 6] In 2020, a recent literature review estimated the incidence of CD in Europe to be 0.4 to 22.8 per 100 000 person-years.[2] In 1998, a prospective study in the area of Liége, Belgium, estimated an incidence of 4.5 per 100 000 person-years.[7] The prevalence of CD in Europe varies from 1.5 to 213 cases per 100 000 people.[5] In 2019, the global burden of disease study (GBD) estimated a prevalence of 153.4 to 199.8 per 100 000 for all ages in Belgium.[6]

2.2 Pathophysiology

The exact pathophysiology of CD is not yet fully understood. However, the most widely accepted theory states that CD is the result of an inappropriate gut mucosal immune response, triggered by dysbiosis in genetically susceptible individuals.[4, 8] CD is thus caused by an interplay of genetic factors, the immune system, the intestinal microbiota, and other risk factors.[9]

To explore the pathophysiological mechanism of CD, more than 100 genetic markers have been studied.[10] The strongest associations were identified with NOD2/CARD15, IL23R and ATG16L1 genes.[10-14] Nevertheless, only 12% of patients diagnosed with CD report a family history.[15] This highlights the importance of other epigenetic factors and risk factors in the pathogenesis of CD.[16] One of those factors is the gut microbiome. Research has observed alterations in the composition and function of the gut microbiota in individuals with CD in comparison to healthy individuals. This

imbalance in the gut microbiome may play a role in the development of CD.[17, 18] Other risk factors that are linked to CD include smoking habits, maternal lifestyle, vitamin D deficiency, diet, and medication (see Box 1).[16] These risk factors affect the enteral permeability, the intestinal immune system and/or gut microbiota, thereby increasing susceptibility to the onset of CD.

Box 1 – Most common risk factors related to the development of CD

Smoking – Smoking is well-described and considered the most important risk factor for the development of CD, as well as for a more complicated disease course.[19] In comparison to non-smokers, the risk of developing CD increases by 40-70% in smokers.[20] Moreover, smoking not only increases the chance to develop CD, smoking is also associated with an earlier onset of CD, increased risk of disease flares, a greater need for immunosuppression, a higher need for surgery and post-operative disease recurrence.[21]

Diet – A low intake of dietary fibre and increased saturated fat intake have been associated with a greater risk to develop CD.[22] Research indicates that diet influences the composition of the intestinal microbiome and a Western diet with large amounts of red meat, high-fat foods, and refined sugars has been linked to intestinal inflammation.[23-26]

Medication – Antibiotics, aspirin, non-steroidal anti-inflammatory drugs (NSAIDs) and oral contraceptives have been implicated as potential risk factors for the development of CD.[27, 28] An association has been described between the use of NSAIDs and the development of CD, particularly at higher doses and with long-term use. Oral contraceptives have been shown to increase the risk of CD 1.5 times when compared to unexposed women.[29]

The strength of the causal relationships between some of the risk factors described in Box 1 and the development of CD remains controversial, as they are not consistently identified across all populations. For example, northern European countries have a very high incidence of CD, despite low smoking rates.[28] Individual cases may involve a combination of different (environmental and epigenetic) factors and ongoing research continues to deepen our understanding of the pathophysiology of CD.[9]

2.2.1 Symptoms

Crohn's disease is a chronic immune-mediated disease, characterised by acute exacerbations interspersed with periods of remission.[30, 31] Patients with CD generally develop their first symptoms between the ages of 15 and 25 years. Patients often report symptoms for several years before a correct diagnosis is made, because these initial symptoms are often heterogenous and non-specific.[32] The key symptoms of CD include chronic diarrhoea (> 6 weeks), abdominal pain (present in 80% of the cases), weight loss (present in 60% of the cases), nausea, vomiting, fever, and fatigue.[33, 34]

Fatigue, defined as an overwhelming sense of tiredness, lack of energy, and feeling of exhaustion, is a common and major concern for people suffering from IBD.[35, 36] Fatigue is often reported by patients as the symptom with the greatest impact on their daily activities and significantly reduces their quality of life.[37, 38] It presents itself in newly diagnosed patients as well as in those with long-standing disease, but is more common in patients with an active disease compared to patients in remission.[39, 40]

Besides the gastrointestinal symptoms, 25-40% of patients with CD develop extraintestinal manifestations (EIM). EIM are conditions associated with CD that do not affect any part of the intestine, but affect the joints (e.g. spondyloarthropathy), skin (e.g. erythema nodosum, pyoderma gangrenosum, psoriasis), liver (e.g. primary sclerosing cholangitis), or eyes (e.g. uveitis, episcleritis, iritis).[41] A pan-European survey showed that most commonly the joints (49%) and skin (34%) were affected.[42]

2.2.2 Clinical course

To date, CD is a chronic disease for which no curative treatment exists, and patients often progress to a more complicated disease over the course of their lives. After 10 years of CD, 30% to 40% of patients will have developed complications such as fistulae (abnormal connections between organs or tissues), abscesses, perianal disease, ulcers or strictures (narrowing of the intestinal passage) which may require surgical resection or develop colorectal cancer.[5, 41, 43]

CD can be categorised into three disease phenotypes according to its disease behaviour: *inflammatory, stricturing and penetrating*.[31] *Inflammatory CD* is characterised by inflammation of the gastrointestinal tract without clinical evidence of strictures or fistulas. Patients with CD may progress from this inflammatory disease state to stricturing (or fistulizing). In *stricturing CD* chronic inflammation leads to fibrosis and luminal narrowing. Eventually, this ongoing transmural inflammation can result in the development of a fistulous tract between the bowel and any adjacent organ, which is characteristic of fistulizing CD. Research reported that 45.9% of patients had a change in disease behaviour during 10 years of follow-up, from non-stricturing, non-penetrating disease to either stricturing (27.1%) or penetrating (29.4%) disease.[7, 31] However, patients presenting with a combination of these phenotypes are not uncommon in clinical practice. In most patients disease activity will regress over time with 62% of patients in clinical remission 10 years after their initial diagnosis.[31]

In contrast to the variable nature of the disease activity, the location of the inflammation in CD tends to remain relatively stable throughout its clinical course. Only 15.9% of patients show a change in disease location during the first 10 years. In half of the patients, CD only affects the terminal ileum and the colon.[31]

To describe these various manifestations and behaviours of IBD in research and clinical practice the Montreal classification is often used. This classification is based on the previously used Vienna classification and provides a standardised classification system, based on the age at diagnosis, disease location, and disease behaviour (Table 1).[44]

Table 1 – Montreal classification of Crohn's disease based on age at diagnosis, location of the disease and disease behaviour

Parameter	Criteria	Symbol
Age at diagnosis (in years)	≤ 16	A1
	17 – 40	A2
	> 40	A3
Location	Ileal	L1
	Colonic	L2
	Ileocolonic	L3
	Isolated upper disease(*)	L4
Disease behaviour	Non-stricturing/non-penetrating	B1
	Stricturing	B2
	Penetrating	B3
Modifier(**)	Perianal disease	P

(*) L4 is a modifier that can be added to L1, L2 and L3 when gastrointestinal disease is present; (**) P is a modifier that can be added to B1, B2 and B3 when concomitant perianal disease is present.

For example, a patient with CD, diagnosed at the age of 35 years, with involvement of the terminal ileum and stricturing, non-penetrating disease, would be classified as A2-L1-B2. The presence of perianal disease is evaluated and considered a disease modifier to distinguish between internal penetrating or stricturing disease behaviour.[45] The rate of perianal complication varies between 10% and 20% at initial presentation and is a particularly severe phenotype with poor quality of life and a complicated disease course.[5, 7, 46, 47] Clinically, the Montreal classification allows stratification of individuals with regard to their risk of disease progression and complications.

Furthermore, several scoring systems measure disease activity, such as the Harvey Bradshaw index (HBI), but the most commonly used is the Crohn's Disease Activity Index (CDAI).[48-50] This measure of disease activity is primarily used in research, but is increasingly common in clinical practice to distinguish patients with active disease (> 150 pt) and patients in remission (< 150 pt).[48, 51]

2.3 Mortality

The mortality rate of CD is considered low. However, it is associated with complications and comorbidities that can affect life expectancy. These complications and comorbidities include: malnutrition, post-operative complications, and a higher risk of colorectal cancer.[52] Over the last three decades, the global mortality rate associated with IBD has decreased by 13%.[6] The global age-standardised death rate decreased from 0.67 per 100 000 people in 1990 to 0.54 per 100 000 people (0.46 to 0.59) in 2019. In Europe, Western Europe is the region with the largest number of deaths (11 981 (95% unit interval 9 244 to 13 315)) and the highest age-standardised death rate (1.11 per 100 000 people).[6] Due to the increased longevity of IBD patients the disability-adjusted life years (DALY) have increased by 30% between 1990 – 2019, and are expected to continue to rise in the future.[6]

2.4 Diagnosis

Initial diagnosis can be difficult and lengthy due to the non-specific symptoms associated with CD. Therefore, the clinical diagnosis of CD is based on a combination of clinical evaluation (e.g. abdominal tenderness and signs of malnutrition), medical history (e.g. symptoms and family history), laboratory tests (e.g. blood and stool tests), endoscopic evaluation, biopsy histology, and in some cases medical imaging (e.g. computed tomography enterography and magnetic resonance enterography).[53-55]

2.5 Treatment

The current treatment of CD aims to relieve symptoms, prevent complications, and improve the quality of life, since no curative treatment exists. The following therapeutic options are considered: drug therapy, surgery, lifestyle changes (e.g. physical activity, dietary changes and smoking cessation) and treatment monitoring.[56]

2.5.1 Drug therapy

The range of available drug therapies for CD has increased over the last two decades, with most drugs aiming to stop the cascade of inflammatory and pro-inflammatory cytokines, with the aim to suppress the overly active intestinal immune system.[57-59] The choice of initial drug treatment from an expanding matrix of drugs is guided by disease phenotype, disease activity and individual characteristics of the patient (Table 2).[4, 31] In general, a treatment plan for patients suffering from CD consists of two phases: *induction* and *maintenance*.

In the *induction phase*, the aim is to suppress the active disease and flare-ups, this treatment is often referred to as "induction therapy". Induction therapy involves a high dose of a steroid or steroid-sparing medication during the initial weeks or months of treatment in order to rapidly induce remission. Medications that are effective and may be used to induce remission include corticosteroids (e.g. budesonide) and biologicals.[60-65] Budosenide is a gut-selective steroid which causes fewer side-effects than systemic corticosteroids and is therefore a preferred treatment for mild to moderate flares. However, if a patient needs repeated courses of steroids (> 2 per year) this may indicate the need for treatment adjustment or a surgical intervention.[32] Severe flare-ups can necessitate (acute) hospitalisation and intravenous steroids.[32]

The *maintenance phase* is initiated when the acute inflammation and symptoms are under control. In this phase, the aim of therapy is to maintain symptom relief and prevent disease flares, while minimising potential side-effects and the risk of complications in the long term.[66] It is possible that the same drug treatment or treatment strategy is utilised for both inducing and maintaining remission, but maintenance therapy often entails a lower dose

of a steroid-sparing medication such as immunomodulators (e.g. azathiopurine, 6-mercaptopurine, methotrexate) or biologicals (Table 2).[67-69] Immunomodulators can be used as maintenance therapy, but have shown to be less effective than biologicals or combination therapies with biologicals.[70] Clinical trials have shown that the combination therapy of anti-TNF and thiopurine is a more effective treatment than monotherapy in severe CD and is considered first-line therapy in this context.[70] In the case of complex disease, specifically perianal fistulising disease, infliximab (Anti-TNF agent) is recommended to induce and maintain remission, but the management of complex perianal disease should always be considered together with the concomitant drug treatment of luminal disease.[58]

Overall, the drug selection always aims to balance treatment efficacy with potential side-effects and (long-term) complications. Therefore, steroids are not an effective long-term treatment strategy as an excessive use of steroids would increase the risk of complications such as osteopenia and infections. After every severe flare-up a rigorous assessment of the current treatment and therapy adherence should be performed.[32]

When remission is achieved, patients often express a desire to discontinue treatment to limit their medication use and concerns about the long-term side-effects. However, it is generally not advised to discontinue medication usage because it increases the risk of relapse, the risk of complications and the need for surgery. Decisions on discontinuation are based on individual evaluation (e.g. age, risks, depth of remission, previous treatment course) and involve discussion between the patient and their treating physician. Only in some select cases discontinuation of treatment can be considered.[71, 72]

Table 2 – List of the most commonly used medications to treat Crohn's disease (non-exhaustive)

Medication	Subcategory	Drug name
Corticosteroids		Budesonide
		Methylprednisone
		Prednisone
Immunomodulators		Azathiopurine
		6-mercaptopurine
		Methotrexate
Biologicals	*Anti-IL12/23 agents*	Ustekinumab
		Risankizumab
	Anti-adhesion molecules	Vedolizumab
	Anti-TNF agents	Infliximab
		Adalimumab
		Golimumab
		Certolizumab
Janus kinase inhibitors		Tofacitinib
		Upadacitinib
		Baricitinib
		Filgotinib
		Abrocitinib

2.5.2 Surgery

Drug treatment alone can be insufficient in patients with complicated CD (e.g. patients with strictures, abscesses and fistulas). In these cases, it can be indicated to perform surgery to provide symptom relief or end a flare-up (Box 2).[4, 73] The indication and timing of surgery should always be discussed in a multidisciplinary team and is dependent of disease severity and disease location. In the past, surgical intervention was often used as a last resort therapy, but more recent research suggests that surgery may play a more central role in the multidisciplinary management of CD, for example in the case of refractory disease or when no further pharmacological treatment is

available.[74] Nevertheless, as a result of the recent pharmacological developments, studies have shown that the overall surgery rates for CD are slowly decreasing in Europe.[75, 76]

Up to half of the patients (30-50%) will require surgery within ten years from their initial diagnosis and about 20% will require a second surgery.[54, 77] Possible surgical interventions for CD include: resection, anastomosis, strictureplasty or drainage of an abscess.[78, 79] In most cases surgery for CD is elective, but sometimes CD can cause acute complications (e.g. perforation, massive haemorrhage, complete bowel obstruction) that require emergency surgery (6–16% of cases).[80]

Box 2 – Most common surgical procedures to treat Crohn's disease

Strictureplasty – This surgical procedure is performed when strictures (narrowed areas) are formed in the intestines due to inflammation and scarring. The surgeon will widen the narrowed section of the intestine, without removing it, restoring the passage of food and stool.[81]

Resection – This involves completely removing the affected part of the intestine and connecting the remaining healthy ends of the intestine. Early surgical resection can be considered in patients with isolated terminal ileal disease.[82]

Colectomy – If CD affects the colon extensively, a colectomy may be necessary. This surgical resection involves completely removing the large intestine and is performed mostly on patients with extensive disease who do not experience mucosal remission after treatment. Depending on the specific situation, the surgeon may also create an ostomy, such as an ileostomy or colostomy, to create an opening in the abdominal wall for waste elimination.[83] In specific cases a proctocolectomy can be performed. This is a type of colectomy, performed in cases where CD affects both the colon and rectum. This surgery involves removing the entire colon and rectum. After the removal of the colon and rectum, an ostomy is created and the end of the small intestine (ileum) is brought out through an opening in the abdomen (ileostomy).[82]

Abscess drainage – An abscess drainage is performed if an abscess (a collection of infected fluid) forms due to inflammation. Surgical drainage is carried out to alleviate symptoms and prevent further complications.[82]

2.5.3 Lifestyle changes

In addition to drug treatment and surgical interventions, the management of CD involves a series of lifestyle changes. These interventions can have a significant impact on the clinical course and outcomes .

Physical activity and exercise have shown modest benefits on IBD-related disease activity, on biochemical markers of inflammation, and on the reduction of flares. A prospective cohort study found that higher levels of exercise were associated with a 24-32% lower risk of symptomatic relapse in patients in remission.[84] Patients with mild to moderate CD are recommended to maintain an active lifestyle with moderate-intensity aerobic and resistance exercise for at least 30 minutes, three times a week.[85]

Nutrition is an important component of IBD management, particularly in patients who show nutritional deficiencies. In active CD, accurate assessment of nutritional status and early treatment of protein/energy malnutrition and micronutrient/vitamin deficiencies are strongly recommended.[86] The most common nutritional deficiencies are: iron, vitamin D, and vitamin B12. Patients with CD should be made aware of the influence of their diet on their disease by their health care practitioner.[87] It has been noted that they often tend to avoid certain foods, rather than increase the intake of dietary components with beneficial properties.[88, 89]

Furthermore, smoking has been associated with a more severe disease phenotype, reduced treatment response, complicated disease behaviour and adverse outcomes in CD.[90] Despite the evidence of the detrimental effects of smoking and the beneficial effects of smoking cessation in patients with CD, the prevalence of smoking remains high and many patients remain unaware of the detrimental effects of smoking on the clinical course and outcome of CD.[91] Smoking cessation programs that involve individual counselling, nicotine replacement, and/or pharmacotherapy have shown to

be effective in helping patients with CD quit and may improve disease outcomes.[92]

2.5.4 Monitoring of treatment

The management of CD requires early detection and close monitoring of the (intestinal) inflammation to prevent complications. Research has shown that chronic and untreated inflammation, even when asymptomatic or minimally symptomatic, results in poor clinical outcomes.[32] Therefore clinical evaluations (e.g. endoscopy, cross-sectional imaging, C-reactive protein or fecal calprotectin) should take place at regular intervals and particularly after a change in treatment dose or frequency.[93] This approach provides the clinician with objective information, making it possible to assess treatment effectiveness and adjust treatment early, if needed. Such tight inflammation control is believed to be essential to prevent (complicated) disease progression (e.g. intestinal cancers, strictures, fistulas and abscesses) and improve rates of mucosal healing, which leads to fewer hospitalisations, less flare-ups and less surgeries.[93] This was illustrated in the CALM study, which showed that among 244 patients with CD, the use of biomarkers, compared with clinical management alone, was associated with improved rates of mucosal healing at 48 weeks.[94]

3 METHODS

This section describes the methods used to identify unmet health-related needs of patients with Crohn's disease. An online survey as well as individual interviews with patients were performed. The methodological approach, including the research protocol and the questionnaire, was submitted to and approved by the ethical committee of the 'Erasmus Hospital Brussels' (P2023/148/B4062023000088). The approval was valid from 27/04/2023 until 31/12/2023.

3.1 Online survey

3.1.1 Data collection tool

3.1.1.1 Development of the online questionnaire

Generic patient unmet needs questionnaire

The questionnaire used in the current study is based on the generic questionnaire developed and described in KCE report 348.[95] Full methodological details of the development of this generic questionnaire can be found in the report. In summary, the questionnaire was developed to identify and assess different dimensions of patients' needs. For each dimension, the KCE research team listed the possible questions related to the dimensions of needs. The questionnaire was validated by a Delphi panel made up of representatives from umbrella organisations of patient associations and sickness funds.

Adaptations made for Crohn's Disease (CD)

The generic questionnaire was adapted to CD by reformulating some questions (e.g. using "Crohn's disease" instead of the generic term "your disease") and by adding questions that are specific for CD (Appendix 2). These additional questions were based on a pragmatic review of the epidemiology and pathophysiology of CD, along with the specific disease characteristics, symptoms, treatment options, adverse events, and relevant

healthcare professionals and services. The questionnaire was reviewed by two external experts in CD.

Translation

The questionnaire for CD was originally developed in Dutch. Thereafter the questionnaire was translated into French by KCE researchers. A comparison of the two language versions was carried out to ensure that both were identical in terms of structure and content. Subsequently, both versions were proofread by research team members.

Online version: Patient Survey

Once the versions were proofread by the research team, the questionnaires were uploaded onto an online platform (Qualtrics, embedded in the KCE website). Five individuals from different age groups and with diverse backgrounds, none with a scientific background, participated in a pre-test of the survey to assess the clarity of the questions and the user-friendliness of the online version. The online questionnaire was adapted based on their feedback. Finally, the research team pre-tested the online versions in both languages.

3.1.1.2 Final questionnaire

Study introduction and patient approval

The questionnaire started with an introduction to the study, describing the objective, requirements for participation, and confidentiality policy. Respondents were asked to provide their informed consent before participation.

Questionnaire structure

The questionnaire consisted of 58 questions, organised around the following ten themes (disease-specific dimensions are flagged by means of an *):

- *General information*: demographic information, including self-identified gender, age, place of residence, level of education, employment status, and whether the respondents were answering for themselves or for another adult (as proxy);
- *Disease**: disease-specific information, including symptoms and their burden, duration of disease, severity of disease and treatment. Questions on hospitalisations due to disease were also included. Respondents were asked if they had or were having a flare-up. A flare-up is defined as the recurrence or worsening of symptoms related to CD after a period during which these symptoms were under control;
- *Other illnesses*: presence of comorbidities;
- *General health status and health-related quality of life (HRQoL)*: the respondents' health status before and after the onset of CD using the EQ-5D-5L[a] as the HRQoL instrument. The EQ-5D-5L asks respondents to describe their health status on five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each item has five response categories, reflecting the level of problems experienced in each dimension (no problems, slight problems, moderate problems, severe problems, extreme problems). In addition, respondents are asked to score their health state before and after diagnosis on a visual analogue scale (VAS), ranging from 0 (worst imaginable health state) to 100 (best imaginable health state);

[a] https://euroqol.org/eq-5d-instruments/eq-5d-5l-about/ (last access: 8 August 2023)

- *Healthcare use and access to care*: contact with healthcare services, such as delay between seeking a first appointment and first consultation, types of specialists consulted, satisfaction with contacts with healthcare professionals, any forgone care due to access barriers, quantity and clarity of information about the disease;
- *Treatment**: disease-specific treatment(s) received, and the level of satisfaction with this (these) treatment(s). General perceptions on treatment effectiveness and treatment burden were also collected. An extensive list of possible adverse events from different treatment options were provided for selection, and the burden for each adverse event was collected;
- *Financial impact*: financial impact of the disease and its consequences;
- *Social support network*: needed social support as a result of the disease.

A combination of pre-defined categories and open field responses

For most of the questions, respondents were given a choice of answers (often based on the literature) but were also given the opportunity to give additional responses in an open field.

For several questions, respondents were asked to indicate their level of satisfaction or level of burden. In many instances, responses to specific questions led to new sub-questions (e.g. when the respondent indicated 'Yes', he/she had to specify his/her answer).

Invitation to participate in an in-depth interview

At the end of the questionnaire, participants were asked whether they would be willing to participate in an individual interview. Information of respondents who indicated their willingness were retained for shortlisting and, if suitable, contacted (see section 3.2.1 Selection of participants).

3.1.2 Recruitment of participants

Recruitment strategy

A multichannel recruitment strategy was used which included online information (KCE website, e-mailing, and social networks) as well as physical posters and flyers in healthcare settings. A link was provided to the KCE website on which interested individuals could find further information and a Quick Response (QR) code to the survey and informed consent. A direct link to the online survey was also provided via the QR code on the recruitment materials. In addition, we asked sickness funds, the Dutch-speaking and French-speaking umbrella organisations of patient associations (VPP and LUSS), disease-specific and general patient organisations, hospitals and universities to share and display the information regarding the call for participation.

Inclusion and exclusion criteria

Respondents had to meet the following criteria to participate in the survey:

- Being 18 years of age or older;
- Received a diagnosis of CD;
- Having been diagnosed with CD for at least two months at the time of the survey;
- Living in Belgium (main residence).

When the respondent completed the survey on behalf of another adult (who met the inclusion criteria but was unable to respond), he/she had to respond as if the patient he/she represented would answer the questionnaire.

When the inclusion criteria were not met, individuals were directed to the end of the survey, and provided with an explanation for their exclusion.

3.1.3 Quantitative data collection process

The questionnaire was launched on the 4th of May 2023 and ran until the 2nd of July 2023. Throughout the three-month period of data collection, the recruitment strategy was subject to continuous monitoring. Depending on the publication schedule of the recruitment material set by involved stakeholders, the project team recontacted the stakeholders with repeated instructions to solicit participation. This was done to ensure maximal awareness and maximise the opportunity for individuals to engage in the data collection initiative.

In total, communication was established with over 169 stakeholders (137 hospital sites, 13 associations, six sickness funds, seven universities, six groups on social media) via e-mail and more than 160 posters were disseminated across the three regions in Belgium (Table 3).

Table 3 – Overview of contacted stakeholders for CD

Type of stakeholder	CD-specific	Not specific	n
University		7	7
Sickness fund		6	6
Hospital site[1]			137
University		24	
Non-university		113	
Association	7	6	13
Social media	6		6
Total			**169**

[1] *14 sites have been visited to deliver materials; all other stakeholders received materials by e-mail or by post.*

3.1.4 Quantitative data analysis

For all continuous variables, the mean ± standard deviation (SD) or median with interquartile range (IQR) for normally and non-normally distributed data respectively, was calculated. For categorical variables, the associated percentages were calculated.

Health-related quality of life (HRQoL) utility scores, were assigned to respondents' EQ-5D-5L health state descriptions using the most recent Belgian value set.[96]

The EQ-5D-5L utility values were collected for two time points: before and after the onset of the disease. A paired-sample t-test was conducted to determine whether there was a significant difference (mean Beta) between the mean utility scores before vs after the onset of the disease.

Stratification and comparative analyses were executed within subgroups. The subgroups of interest for CD were identified based on having had surgery (surgery and no surgery), having been hospitalised for CD (hospitalisation and no hospitalisation), age (< 50 years and > 50 years) and time since diagnosis (< 10 years and > 10 years).

Continuous variables were compared between the predefined subgroups using Student's t-test or Mann-Whitney U test depending on the distribution of the data, while chi-square test or Fisher's exact test were used to analyse categorical variables.

Univariate regressions were performed on a selection of variables in order to identify potential relationships between demographic characteristics, clinical factors (e.g. number of flare-ups) and the EQ-5D-5L utility scores. Univariate linear models were used with a factorisation of categorical variables where applicable; continuous variables did not undergo any data transformation.

The significance level was set at 0.05 for all statistical tests. All statistical analyses were performed using R version 4.3.0 (R Foundation for Statistical Computing, Vienna, Austria).

Open field responses were first analysed thematically and recoded into existing or newly defined categories when appropriate. Any recoding was done by preserving the main idea(s) behind the initial response and was verified by another native-speaking member of the research team. If the response could be interpreted in different ways, the response was classified under 'Others' to avoid misinterpretation. Open field answers in the online survey have also been processed using NVIVO® software.

3.2 Individual interviews

The guidance for the qualitative approach to identify patient needs has been developed in a previous KCE research project.[95] This approach was applied to CD to deepen our understanding of patients' perspectives on their unmet needs. The data collection was completed by a series of semi-structured individual interviews, developed in the context of KCE Report 348.[95] This methodology was first used in the KCE Report 344.[97]

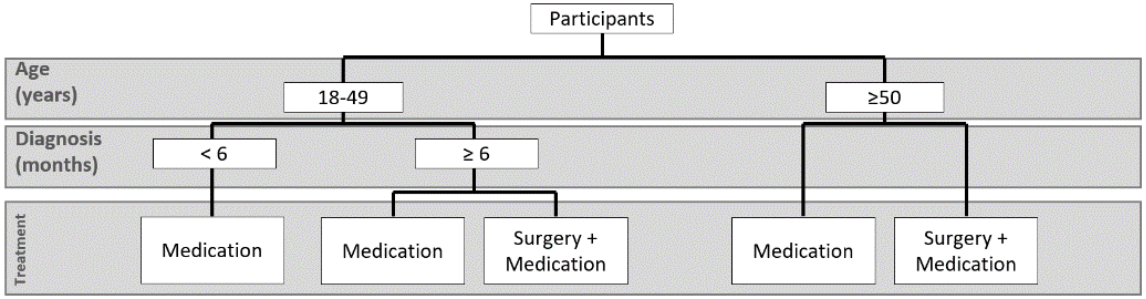
3.2.1 Selection of participants

Respondents participating to the online survey (see section 3.1 – Online survey) were offered the opportunity to participate in an individual interview. They were invited to leave their contact details so that they could be contacted by the research team if they met the inclusion criteria.

The aim was to conduct 20 individual interviews, with a distribution of 10 interviews in French and 10 in Dutch for each. To ensure a broad representation of respondent profiles, the researchers prioritised the recruitment of participants willing to participate in the interview from each language group, based on the following segmentation criteria (– Segmentation of potential candidates with CD to participate in a qualitative interview):

- Age: between 18 and 49 years or ≥ 50 years;
- Diagnosis: being diagnosed > 6 months ago or being diagnosed < 6 months ago;
- *Treatment*: received medication only or received both medication and (a) surgical intervention(s)

Figure 1 – Segmentation of potential candidates with CD to participate in a qualitative interview



In each segment of the population that volunteered for the interview through the online survey, two participants were randomly selected, one for each language. When there were insufficient candidates in a specific segment, additional candidates were contacted in adjacent categories or with another mother tongue (e.g. including a French/Dutch speaking participant because no Dutch/French speaking participant volunteered in the segment).

3.2.1.1 Contact procedure

Participants selected to participate in the interviews received a phone call to confirm their willingness to participate and to set the date for the interview. Once they agreed, participants received the confirmation and informed consent form by e-mail. The e-mail included confirmation of practical details such as the scheduled time, date, and a direct link to access the meeting on Teams®. In a separate e-mail, they received the informed consent document as well as the information on how to sign it via Adobe® sign. Once signed by both parties (the participant and the researcher leading the interview), participants received another e-mail with a copy of the signed document.

If a selected candidate did not respond to three phone call attempts and e-mailing, or refused to participate, another candidate within the same segment was randomly selected. Non-selected candidates were informed on their status via e-mail to ensure transparency and communication regarding the selection process.

3.2.2 Qualitative data collection tool

3.2.2.1 Development of the interview guide

Generic interview guide

The interview guide used in the current chapter is based on the generic tool developed in the context of KCE Report 348.[95] The topics covered during the interviews were derived from KCE Report 344.[97]

Adaptations made for CD

Some parts of the generic interview guide were adapted to the disease-specific context, based on the main concerns reported by participants in the online survey and in the disease-specific literature review for CD.

Translation

The interview guide was initially developed in French and subsequently translated into Dutch by KCE researchers. A comparison of the two versions was carried out to ensure that both versions were identical in terms of structure and content. Subsequently, both versions were proofread by team members.

3.2.2.2 Final interview guide

The final interview guide is presented in the Appendix 4. The interview guide covers the following topics (disease-specific dimensions are identified by *):

- Symptoms*
- Impact of the disease*
- Patient journey leading to the diagnosis*
- Diagnosis and treatment*
- Encountered obstacles
- Information and support network
- Relationships with the medical profession
- Social and family relations

3.2.3 Qualitative data collection process

Participants were invited to take part in the interview via a secured teleconference. Although the participants had the option to request an in-person interview if they preferred, all interviews were conducted digitally.

Interviews were conducted via Teams© in French by a native French-speaking researcher (RVG) and in Dutch by a native Dutch-speaking researcher (JD) in summer 2023. Both researchers had experience in public health and in leading semi-structured interviews. The interviews lasted approximately one hour each. Each interview was recorded and transcribed verbatim by the research team. To ensure confidentiality and privacy, all names of participants, institutions, and care providers were anonymised in the research.

3.2.4 Qualitative data analysis

A qualitative thematic analysis of the interview transcripts using NVIVO® software was performed, which structured the collected information and facilitated the analysis by the researchers (see Appendix 4: Qualitative analysis code).

The coding process for the French-speaking material, which includes transcripts of interviews and responses to open questions in the online survey, was conducted by one native-speaking researcher (RVG). Simultaneously, the Dutch-speaking material was coded by another native-speaking researcher (JD). These two researchers collaborated closely to develop a shared nodes tree, which served as the structural foundation for reporting the research results.

3.3 Literature review

In addition to the primary data collection through a national patient survey and qualitative, semi-structured interviews, a secondary data collection process was initiated to enrich the NEED database and capture additional patient (e.g. mortality data, disability weights), societal and future unmet needs. This secondary data collection involved a pragmatic, non-systematic review of the literature, which was conducted between March 2023 and December 2023.

For each criterion included in the NEED assessment framework, we searched for data in online databases, published scientific literature (through PubMed and Google Scholar), and/or in the grey literature. We specifically focused our search primarily on Belgian data and if no data were available European data. Furthermore, we specified our literature search as much as possible on CD, however if no specific data on CD were found data on IBD in general were used. This should be taken into account when interpreting the results obtained from these data.

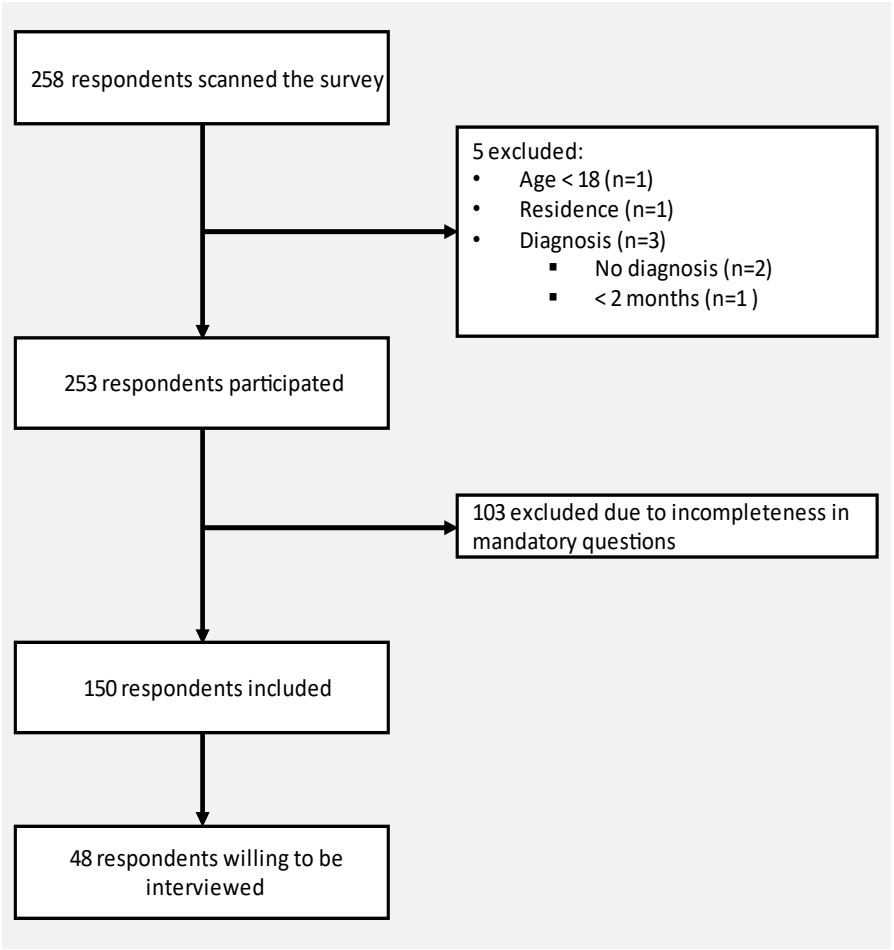
In PubMed, a restriction to systematic reviews and then to reviews was applied; if no reviews were identified the limitation was removed to yield primary studies. In PubMed, reference lists of relevant articles were screened, and the PubMed tabs "similar articles" and "cited by" were used. Data on life expectancy (years of life lost), the prevalence and incidence of CD were extracted from the GBD study. Evidence on the future incidence and prevalence of CD and on inequities in unmet needs was searched in the published literature through PubMed. Evidence on CD inequities were searched via Pubmed with key search terms "Social inequality" or "Inequity" or "Socioeconomic factor"[Majr], and "Crohn disease"[Majr] or "Inflammatory bowel disease"[Majr]. Information on comorbidities was searched for by using the key words "comorbidity"[MeSH Terms] and "Crohn disease"[Majr] or "Inflammatory bowel disease"[Majr].

Evidence on the value for money of standard of care, productivity losses and the future economic burden of CD were searched for using the key words "economic burden" or "productivity losses" or "cost of illness" or "return to work" and "Belgium" or "Europe" and "Crohn disease" or "Inflammatory bowel disease". Information on the environmental impact of the standard of care was searched for using the key words "environmental impact" and "Crohn disease" or "Inflammatory bowel disease".

4 RESULTS – UNMET PATIENTS NEEDS

Between May 2023 and June 2023, 258 individuals initiated the survey for CD. From this cohort, five participants did not meet the inclusion criteria, resulting in a cohort size of 253 eligible patients. Questionnaires without responses to a mandatory question were deemed incomplete and hence excluded from the analysis (n=103). Consequently, the final dataset included 150 respondents in total (Figure 2).

Figure 2 – Flow diagram of the respondents participating in the online survey



4.1 Description of participants

4.1.1 Surveyed participants

The survey sample consisted of 72.0% female participants. Geographically, Wallonia emerged as the most represented region, encompassing 48.7% of respondents. Among the provinces, Liège, East-Flanders, and Hainaut had the highest rates of participation. Linguistically, the French-speaking population constituted 56.7% of the respondents. The mean age of survey participants was 43.4 years (SD: 13.7); almost half were aged between 25 and 44 years, 36.0% were between 45 and 64 years old and only 2.7% were above 75 years old.

A substantial proportion of participants have higher levels of education, with 32.7% holding Bachelor's degrees, almost one quarter possessing a Master's or a Doctorate degree. More than three quarters (78.0%) reported being engaged in paid employment before their CD diagnosis, whereas 32.0% reported they were students prior to the diagnosis of CD. Around 2% had been unemployed and around 1% had been incapacitated before their diagnosis.

Regarding current occupation, one out of five respondents were not actively working due to factors such as disability, retirement, or unemployment. The overwhelming majority of participants (94.6%) completed the online questionnaire for themselves, while a minority (5.3%) responded on behalf of another adult (Table 4).

Table 4 – Demographic distribution of online survey participants (n=150)

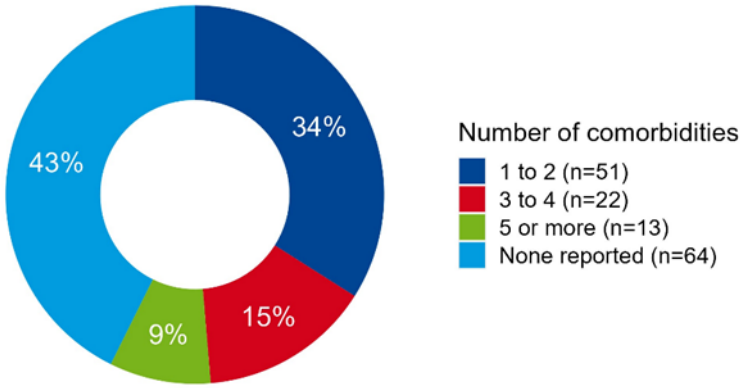
Variable		n (%)
Status of the respondent: completing the survey for		
	Themselves	142 (94.6)
	Another adult	8 (5.3)
Gender		
	Women	108 (72.0)
	Men	42 (28.0)
Language		
	French	85 (56.7)
	Dutch	65 (43.3)
Region		
	Wallonia	73 (48.7)
	Flanders	67 (44.6)
	Brussels	10 (6.7)
Province		
	Liège	40 (26.7)
	East Flanders	25 (16.7)
	Hainaut	16 (10.7)
	Limburg	14 (9.3)
	West Flanders	12 (8.0)
	Antwerp	11 (7.3)
	Walloon Brabant	11 (7.3)
	Brussels	10 (6.7)
	Flemish Brabant	5 (3.3)
	Luxembourg	5 (3.3)
	Namur	1 (0.7)
Age group (in years)		
	18-25	9 (6.0)
	25-44	74 (49.3)

45-64	54 (36.0)
65-74	9 (6.0)
≥75	4 (2.7)
Paid work before diagnosis	
Yes	117 (78.0)
Occupation just before diagnosis	
Employee	52 (34.7)
Worker	36 (24.0)
Disabled	2 (1.3)
Retired	0
Student	48 (32.0)
Self-employed	4 (2.7)
Unemployed	3 (2.0)
Other	5 (3.3)
Occupation today	
Employee	54 (36.0)
Worker	45 (30.0)
Disabled	15 (10.0)
Retired	14 (9.3)
Student	10 (6.7)
Self-employed	6 (4.0)
Unemployed	2 (1.3)
Other	8 (5.3)
Highest level of education	
*Lower level of education**	56 (37.3)
*Higher level of education***	86 (57.3)
*Other diploma****	8 (5.4)

** No diploma or primary education, Lower secondary education, Upper secondary education; **Bachelor's, master's, or doctoral degree; *** Other diploma, Not sure*

Most participants (57.3%) reported having at least one comorbidity and roughly a quarter of them reported having more than two (Figure 3). The four most frequently reported comorbidities were disorders of the musculoskeletal system (30.0%), skin diseases (18.0%), digestive tract diseases (14.7%) and mental health disorders (12.0%).

Figure 3 – Number of comorbidities among the participants with CD (n=150)



4.1.2 Interviewed participants

Out of the 150 patients included in the study, 48 patients expressed their willingness to participate in an interview. Ultimately, 20 interviews were conducted, with 35% being Dutch-speaking and 65% French-speaking. The majority of participants (60%) in the interviews were female (Table 5).

Table 5 – Description of interview participants with CD (n=20)

ID	Language	Gender	Age category (years)	Time since diagnosis	Surgery due to CD
1F1	FR	F	20-29	2 to 6 months	No
2F1	FR	F	40-49	5 to 10 years	No
2F2	FR	M	30-39	> 10 years	No
2F3	FR	F	40-49	> 10 years	No
2F4	FR	F	40-49	> 10 years	No
2F5	FR	F	30-39	5 to 10 years	No
3F1	FR	M	30-39	> 10 years	Yes
3F2	FR	F	40-49	5 to 10 years	Yes
3F3	FR	F	30-39	> 10 years	Yes
4F1	FR	F	50-59	> 10 years	No
4F2	FR	F	50-59	> 10 years	No
5F1	FR	M	50-59	5 to 10 years	Yes
5F2	FR	M	60-69	> 10 years	Yes
2N1	NL	M	20-29	> 10 years	No
2N2	NL	M	30-39	>10 years	No
3N1	NL	F	30-39	> 10 years	Yes
4N1	NL	F	60-69	> 10 years	No
4N2	NL	F	60-69	> 10 years	No
5N1	NL	M	60-69	> 10 years	Yes
5N2	NL	M	50-59	> 10 years	Yes

FR: French-speaking; NL: Dutch-speaking; F: Female; M: Male

4.2 Unmet health needs

4.2.1 Impact on general health-related quality of life (HRQoL)

CD increased the proportion of slight, moderate and severe health problems in all EQ-5D-5L dimensions

The assessment of the impact of CD on patients' general HRQoL was based on their self-reported problems on the EQ-5D-5L before and after the onset of their CD (see Appendix 2: Survey). The statistically significant reduction in EQ-5D-5L utility score (see section 3.1.4 – Quantitative Quantitative data analysis) from 0.85 (95% CI: 0.82; 0.88) to 0.70 (95% CI: 0.67; 0.74) (mean beta: -0.15; 95% CI: -0.20; -0.10; p<0.0001) signifies a decline in HRQoL due to CD (Table 6).

For all dimensions, the proportion of respondents with health problems increased after the onset of CD. This increase is important for four out of five dimensions: difficulties to perform usual activities (+55.3% points), pain/discomfort (+46.0% points), mobility (+34.7% points), anxiety/depression (+30.0% points), while it is more restricted for the self-care dimension (+10.6% points).

Across the different quality of life dimensions, a shift from patients with no problems before onset of the first CD symptoms to slight, moderate or severe problems today can be observed.

The highest increase in number of individuals reporting severe problems today concerned the ability to carry out usual activities (+9.4% points) and anxiety/depression (+4% points). For all EQ-5D-5L dimensions, a limited proportion of participants reported extreme problems today (Table 7; Figure 4).

Table 6 – EQ-5D-5L utility score before and after the diagnosis of CD

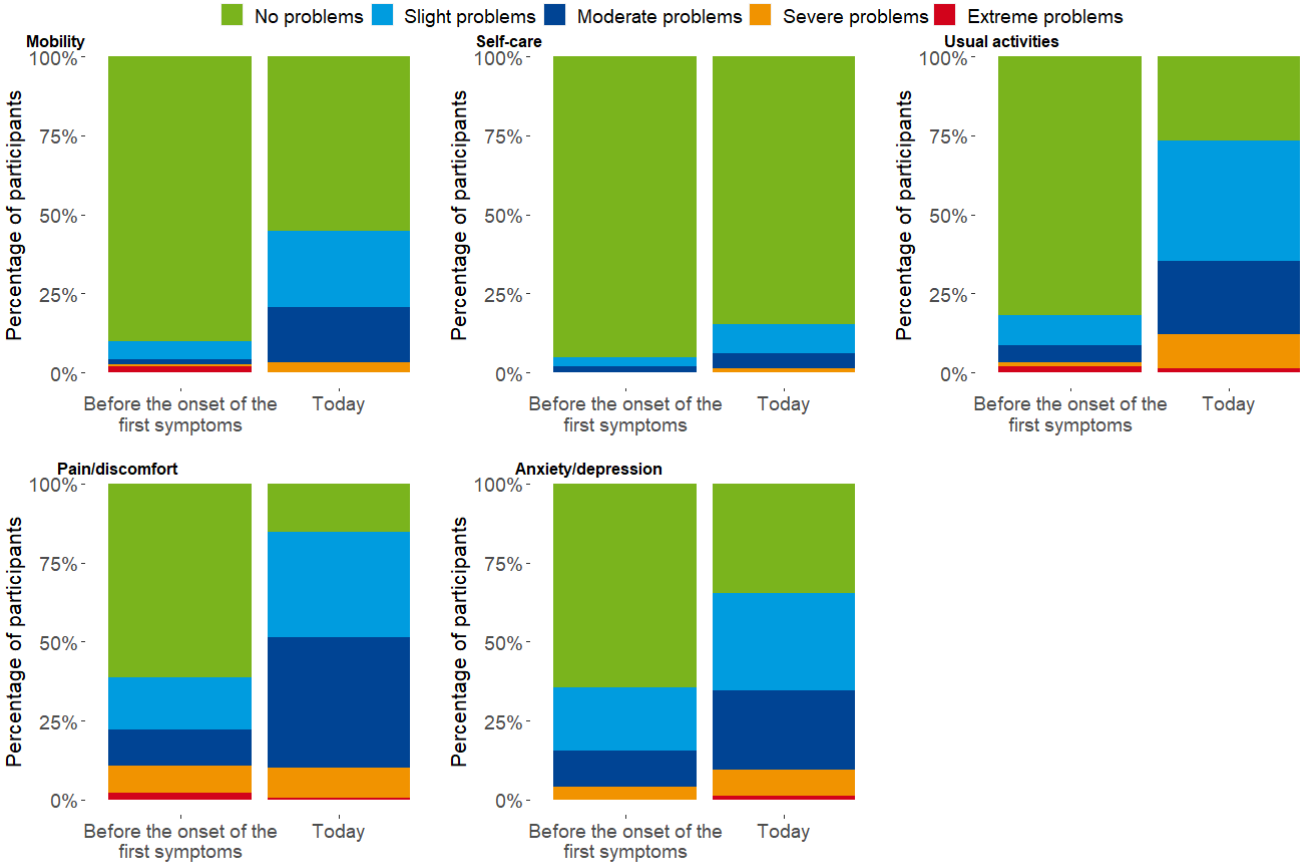
Variable	Mean	SD	95% CI	p-value
EQ-5D-5L before	0.85	0.20	0.82;0.88	
EQ-5D-5L after	0.70	0.22	0.67;0.74	
Beta[1]	-0.15	0.30	-0.20;-0.10	

*[1]Beta= [EQ-5D-5L after] – [EQ-5D-5L before]; New Belgian tariffs have been used to valuate the individual scores obtained with EQ-5D-5L tool [96]; *Paired t-test total before-after: p<0.0001; SD=Standard Deviation; CI=Confidence Interval*

Table 7 – Change in the self-reported level of problems on each EQ-5D-5L dimension before onset of first symptoms of CD and today (n=150)

Level of problems	Today-Before (% points) Mobility	Today-Before (% points) Self-care	Today-Before (% points) Usual Activities	Today-Before (% points) Pain/discomfort	Today-Before (% points) Anxiety/depression
No problems	-34.7	-10.6	-55.3	-46.0	-30.0
Slight problems	+18.0	+6.6	+28.7	+16.7	+10.7
Moderate problems	+15.3	+2.7	+18.0	+30.0	+14.0
Severe problems	+2.0	+1.3	+9.3	+0.7	+4.0
Extreme problems	-0.7	0.0	-0.7	-1.3	+1.3

Figure 4 – Self-reported level of problems on each EQ-5D-5L dimension before the onset of first symptoms of CD and today (n=150)



Based on univariate regressions, it appears that two factors impact the change in EQ-5D-5L utility score, the region of residence and the number of flares in the last years. The region of residence has a significant impact on the change, with patients living in Wallonia having a difference in score on average 0.10 ($p < 0.05$) higher than patients living in Flanders. The number of flare-ups also has a strong link with the change in EQ-5D-5L utility score, in particular for individuals that report to have had three or more flares in the last year. On average, patients who report to have three or more flare-ups see a decrease of 0.23 on their EQ-5D-5L utility score.

In the literature no Belgian data on HRQoL (e.g. EQ-5D-5L, EQ-5D-3L) was reported for individuals suffering from CD. A study using Danish data from 2010-2013 reported an average EQ-5D-3L score of 0.744 for patients living with CD.[98] A Finnish study that collected HRQoL data in 2000-2001 to evaluate the impact of chronic conditions reported a similar average score of 0.742 for patients suffering from IBD.[99]

Impact on emotional and sexual life

Emotional and sexual life is another dimension of social relations that patients highlighted as problematic during the interviews. Given the symptoms of CD, it is not always easy for patients to thrive in their sexual life. The impact of difficulties in leading a sexual and sentimental life due to CD can go as far as to the deliberate choice not to have children.

> *"For example, sexually as well. So if you sleep somewhere else now, because you have no control over your anus, in my case, and you go to sleep somewhere, or with someone, or in a hotel or whatever. So, in your head, knowing that you are not at home, if you encounter that at home, it's not a problem, you clean it up and it's... That you try to cover up. That's not easy. Sexually, it's the same thing. It's not... so logical for someone who suddenly loses their bowel movements, that's not... You can't just flip a switch, and that's not easy. And if you do enter into new relationships, how do you explain it?" (5N1)[1]*

> *"We don't talk about sexuality either, so it sounds really silly, but uh... It's something very embarrassing from the moment you have fistulas, from the moment you don't control yourself and you have... Loss of stool or things like that, well I mean in terms of intimacy, and that's something I've never talked about." (3F2)[2]*

> *"Because hey, when you have a pouch, when you have an ostomy, you're scared of sex too, and you have to think about all that." (4F2)[3]*

> *" The decision not to have children, even though that was my wish, is a consequence of that. Later in life, when I was already in my mid-40s, I realized that low self-esteem was part of it, I also thought, who would ever want someone with such a disease in a new relationship ? " (4N2)[4]*

Associated comorbidities

Seventy-five percent of respondents reported health conditions that may be associated with CD

Among the surveyed individuals, 112 respondents (74.7%) disclosed on average one condition that may be associated with CD. Further analysis indicated that 48.7% of the participants reported chronic fatigue and 46.7% of participants reported joint inflammation(s). Additionally, 24.7% of the cohort acknowledged the presence of a fistula. Only a fifth of respondents (n=29) indicated to have no health conditions associated with CD (Table 8).

Symptoms such as joint pain were also mentioned by the patients interviewed.

> *"I don't just say because I also have a lot of rheumatological problems. And finally, spondylitis has now come out as well. So I explain that in such a way that I also have very diverse complaints. Not just gut-related." (2N1)[5]*

Respondents who received surgery reported more frequently health conditions that may be associated with CD

Almost a quarter of the survey respondents indicated that they had undergone surgery (24.0%). This subgroup reported health conditions associated with CD more frequently (94.4%) than patients who had not undergone surgery (68.4%) and this difference was statistically significant (p<0.01). Patients who had undergone surgery (17/36) reported more frequently to have a fistula compared to patients who had not undergone surgery (surgery 47.2% versus no surgery 16.8%, p<0.01) (Table 8).

Table 8 – Conditions that may be associated with CD, by surgery (n=149)

Symptoms	Surgery n=36 n (%)	No surgery[1] n=113 n (%)	p-value	Total n (%)
Patients with conditions that may be associated with CD	34 (94.4)	78 (68.4)	**	112 (75.2)
Chronic fatigue	23 (63.9)	50 (44.2)	NS	73 (49.0)
Joint inflammation(s)	21 (55.6)	49 (43.4)	NS	70 (46.7)
Diseases of the liver and/or bile ducts	6 (16.7)	14 (12.4)	NS	20 (13.3)
Skin lesions	4 (11.1)	15 (13.3)	NS	19 (12.7)
Eye manifestations	2 (5.6)	9 (8.0)	NS	11 (7.3)
Osteoporosis	3 (8.3)	8 (7.1)	NS	11 (7.3)
None	1 (2.8)	28 (24.8)	**	29 (19.5)
I don't know	2 (5.6)	13 (11.5)	NS	15 (10.1)

** Fisher's exact test, NS=Not significantly different, * p-value <0.05, ** p-value <0.01, *** p-value <0.001; [1]One respondent did not indicate the treatment status and was excluded;*

Years of life lived with disability (per case)

In 2013, the GBD study assessed the disability weights for a set of 255 health states, of which symptomatic IBD was one of them, this resulted in a disability weight of 0.231 [0.156 – 0.320] for symptomatic IBD.[100] The GBD study in 2019 reported an age standardized rate of 21.45 [14.24 – 30.70] years of life lost due to disability (YLD) per 100 000 for inflammatory bowel diseases in Belgium. In Europe a rate of 21.03 [14.10 – 28.87] YLD per 100 000 was reported.[6]

4.2.2 Impact on physical health

The three most frequent reported physical symptoms related to CD were diarrhoea, fatigue or exhaustion, and cramps

Almost all respondents (n=149) reported current or past physical symptoms related to CD. Most participants (87%) reported having more than four physical symptoms. Physical symptoms that were reported in more than 40% of respondents were diarrhoea (87.3%), fatigue or exhaustion (80.7%), cramps (75.3%), lack of energy (71.3%), urgency or stool urge (70.0%), joint pain or inflammation (58.7%), continuous abdominal pain (49.3%), dry painful or itchy skin or rash (45.3%), anal pain (44.0%), weight loss (42.7%), nausea or vomiting (42.0%), and headache (41.3%) (Figure 5;Table 9).

Figure 5 – Frequency of physical symptoms reported by respondents with CD (n=150)

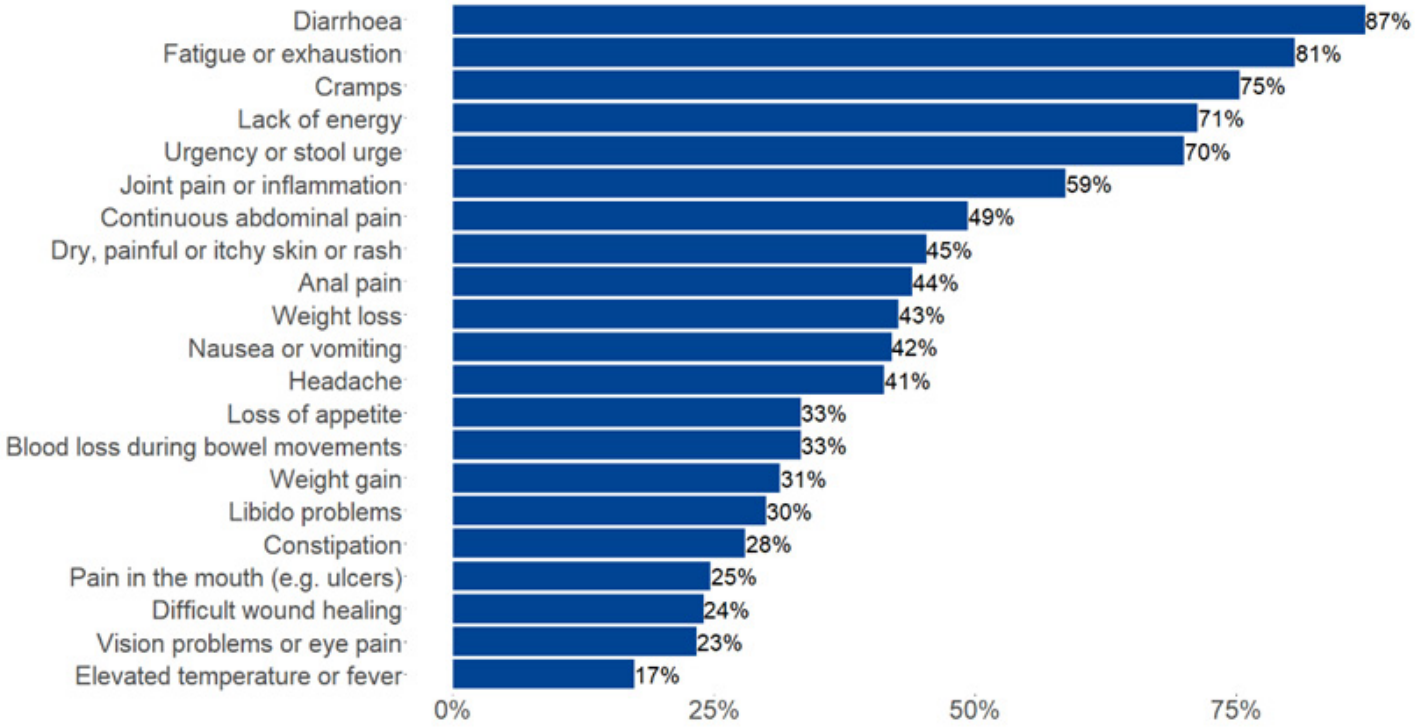


Table 9 – Distribution of the reported physical symptoms by level of burden (n=150)[1]

Physical symptoms	Symptom frequency n (%)	Reported burden n (%)			
		Not at all burdensome	Slightly burdensome	Rather burdensome	Very burdensome
Diarrhoea	131 (87.3)	0	13 (10.0)	44 (33.8)	73 (56.2)
Fatigue or exhaustion	121 (80.7)	0	6 (5.0)	45 (37.5)	69 (57.5)
Cramps	113 (75.3)	0	7 (6.2)	48 (42.9)	57 (50.9)
Lack of energy	107 (71.3)	0	6 (5.7)	44 (41.5)	56 (52.8)
Urgency or stool urge	105 (70.0)	0	9 (8.7)	25 (24.0)	70 (67.3)
Joint pain or inflammation	88 (58.7)	0	15 (17.2)	36 (41.4)	36 (41.4)
Continuous abdominal pain	74 (49.3)	0	1 (1.4)	32 (43.2)	41 (55.4)
Dry, painful or itchy skin or rash	68 (45.3)	2 (2.9)	20 (29.0)	31 (44.9)	15 (22.1)
Anal pain	66 (44.0)	1 (1.5)	11 (16.9)	22 (33.8)	31 (47.7)
Weight loss	64 (42.7)	9 (14.3)	27 (42.8)	15 (23.8)	12 (19.0)
Nausea or vomiting	63 (42.0)	0	9 (14.3)	29 (46.0)	25 (39.7)
Headache	62 (41.3)	0	5 (8.2)	39 (63.9)	17 (27.9)
Blood loss during bowel movements	50 (33.3)	3 (6.1)	16 (32.7)	17 (34.7)	13 (26.5)
Loss of appetite	50 (33.3)	1 (2.0)	20 (40.0)	20 (40.0)	9 (18.0)
Weight gain	47 (31.3)	0	4 (8.5)	18 (38.3)	25 (53.2)
Constipation	42 (28.0)	1 (2.4)	7 (16.7)	17 (40.5)	17 (40.5)
Pain in the mouth due to, for example, ulcers	37 (24.7)	1 (2.7)	11 (29.7)	15 (40.5)	10 (27.0)
Difficult wound healing	36 (24.0)	1 (2.8)	10 (27.8)	19 (52.8)	6 (16.7)
Vision problems or eye pain	35 (23.3)	0	8 (22.2)	14 (38.9)	13 (37.1)
Elevated temperature or fever	26 (17.3)	1 (4.0)	5 (20.0)	13 (52.0)	6 (24.0)

During the interviews, respondents stated that they were not always sure about the origin of the symptoms they experienced, i.e. whether their symptoms were related to CD or not. For instance, they did not know if CD is the cause or the consequence of their symptoms or if these symptoms are related to treatment side-effects.

> *"Well, I don't know if it's due to Crohn's disease, the [TNF inhibitor] treatment, and there's also obviously the antibiotic that I'm getting by injection that can also give fatigue and muscle aches so uh... all in one, I don't know if it's Crohn's or not, but I do know that Crohn's was still very tiring." (5F2)[6]*

> *"Until now actually that I'm starting to have other symptoms, it's actually neuropathy, damage to the nerves somewhere that they're still investigating right now, so, so far I've actually been very good, my intestines were also very good, but unfortunately then there are other things that come up." (3N1)[7]*

> *"So then the difficulty for me is that I have both Crohn's disease and irritable bowel syndrome and so there are things, sometimes it's a little... Is it the chicken or the egg, it's complicated. But I think I have more symptoms due to irritable bowel that can be a little unpleasant. But Crohn's, frankly I think the drug does its job well and so, uh... I don't have a period of diarrhoea, or that's it, no." (4F1)[8]*

The majority of survey respondents experienced a flare-up during the last year

A total of 94 respondents (62.7%) reported to have experienced at least one flare-up during the last year. A flare-up signifies a period marked by heightened inflammation and exacerbated symptoms in the gastrointestinal tract. From the interviews, it appeared that these symptoms commonly included abdominal pain, diarrhoea, and fatigue. Among those who had experienced a flare-up, over half (52/94) reported having one or two flare-ups in the last year. In 10.7% of the entire cohort, a flare-up persisted for the entirety of the year (Table 10).

Table 10 – Number of flare-ups reported by survey participants during the last year (n=150)

	n (%)
Yes	
1 - 2 flares	52 (34.7)
≥ 3 flares	26 (17.3)
Flare that lasted all year	16 (10.7)
No flares	51 (34.0)
I don't know	5 (3.3)

One out of five respondents was experiencing a flare-up at the time of participating in the survey

Within the timeframe of the survey, 28 respondents (18.7%) reported experiencing a flare-up (Table 11).

Table 11 – Flare-up status of survey participants at time of participating in the survey (n=150)

	n (%)
No	116 (77.3)
Yes	28 (18.7)
I don't know	6 (4.0)

Flare-ups as very painful and constraining episodes

Flare-ups are described by the interviewed patients as very painful and constraining episodes that are very difficult to control. During a flare-up pain is described as very intense. The patient may be unable to drink even a drop of water, to carry out a professional/student activity or simply do anything other than go to the toilet. Besides the intensity of the flare-ups, the frequency and length (up to several weeks) were also signalled by the interviewees.

"With the pain that it is... It's unmanageable actually. People don't realize what it's like to be on the toilet for two hours. We get up "oh no, I have to come back" with terrible cramps, or when it had reached my oesophagus, for three weeks I didn't even know how to drink a drop of water. A drop of water did not pass." (2F1)[9]

"Of course, you can't do much during a crisis, then, standing up for ten minutes is actually a long time, I thought it was a while ago, but I can still remember it well, then it's actually constantly walking to and from the toilet." (3N1) [10]

Although these symptoms were not directly captured in the survey, the interviews highlighted other existing symptoms, such as fever flare-ups or mouth ulcers that prevent patients from eating.

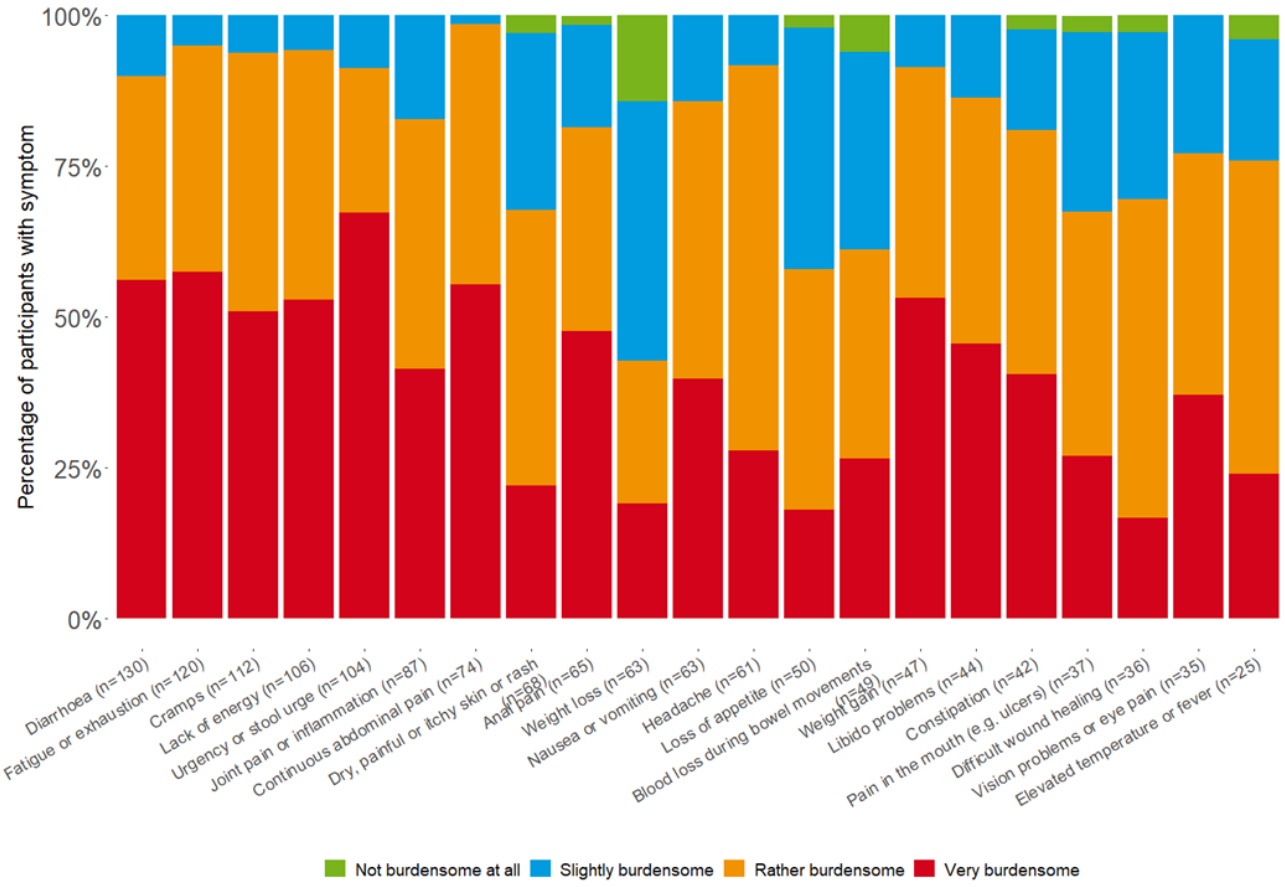
"I started having pain in my iliac fossa, diarrhoea, vomiting, fever, and finally a classic flare-up." (2F3) [11]

"I had a little bit of pain in my duodenum as a result, and so he gave me [name antispasmodic] and he said, 'It's going to pass, 'Don't worry!' and then it went on like that for months and then at some point I had a huge attack of haemorrhoids that I couldn't walk anymore and canker sores in my mouth. I didn't know how to eat anymore. My cheek had swollen, I looked like a hamster." (1F1)[12]

Continuous abdominal pain was the most (rather or very) burdensome symptom

For each reported symptom, respondents indicated how burdensome they felt it was. Among the reported physical symptoms, continuous abdominal pain was qualified as the most burdensome symptom by the respondents who experienced this symptom (47/150). Notably, 98.6% of participants expressed that this symptom was very or rather burdensome. The symptoms that were most frequently considered to be very burdensome were stool urgency (experienced by 70.0% of the participants), fatigue or exhaustion, (experienced by 80.7% of the participants) and diarrhoea (experienced by 87% of the participants).

Figure 6 – Level of burden of the reported physical symptoms (n=150)[1]



[1] The graph is ordered by frequency (leftmost highest frequency). One respondent did not report the level of burden for the following physical symptoms: Diarrhoea, Urgency or stool urge, Blood loss during bowel movements, Anal pain, Cramps, Weight loss, Joint pain or inflammation, Elevated temperature or fever, Headache, Lack of energy, Fatigue or exhaustion and was excluded.

In the Pain/Discomfort dimension of the EQ-5D-5L, individuals with CD reported a notable increase in pain and discomfort today. The percentage of participants reporting "No problems" category today decreased by 46.0% points compared to before the onset of first CD symptoms, which signifies a substantial elevation in pain or discomfort levels following the onset of CD symptoms. Furthermore, the percentage of individuals reporting "Slight problems" today increased by 16.6% points compared to before the onset of first symptoms, indicating an increase in slight pain or discomfort (Table 12). Changes in the distribution of self-reported level of problems with pain/discomfort before the onset of first CD symptoms and today can be observed from Figure 7.

Table 12 – Change in the self-reported level of problems on the dimension pain/discomfort of the EQ-5D-5L before onset of first CD symptoms and today (n=150)

Level of problems	Before (%)	Today (%)	Difference (% points)
No problems	61.3	15.3	- 46.0
Slight problems	16.7	33.3	+16.7
Moderate problems	11.3	41.3	+30.0
Severe problems	8.7	9.3	+0.7
Extreme problems	2.0	0.7	- 1.3

Figure 7 – Changes in self-reported level of problems with pain/discomfort of the EQ-5D-5L before onset of first CD symptoms and today (n=150)

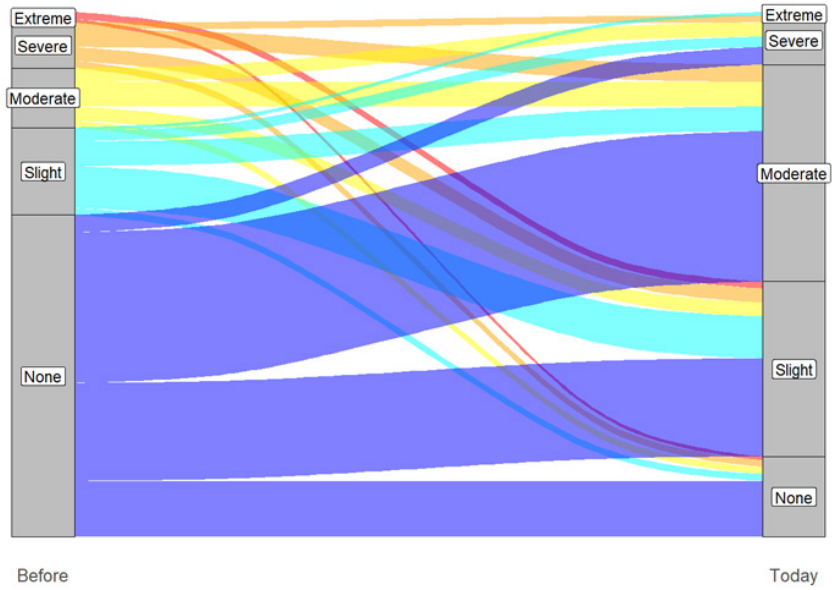
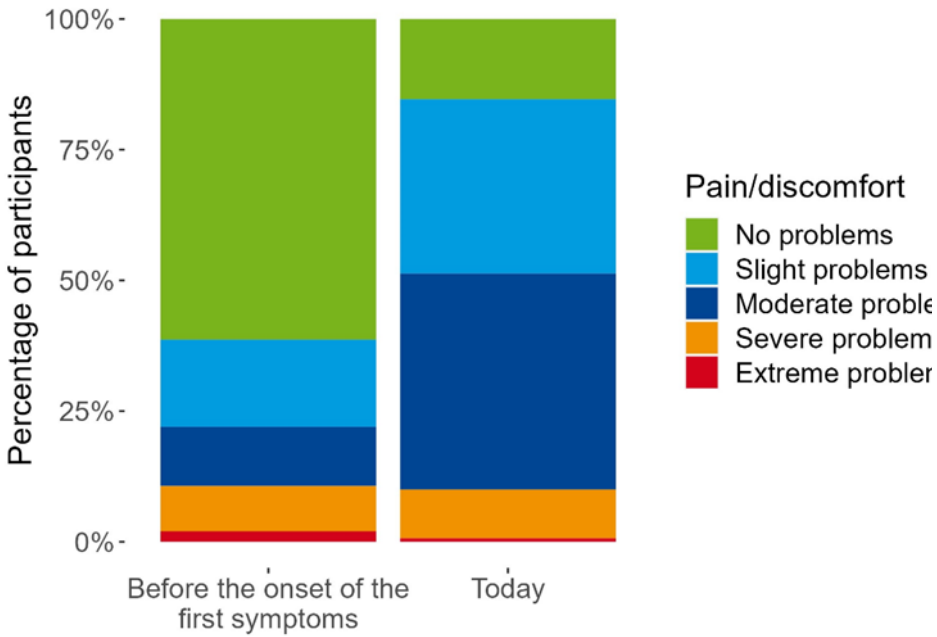


Figure 8 – Distribution of self-reported level of problems with pain/discomfort of the EQ-5D-5L before onset of first CD symptoms and today (n=150)



The qualitative analysis gives insights into *how* these symptoms impact patients' physical health. The impact of diarrhoea and cramps, and of nausea or vomiting, were explained during the individual interviews with patients. Patients described the severity of their symptoms and their consequences, in particular the need to spend long hours in the restroom.

> *"It was big, big cramps in my abdomen. Vomiting all day long." [...] "So I had the symptoms of pain, I had the symptoms of bloating, I had the symptoms of vomiting, I had the symptoms of going to the toilet very regularly, I had this fistula there as well." (3F1)[13]*

> *" I have to say, I was diagnosed in 2011, but actually since I was 16 years old I have had intestine problems on and off, so I also knew, there had to be something wrong. " (3N1)[14]*

> *"So I was going to the bathroom very, very, very regularly, and I was bleeding. So at first we thought it was gastroenteritis, which was a regular occurrence. But I was in pain... well, incredible. I was very tired. I couldn't sleep. And it went on like that for months." (3F3)[15]*

The impact of fatigue, reported by more than 80% of survey respondents, was also specified during the interviews. Intense fatigue and a permanent state of weakness was reported, which requires more rest thereby impacting daily activities (e.g. driving).

> *"I used to take long naps, spend a lot of time on the couch, and I kept telling my mom all the time 'I'm incubating something, I don't know what', and I didn't have a fever, but I felt my brain heating up, really. I felt there was inflammation but I didn't have a fever." (2F5)[16]*

> *"Been home for a week, and I found the fatigue very heavy, I would always sleep and sleep and at one point I said, I have to get over it." (2N1)[17]*

Weight loss which was reported as a symptom by 42.7% of survey participants, was also reported during the interviews.

> *"That was the first time I didn't really know I had it, and then I had lost ten kilos, I wasn't well at all and then I was hospitalized. I had lost ten kilos at the time, dehydrated. Then I was actually in the hospital for ten days." (2N1)[18]*

4.2.3 Impact on psychological health

The three most frequently reported psychological symptoms related to CD were stress, fear or anxiety, and feeling down, depressed or sad.

Overall, 72% of participants reported suffering from at least one psychological symptom, and most (57.3%) reported more than one.

Psychological symptoms that were reported by more than 30% of respondents were stress (47.3%), fear or anxiety (43.3%), feeling down, depressed or sad (41.3%), feelings of restlessness, nervousness or irritability (39.3%), mood swings (30.7%), and anger or aggressiveness (29.3%) (Figure 9).

Figure 9 – Frequency of psychological symptoms reported by respondents with CD (n=150)

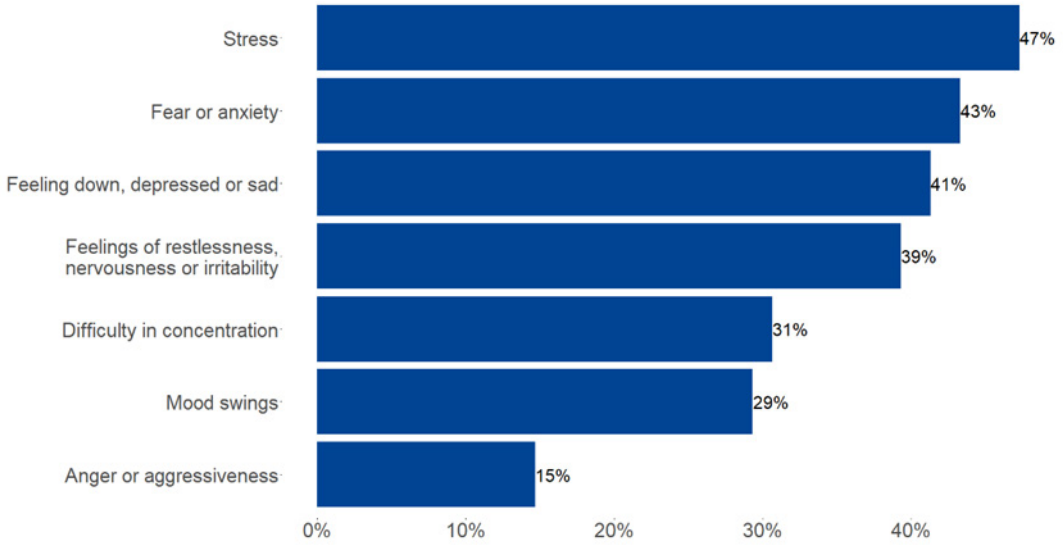


Table 13 – Distribution of the reported psychological symptoms by level of burden (n=150)

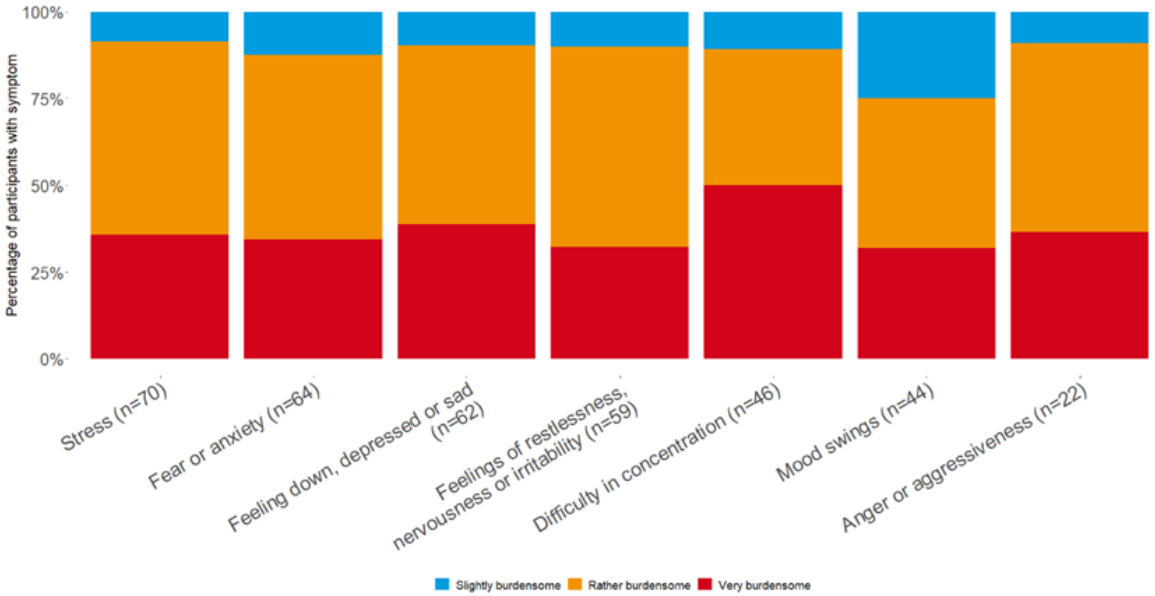
Psychological symptoms	Symptom frequency n (%)	Reported burden n (%)			
		Not at all burdensome	Slightly burdensome	Rather burdensome	Very burdensome
Stress	71 (47.3)*	0	6 (8.6)	39 (55.7)	25 (36.7)
Fear or anxiety	65 (43.3)*	0	8 (12.5)	34 (53.1)	22 (34.4)
Feeling down, depressed, or sadness	62 (41.3)	0	6 (9.7)	32 (51.6)	24 (38.7)
Feelings of restlessness, nervousness or irritability	59 (39.3)	0	6 (10.2)	34 (57.6)	19 (32.2)
Difficulty in concentrating	46 (30.7)	0	5 (10.9)	18 (39.1)	23 (50.0)
Libido problems	45 (30)*	0	6 (13.6)	18 (40.9)	20 (45.5)
Mood swings	44 (29.3)	0	11 (25.0)	19 (43.2)	14 (31.8)
Anger or aggressiveness	22 (14.7)	0	2 (9.0)	12 (54.5)	8 (36.4)

** One respondent did not report the level of burden for the following psychological symptoms: stress, fear or anxiety, libido problems and was thus only included in "total"*

Stress was reported as being the most (rather or very) burdensome psychological symptoms.

Stress is the most burdensome psychological symptom reported (93.4%). It is noteworthy that all psychological symptoms were rated as "very" or "rather" burdensome by at least 75% of participants reporting these symptoms. The symptoms most frequently considered as very burdensome were: difficulty in concentrating and libido problems. The level of psychological distress is higher in comparison to the burden of the physical symptoms, which had a minimum rating of 42% (Figure 10).

Figure 10 – Level of burden of the reported psychological symptoms (n=150)[1]



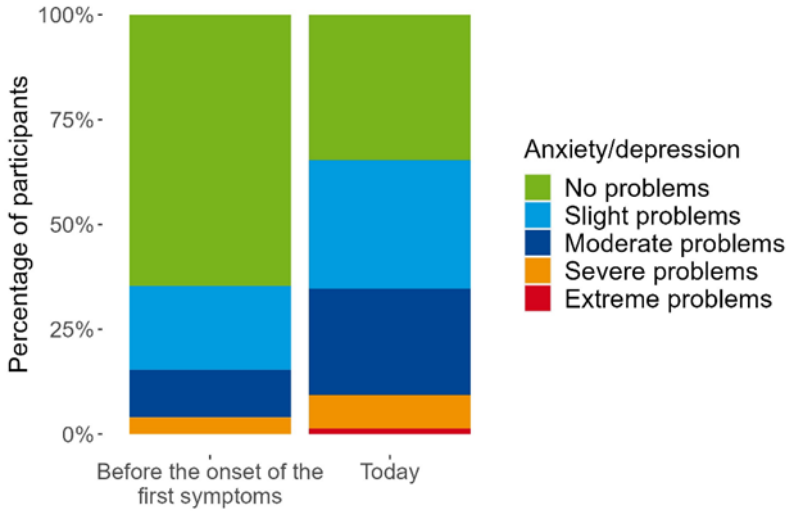
[1]*One respondent did not report the level of burden for th*e following *psychological* symptoms: stress, fear or anxiety, libido problems and was excluded; *the graph is ordered by frequency (leftmost highest frequency).*

The anxiety/depression dimension of the EQ-5D-5L demonstrated a substantial increase in emotional distress among individuals with CD. The "No problems" category decreased by 30.0% points, this indicates a significant rise in anxiety or depression following the diagnosis of CD. Additionally, both the "Slight problems" and "Moderate problems" categories show increases, indicating heightened levels of anxiety or depression (Table 14).

Table 14 – Changes in the distribution of self-reported level of problems on the dimension "anxiety/depression" of the EQ-5D-5L before onset of first CD symptoms and today (n=150)

Level of problems	Before (%)	Today (%)	Difference (% points)
No problems	64.7	34.7	-30.0
Slight problems	20.0	30.7	+10.7
Moderate problems	11.3	25.3	+14.0
Severe problems	4.0	8.0	+4.0
Extreme problems	0.0	1.3	+1.3

Figure 11 – Distribution of self-reported level of problems on the dimension anxiety/depression of the EQ-5D-5L before onset of first CD symptoms and today (n=150)



Patients reported that it is not always easy to accept the disease and live with it daily. Sickness leads to feelings of being depressed about their general state of health. They would simply like to live the life they wish.

> *" Psychologically, living with a continuous illness and pain, I don't always find it easy. And sometimes I think, you know, if you have cancer, you get support. That's very important, including psychological support. But for other chronic conditions, that's not always the case, even though it also has a huge impact on your life." (2N1)[19]*

> *"In fact, the vicious cycle between having this disease, and it depresses, and actually you're depressed because you're not well, but you're also not well because you're depressed... So this vicious cycle with mental health, very complicated to live with." (2F5)[20]*

> *"I say, 'I don't need people to feel sorry for me. I don't need a therapist' And in the end, I do ! Psychological support is needed. I didn't want to, but now it feels really, really good, and I should have done it all along. But it was also the whole context, the announcement of the illness, the fact that I wasn't well, there were all these treatments that are so heavy and tiring, it wasn't going well at work. Frankly, I admit I didn't want to... I was depressed, yes, yes." (2F1)[21]*

In interviews, patients highlighted the psychological impact related to the lack of visible physical symptoms. The fact that the disease is invisible affects patients psychologically, as they feel less legitimate in dealing with it.

> *"Yes, I sometimes have a bit of a hard time with it, because people don't see it, so you can have a lot of problems with an appearance, someone can say to you, you look good, while you actually know that you really don't feel well, that you have cramps, or you have to constantly walk to the toilet, Or indeed you are very tired, sleep badly, people don't see it, it's an invisible disease." (3N1)[22]*

> *"Physically, it's not visible when we're not feeling well, so it's not like having a broken arm or a cast on your foot, people don't see it and so it's like 'stop complaining'. We're in pain, we turn white because of the pain, but people don't realize it. So no, the people around us don't understand". (3F2)[23]*

Because of the invisible aspect of the disease, patients expressed the need to show their illness more to their loved ones (e.g., by giving self-injections in public) so that they become aware of the real aspect of the illness.

> *"I don't necessarily hide it either. In fact, sometimes I do it on purpose with my family. I inject [name TNF inhibitor] in front of everyone. Which disgusts my children obviously, but sometimes I feel like it's necessary for them to understand. It's silly, isn't it? But I do it in the thigh when it's like that, but hey, I change my injection site every 15 days, but every once in a while I don't hide to do it. To show that, well, yes, I have something. So yes there is a little problem of legitimacy with the disease, yes. (2F4)[24]*

The stress described by the patients interviewed also stems from fear of seeing the disease progress (e.g. new flares) or of their condition deteriorating over time.

> *"Well, actually, it's still something, I always feel like ... yes, the image of having a sword of Damocles hanging over your head." (2F3)[25]*

> *"Well, there were periods that I think were too short, unfortunately, where I was able to rest physically and psychologically because things were getting better, but in the end you're never at ease." (3F2)[26]*

> *"I went to a psychologist once. Then I didn't like it at all. I could hardly wash my hands, that pain, everything I touched. And I knew it was irreversible. And it may have worsened, too." (4N1)[27]*

Interviewed patients highlighted the psychological impact that embarrassing situations can have, as CD can lead to socially awkward situations (e.g. uncontrolled bowel movements). Patients testified that they were not psychologically prepared to deal with such situations.

> *" ... In my case, anus is no longer in control. And you're going to sleep somewhere, or at someone's house, or at a hotel, or whatever. So, knowing in your head that you're not at home, if you encounter that at home that's not a problem, you clean that up and it's... That you try to cover that. That's not easy, is it? " (5N1)[28]*

> *"I went for a walk, I had just eaten, and now, fortunately, it was in the woods but... Then a little accident and then I wasn't ready psychologically. And it's silly because we tell ourselves it can happen to anyone in fact but, yes it still has a psychological impact." (1F1)[29]*

> *" I always have to have a toilet within reach. So every time I go, a shop, ah there's a toilet, a city, in that shop, I can go there. So in the back of my mind, because if I have to go, I have to go. So at that time there were such thick sanitary pads, those pants, diaper pants, that didn't exist back then. So yes, I was always insecure. " (4N1)[30]*

In the literature, patients indicated that little attention was paid to the psychological aspect of CD, especially right after receiving the diagnosis and subsequent clinical encounters. A recent Belgian study reported a perceived **lack of psychological support** through patient interviews.[101] Furthermore, a systematic review on psychological symptoms showed that anxiety (18-35%) and depression (20-34%) are common psychological symptoms in CD.[102] However, these symptoms may remain unaddressed in such cases where appropriate psychological support is lacking.

4.2.4 Impact on autonomy

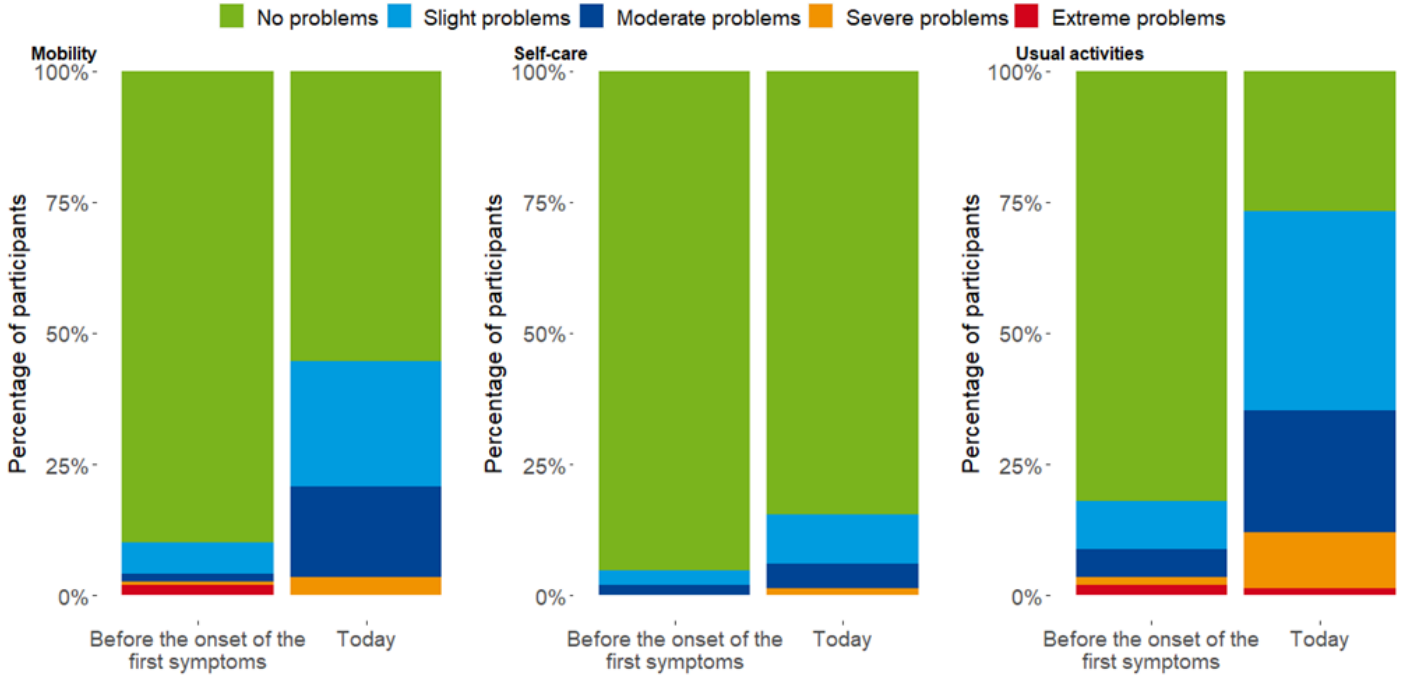
Individuals diagnosed with CD face notable challenges across several autonomy-related dimensions of the EQ-5D-5L, including mobility, self-care, and usual activities.

In terms of mobility, a 34.7% points reduction was observed in the percentage of individuals reporting "no problems" today compared to before the onset of first CD symptoms, indicating a substantial decrease in mobility levels. Conversely, the percentage of individuals reporting "slight problems" saw an 18.0% points increase, signifying a heightened prevalence of mild mobility issues. Similarly, in the "self-care" dimension, there was a 10.6% points decline in the percentage of individuals reporting "no problems", underscoring a decrease in individuals' ability to manage self-care tasks following the onset of CD. Furthermore, the percentage of individuals reporting "no problems" related to "usual activities" decreased by 55.3% points between today and before the onset of first CD symptoms, indicating a reduction in the capacity to carry out typical daily tasks. This was supported by a 28.7% points increase in the percentage of respondents reporting "slight problems" (Table 15).

Table 15 – Changes in the distribution of self-reported level of problems on the dimension 'autonomy" of the EQ-5D-5L before the onset of the first symptoms of CD and today (n=150)

Level of problems	Mobility			Self-care			Usual activities		
	Before (%)	Today (%)	Difference (% points)	Before (%)	Today (%)	Difference (% points)	Before	Today	Difference (% points)
No problems	90.0	55.3	-34.7	95.3	84.7	-10.7	82.0	26.7	-55.3
Slight problems	6.0	24.0	18.0	2.7	9.3	6.7	9.3	38.0	28.7
Moderate problems	2.0	17.3	15.3	2.0	4.7	2.7	5.3	23.3	18.0
Severe problems	1.3	3.3	2.0	0.0	1.3	1.3	1.3	10.7	9.3
Extreme problems	0.7	0.0	-0.7	0.0	0.0	0.0	2.0	1.3	-0.7

Figure 12 – Distribution of self-reported level of problems on autonomy-related dimensions of the EQ-5D-5L before the onset of the first CD symptoms and today (n=150)



In the literature, evidence was found about the impact of IBD on patients' daily life. An international survey among 4 670 IBD patients from 25 countries revealed that a third of IBD patients felt their intimate relationships were compromised, 25% felt it is difficult to maintain friends, 67% was concerned about the availability of toilets when planning to attend an event, and 40% woke up frequently due pain associated with their IBD.[42]

4.2.5 Impact on life expectancy

As described in the introductory chapter, the mortality rate of CD is considered low and primarily associated with complications and comorbidities that occur as a result of the disease. In Europe, the reported years of life lost (YLL) due to IBD are 18.85 [15.12 – 20.42] for Western Europe, 11.95 [10.00 – 13.79] for Central Europe and 14.46 [12.37 – 16.65] for Eastern Europe in 2019.[6]

Key points

- **The onset of CD increased the proportion of self-reported problems on all EQ-5D-5L dimensions. This increase was particularly important for the following dimensions: difficulties to perform usual activities (+55.3%), pain/discomfort (+46.0%), mobility (+34.7%), anxiety/depression (+30.0%).**
- **Most participants (87%) reported having more than four physical symptoms. The three most frequently reported physical symptoms were diarrhoea (87.3%), fatigue or exhaustion (80.7%) and cramps (75.3%). Less frequently reported was continuous abdominal pain (49.3%), but this symptom was qualified as the most burdensome symptom by survey respondents. Among participants who reported this symptom, 98.6% expressed that it was very or rather burdensome.**
- **The three most frequently reported psychological symptoms were stress (47.3%), fear or anxiety (43.3%) and feeling down, depressed, or sad (41.3%). Although all psychological symptoms were rated as very or rather burdensome by at least 75% of respondents, stress was considered the most burdensome psychological symptom. Among participants reporting this symptom, 93.4% qualified it as very or rather burdensome.**
- **In the interviews, patients described burdensome consequences of the symptoms: need to spend long hours in the restroom, permanent state of weakness, requiring frequent sleep and impacting everyday activities (e.g. driving). Such symptoms can also lead to embarrassing and socially awkward situations that have a psychological impact on patients. Additional psychological symptoms also have a strong impact on patients: patients feel less legitimate as the disease is not visible, patients are afraid to see the disease progress and their condition deteriorate.**
- **During the interviews and in the identified literature, patients reported a perceived lack of psychological support.**
- **The disability weight of symptomatic IBD is 0.231 [0.156 – 0.320] and the GBD study reported an age standardized rate of 21.45 [14.24 – 30.70] years of life lost due to disability (YLD) per 100 000 for inflammatory bowel diseases in Belgium.**
- **The mortality rate of CD is considered low and primarily associated with complications and comorbidities that occur as a result of the disease. No Belgian data regarding the mortality rate of CD were found in the literature.**

4.3 Unmet healthcare needs

4.3.1 Effectiveness of treatment

The literature shows that patients with CD have several unmet needs concerning their current treatment.[101] One of the most important needs expressed by patients, is the need for improved treatment or management of gastrointestinal symptoms. In line with our survey results, other studies have described that gastrointestinal symptoms profoundly impact patients' HRQoL, psychological well-being, and social life. The **inadequate control of gastrointestinal symptoms** is linked to reduced energy and fatigue, stemming partly from sleep disturbances and nocturnal defecation.[103] Secondly, the unpredictability of the occurrence of these symptoms places a high psychological burden on patients and limits their (sense of) freedom.[101]

Moreover, the current medical treatment is associated with a range of **safety concerns**, including the potential of severe side-effects such as infection, malignancy, and hepatoxicity, especially with long-term treatment.[104, 105] A European patient survey showed that 42% of IBD patients had experienced side-effects from corticosteroid treatment and 49% were concerned about the long-term effects of corticosteroids.[42] However, there is a **lack of evidence to determine the ideal duration of therapy and when therapy can be safely discontinued**, as randomised controlled trials rarely provide

data beyond one year. Future initiatives, such as registry-based studies (e.g. I-CARE initiative), may provide additional data on the long-term safety of different medical therapies.[53, 106]

In addition to concerns about the potential side-effects and the long-term safety, t**he variability in individual responses to drug treatment** poses another issue. Several studies indicate that a significant proportion of patients report suboptimal outcomes due to **non-response or loss of response over time**.[66] Merely 20-30% of patients report consistent benefits from drug treatment and the reported remission rates in induction trials are often below 50%.[107] Currently, it is **impossible to identify the most effective drug before commencing treatment**, this results in delayed recovery and compromises both short and long-term outcomes.

Furthermore, **all current methods** including clinical assessment, blood tests, endoscopy and imaging, **have limitations in accurately predicting disease flares or evaluating treatment response**. To date, the accurate assessment of disease activity relies on **invasive procedures** to potentially identify early treatment failure. However such procedures are inconvenient for patients and may negatively affect compliance with their monitoring strategy and thus ultimately their clinical outcome. Consequently, there is a growing emphasis on non-invasive strategies in research to monitor disease activity, predict relapse and guide treatment decisions.[108-110]

During the interviews, patients testified on the effectiveness of surgical treatment, at least for a certain period of time, with the amount of time varying by patient. Interviewed patients reported substantial improvement in HRQoL thanks to the surgical treatment.

> *"I don't regret my ostomy. Because I'm no longer stressed about being able to go out. Except sometimes... Because sometimes it's unpredictable so you still have to empty it. But I have regained a quality of life, that is to say that I can function normally, without worrying, without stress, without interrupting a meeting, without..." (3F3)[31]*

> *" And then I started taking medication, I also had surgery in 2000 I think. 1999 I think, had surgery, then started taking medication and then nothing more. Immediately no more complaints, no cramps, diarrhoea though. The need to go to the toilet, yes, but for the rest never nothing anymore." (5N2)[32]*

Drug treatments are also perceived by the patients interviewed as being effective. Specifically, they highlighted the impact of drug treatment on the alleviation of their symptoms as well as on the improvement of their daily life in general.

> *" And I came in limping from the pain, from the joints. And an hour after the infusion I was already jumping. I said, how is this possible? But because people didn't realize at the time... The fact that you had to have that infusion regularly, made me switch from the infusion to [name immunomodulator]. I've been good for a number of years." (4N2)[33]*

> *"In my daily life I'm fine, I'll say, thanks to the [name TNF inhibitor], I thank the [name TNF inhibitor] every day who allows me to stand up and know how to do everything I can do too." (4F2)[34]*

> *"The [name interleukin inhibitor] works very well, I do an injection every 8 weeks, and in any case for Crohn's and Verneuil for the moment it works perfectly. Oh, really. It works very well." (2F1)[35]*

Interviewees explained how the treatments were often not permanently effective. Patients are required to change treatments over time.

> *"Yes, it was usually between one and two years that it was effective, so I had both drugs on a drip in the day hospital, as well as... Currently I have the [name interleukin inhibitor]; It's a shot in the stomach." (3F3)[36]*

> *" Yes, because at the moment I've been without medication for 9 weeks now, so I don't know which one I'm going to have. [...] That's difficult, the treatments are limited and I know they go in degrees, so if the lightest form doesn't help, then they go to the next step and the next step, but they're also quite limited in that, I know they do studies on that, but yes, it's not like you can choose from 100 different drugs and the*

one that gives the least side effects, that you can actually take that. " (3N1)[37]

Sometimes, several treatments are tested before finding one that really works.

"Since I've had surgery and I've been on treatment, we've finally found the right treatment because I've been on five different treatments, I'm on the fifth I think now, I have absolutely nothing." (3F1)[38]

"That's kind of the stepping-stone theory. You try something first and if it doesn't work, they move on to the next. And you have to go through that whole train. To finally end up with something that does work. But it also depends a lot on your approach. Whether you reason along and try to follow everything rationally. And at some point it has to say stop. [...] Because they said that I was out of treatment, while I was still getting the treatments with baxters and such, which have been going on for 15 years now, that I am getting biological treatment. " (4N2)[39]

It appeared that the prescribed treatments might not work as desired, which causes a sense of hopelessness in the patient, who wondered if it was still worth continuing a treatment.

"He doesn't have any treatment... Finally... so [name immunomodulator A] that was quickly over, [name TNF inhibitor A] still worked for a long time and then it does... so, I didn't respond to [name TNF inhibitor A] anymore and so when you don't respond to a treatment anymore, well necessarily first you increase the intake, so now, I no longer injected myself every two weeks but every week, and after x amount of time we do it again. No, it really didn't work, so we changed. Then I took another molecule, I don't remember which one. It didn't work either, after... I think that after a year I was already unresponsive and here I am on [name TNF inhibitor B], with [name immunomodulator B], and here we have just done a test again because it's been a month and a half that I'm really not well [...] so I'm at the stage where I'm wondering if it's still worth taking a treatment." (3F2)[40]

Although nutritional adaptation is a widespread treatment reported by almost a quarter of the survey respondents (23.4%): some explained that they had to find their own adaptations through trial and error, while others said that they would have benefitted from this support as soon as the disease was diagnosed because diet led to good results on their health status.

"I've learned, and that's it, just to know myself. Especially since... uh.. Did we see a nutritionist once, I don't know... But there wasn't ... From the information I've seen or read, there wasn't really any instructions saying "you have Crohn's disease so you can't eat this anymore because it's going to have a negative impact". You had to see for yourself." (2F2)[41]

"Yes. No, no, I did it on my own initiative... Because he [= the doctor] was a bit behind... Uh, well, because we didn't necessarily have a study on it, but I immediately told myself, right away, it's not possible that it's not related to what I eat. I don't eat well." (2F5)[42]

"Then I found a way out myself, by chance, because at one point I wanted to lose weight, I had followed a protein diet. And the weird thing was, from the moment I only ate those jars, my diarrhoea was gone. Not 100%, but every now and then I had a breakthrough day, but liveable. " (4N2)[43]

"What would have really helped me at the beginning was to say to myself, 'Well, there you go, make an appointment directly with a nutritionist or with someone specialized in food, because your disease is closely linked to that', that's kind of my diagnosis of what I could eat and what I couldn't eat, and even from one day to the next it's not even the same thing." (3F2)[44]

It was also reported that following a drastic diet (i.e. rotation of certain foods for several months, juice,…) was not sustainable in the long term because it might be too difficult to follow due to its restrictive nature. Sometimes it is also socially difficult to strictly follow the recommended dietary treatment (e.g. diet in a restaurant).

> *"That was real juice huh, I just got juice from carrots and juice from rice, I got that as food, as weird as that sounds. And diet I have followed and done all that. Now I have the rule, everything I eat, I eat in moderation and everything I feel like I eat. " (5N1)[45]*

> *"The rotation diet, I have to say, actually has consequences for a year and a half, but is difficult to keep in the long term. For example, I wasn't allowed to eat yeast for a year, not eat tomatoes for six months and then I had to start building it up again, but keep rotating, because that's difficult in everyday life, even when you go to a restaurant, you can't ask yes, I have to fry my meat in sunflower oil today. " (3N1)[46]*

4.3.2 Burden of treatment

4.3.2.1 Description of treatment use and satisfaction

Survey participants were asked what medical treatment they were currently having or had in the past for their CD. Nearly all respondents (96.7%) said that they were currently following or had followed a treatment for CD. The most common treatments were prescribed drugs (95.9%), surgical procedures (24.8%) and nutritional adaptation (23.4%) (Table 16).

Both in the subgroup of respondents diagnosed with CD less than ten years ago and in the subgroup diagnosed more than 10 years ago, the use of biologicals emerged as the most prevalent treatment modality (<10 years: 63.2%; >10 years: 69.3%). Patients who had been diagnosed less than ten years ago notably reported a significantly higher frequency of corticosteroid treatment for CD compared to those diagnosed more than ten years ago (<10 years: 59.6%; >10 years: 31.8%; p-value<0.001). Patients diagnosed more than ten years ago reported a significantly higher prevalence of surgical procedures compared to the cohort of patients who had been diagnosed less than ten years ago (<10 years: 10.5%; >10 years: 34.1%; p-value<0.01). There were noteworthy differences in the proportion of individuals using different surgical treatments since diagnosis. Specifically, there was a significant difference in the management of fistulas between the two cohorts (<10 years: 5.3%; >10 years: 19.3%; p-value<0.05). Similarly, a significant difference was observed for intestinal resections (<10 years: 5.3%; >10 years: 26.1%; p-value<0.01).

Table 16 – Self-reported treatment for CD by time since diagnosis (n=145)[1]

Treatments	Less than 10 years n=57 n (%)	More than 10 years n=88 n (%)	p-value	Total n=145 n (%)
Prescription drugs	55 (96.5)	84 (95.5)	NS	139 (95.9)
Biologics	36 (63.2)	61 (69.3)	NS	97 (66.9)
Corticosteroids	34 (59.6)	28 (31.8)	***	62 (42.8)
Immunomodulators	18 (31.6)	25 (28.4)	NS	43 (29.7)
Aminosalicylates	10 (17.5)	7 (8.0)	NS	17 (11.7)
JAK inhibitors	1 (1.8)	3 (3.4)	NS	4 (2.8)
Others[2]	4 (7.0)	6 (6.5)	NS	10 (6.9)
Non-prescription drug	5 (8.8)	13 (14.8)	NS	18 (12.4)
Physiotherapy	11 (19.3)	14 (15.9)	NS	25 (17.2)
Nutrition support	14 (24.6)	20 (22.7)	NS	34 (23.4)
Surgical procedures	6 (10.5)	30 (34.1)	**	36 (24.8)
Resection of intestines	3 (5.3)	23 (26.1)	**	26 (17.9)
Fistula	3 (5.3)	17 (19.3)	*	20 (13.8)
Abscess	2 (3.5)	9 (10.2)	NS	11 (7.6)
Stoma	0	6 (6.8)	NS	6 (4.1)
Strictureplasty	0	3 (3.4)	NS	3 (2.1)
Others[3]	0	1 (1.1)	NS	1 (0.7)
Others[4]	4 (7.0)	6 (6.8)	NS	10 (6.9)

*[1]Five respondents indicated "No" to the question if they are receiving or have received a treatment for CD; Fisher's exact test, NS=Not significantly different, * p-value <0.05, ** p-value <0.01, *** p-value <0.001. [2]Others = "Antidepressants and Imodium", "CD is under control because of surgical intervention", "Immunodepressant", "Nexiam", "Questran", "Pantomime 40, spasmodem", "pain medication". [3]Others = "Treatment of an anal fissure". [4]Others = "Perfusion treatment", "Subdermal injection at the hospital", "several biologics/drugs as a participant in clinical trials", "Nutritional supplements".*

A quarter of respondents underwent surgery

Among the respondents younger than 45 years of age, 14.5% underwent surgery (12/83). Surgery was most prevalent in the age category 45 to 64 years, representing 52.8% (19/26) of all surgical cases. A significant difference in age distribution between the participants with and without surgery was evident (p-value <0.05), with an absolute difference exceeding 20% points observed for the age groups of 25 to 44 years (surgery: 30.6%; no surgery: 55.3%) and 45 to 64 years (surgery: 52.8%; no surgery: 30.7%) (Table 17).

Table 17 – Distribution of participants by age group and surgery (n=150)

Age groups (in years)	Surgery n=36 n (%)	No Surgery n=114 n (%)	p-value	Total n (%)
			*	
18-25	1 (2.8)	8 (7.0)	NS	9 (6.0)
25-44	11 (30.6)	63 (55.3)	*	74 (49.3)
45-64	19 (52.8)	35 (30.7)	*	54 (36.0)
65-74	4 (11.1)	5 (4.4)	NS	9 (6.0)
≥75	1 (2.8)	3 (2.6)	NS	4 (2.7)

*Fisher's exact test, NS=Not significantly different, * p-value <0.05, ** p-value <0.01, *** p-value <0.001*

Surgery was most common in patients who had been diagnosed with CD for a longer period of time

Of all patients who received surgery (n=36), 30 of them (83.3%) were diagnosed more than 10 years ago. Surgery rates in the other categories (2-6 months; 6 months-2 years; 2-5 years and 5-10 years) were rather low as shown by (Table 18).

Table 18 – Distribution of participants by time since diagnosis and by surgery (n=150)

Time since diagnosis	Surgery n=36 n (%)	No Surgery n=114 n (%)	p-value	Total n (%)
2 to 6 months	1 (2.8)	5 (4.4)	NS	6 (4.0)
6 months to 2 years	1 (2.8)	14 (12.3)	NS	15 (10.0)
2 to 5 years	3 (8.3)	14 (12.3)	NS	17 (11.3)
5 to 10 years	1 (2.8)	18 (15.8)	NS	19 (12.7)
More than 10 years	30 (83.3)	63 (55.3)	**	93 (62.0)

*Fisher's exact test, NS=Not significantly different, * p-value <0.05, ** p-value <0.01, *** p-value <0.001*

For all treatments, more than 86.6% of the participants expressed being "very satisfied" or "rather satisfied" with the treatment they received. The highest level of satisfaction was reported for prescription drugs, with 91.4% indicating "rather satisfied" or "very satisfied". However, nutritional adaptation, which is a frequent form of management, revealed a lower satisfaction rate, with approximately one in four participants (26.4%) reporting being "rather unsatisfied" or "very unsatisfied" with the treatment they received (Table 19).

Table 19 – Distribution of respondents' satisfaction level with CD treatment, by treatment type (n=145)

	Very satisfied n (%)	Rather satisfied n (%)	Rather unsatisfied n (%)	Very unsatisfied n (%)	Total n (%)
Prescription drug	59 (42.8)	67 (48.6)	12 (8.7)	0	138 (95.2)
Surgery	22 (61.1)	10 (27.8)	3 (8.3)	1 (2.8)	36 (24.8)
Nutritional adaptation	9 (26.5)	16 (47.1)	8 (23.5)	1 (2.9)	34 (23.4)
Physiotherapy	13 (52.0)	7 (28.0)	5 (20.0)	0	25 (17.2)
Non-prescription drug	6 (33.3)	8 (44.4)	4 (22.2)	0	18 (12.4)
Others[1]	5 (45.5)	5 (45.5)	1 (9.1)	0	11 (0.7)
Total	114 (43.5)	113 (43.1)	33 (12.6)	2 (0.8)	

[1]Others = "Perfusion treatment", "subdermal injection at hospital", "Several biologicals/drugs as participant in clinical trials", "Nutritional supplements".

4.3.2.2 *Experienced burden of treatment*

More than half of the respondents who received a treatment considered their overall treatment to be burdensome.

Interestingly, a significant difference in the experience of perceived burden was observed between individuals who had undergone surgery and those who had not ($p<0.05$). Almost one in five participants (18%) considered their treatment to be rather or very burdensome. Participants who had not undergone surgery expressed more frequently that their treatment was not burdensome at all (Table 20,Table 21).

Table 20 – Distribution of respondents' experienced burden of treatment by surgery status (n=145)[1]

	Surgery n=36 n (%)	No surgery n=109 n (%)	p-value	Total n (%)
			*	
Very burdensome	5 (13.9)	2 (1.8)	*	7 (4.8)
Rather burdensome	5 (13.9)	14 (12.8)	NS	19 (13.1)
Somewhat burdensome	16 (44.4)	42 (38.5)	NS	58 (40.0)
Not burdensome at all	10 (27.8)	48 (44.0)	NS	58 (40.0)
I don't know	0	3 (2.8)	NS	3 (2.1)

*[1]Five respondents indicated "No" to the question if they are receiving or have received a treatment for CD; Fisher's exact test, NS=Not significantly different, * p-value <0.05, ** p-value <0.01, *** p-value <0.001*

Table 21 – Distribution of reasons for very or rather burdensome CD treatment (n=26)[1]

	Total n=26 n (%)
Side-effects	22 (84.6)
It forces me to constantly deal with my illness/treatment	12 (46.2)
I have been on treatment for a long time	7 (26.9)
It demands a very strict life discipline	6 (23.1)
It needs to take place in the hospital	2 (7.7)

The most prevalent reason for respondents to report their treatment as rather or very burdensome was side-effects (84.6%).

Interviewed patients highlighted that burdensome treatments also impacted their mental health. Going back and forth to hospital also generates a psychological burden. The uncertainty surrounding the effectiveness of treatments and the possible side-effects were also cited as having a psychological impact on the patient.

> *"How can I put it... To be done... Being wicked for almost a year is still long, painful, not only physically but psychologically it's, that's it... Every day, having this care is difficult. [...] It's heavy, even in terms of organization, and then that's it psychologically and all that." (2F2)[47]*

> *" Yes. I also realize that every medicine will have its side effects and that is not always easy and that sometimes has some anxiety, but there is not much you can do about it, except of course wait and see what that gives it, but that is not so nice. " (3N1)[48]*

> *"It's not just Crohn's, there's the operations, there's the effects of the operations, it plays a psychological role because we're not prepared to go back and forth to the hospital, we were promised that the sack would*

be the miracle solution, and it's true that I had regained a quality of life in relation to the back and forth movements to the bowel movements and the pain, But I got other things in return." (3F3)[49]

Burden associated to treatment

The burden associated with the treatment of CD was further explored during the interviews. Although the treatment burden did not prevent patients from following their medical treatment, they imposed constraints on patients' lives, usual activities and access to care.

For example, the fact that the treatment is time-consuming (e.g. perfusions) has been highlighted. Having to make regular visits to the hospital for their treatment created a substantial burden on patients' personal time and planning.

" I'm glad that medication exists. But on the other hand, I sometimes have to bend over backwards to be able to go to my examinations and to be able to get everything arranged." (3N1)[50]

"I know that going to the day hospital every 6 or 8 weeks, getting an IV in my arm, and it runs for three hours, it drove me crazy to lose a morning... A precious morning in the week." (2F4)[51]

"The first two IV are four hours. So uh yes we have what it is, half an hour of corticosteroids and after that, it's the treatment, then we stay under observation for an hour to see if we can tolerate the treatment well and then we can go home." (1F1)[52]

Also practical considerations contributed to the burden of treatment. For example, injections that patients can administer themselves need to be kept in the refrigerator. Patients reported obstacles in this regard, when having a small refrigerator or when travelling abroad, for example.

"But in fact the boxes are big, and I live in an apartment, well it's a technical question but you have to keep it in the fridge, and I have a small fridge so I only take one box at a time." (3F2)[53]

"And then there's the fact that it can be kept in the fridge, so you have young people at home taking your box of [name TNF inhibitor] out of the fridge to go put their beers in. And obviously it's a treatment that can't be in the open air, so you have to constantly explain "the box that's in the fridge, you shouldn't take it out!" (2F4)[54]

Participants testified that the significant frequency or complexity of their treatment often required a lot of self-discipline and planning from their part. Maintaining this in the long run was difficult for many patients, particularly during times when they were not closely followed up by a clinician.

" Now I take something like 15 medications. So that's about six different ones. And if you take that [hypolipidemic ion exchange resin], that that they suggest to make my stool firmer. That was three times a day, in the morning, in the afternoon and in the evening. They would have increased it to four times a day, but when you have to take that on top of everything else and you have so much pressure to figure out when to take all your medication, it becomes a burden instead of a relief. " (5N1)[55]

For example, patients tend to reduce the dosage or frequency of treatment when they started to feel better. Some patients have reported that because of this, they preferred to go to the hospital to receive their treatment.

"We've talked about it with my gastro but I know how it's going to go, like it's once a week or once... I'm going to forget about it. I'm going to do this for the first two weeks, and then since I feel good I'm going to forget about it, and then I'm having seizures again, so I'd rather go to the hospital." (4F2)[56]

" Of course, I've experienced the fact that you take the pills, you're good and you stop taking them and then you see that you think everything will be alright again, but after a few years you eventually relapse." (2N1)[57]

"I've already made the little mistakes of a chronic patient, since the great specificity of chronicity is self-medication [...]. So as soon as I get

better, I'm not going to say that I'm self-medicating, but I'm putting a little distance between myself and the treatment [...]. Now I self-inject the medication, and I notice that the better my health is, the less vigilant I am about the deadlines." (2F4)[58]

Beyond the burden of treatment, participants also highlighted an important burden associated with their overall care: the significant time consumed by the regular follow-up consultations, and by the numerous investigations they had to routinely go through (e.g. regular blood tests).

"It's always, there's always a wait, it's long... In fact, what is, well, I still have a medical calendar that is more important than my friends for example. I have at least one appointment a month. Once it's gastro, and then you have to go and do a blood test, then you have to go and do this, there are tests, well, there are plenty of things to do." (4F1)[59]

4.3.2.3 Description of side-effects of treatment

Treatments with side-effects

All survey participants who received treatment for CD reported suffering from side-effects of their treatment (145/145).

The most frequently reported side-effects were fatigue or exhaustion (66.9%), weight gain (32.4%), skin irritation or eczema (27.6%), nausea and/or vomiting (21.4%), diarrhoea (20.0%), change of external characteristics (15.9%), and infection (13.1%) (Table 22).

Patients who underwent surgery more frequently reported experiencing weight gain and infection as side-effects of their treatment.

Participants in the qualitative study highlighted that identifying treatment side-effects is sometimes challenging because they overlap with CD symptoms (e.g. diarrhoea, fatigue, and skin conditions). The timing of symptom occurrence (in relation to treatment initiation), and the specificities of symptoms (e.g. type of skin condition) could possibly help; however, we did not collect these specific data in this study.

Table 22 – The 10 most frequently reported side-effects due to CD treatment by surgery status

	Surgery n=36 n (%)	No surgery n=109 n (%)	p-value	Total n=145 n (%)
Fatigue or exhaustion	28 (77.8)	69 (63.3)	NS	97 (66.9)
Weight gain	18 (50.0)	29 (26.6)	**	47 (32.4)
Skin irritation or eczema	13 (36.1)	27 (24.8)	NS	40 (27.6)
Nausea and/or vomiting	9 (25.0)	22 (20.2)	NS	31 (21.4)
Diarrhoea	11 (30.6)	18 (16.5)	NS	29 (20.0)
Change of external characteristics	8 (22.2)	15 (13.8)	NS	23 (15.9)
Infection	10 (27.8)	9 (8.3)	**	19 (13.1)
Constipation	3 (8.3)	8 (7.3)	NS	11 (7.6)
Acne	4 (11.1)	6 (5.3)	NS	10 (6.9)
Renal impairment	3 (8.3)	7 (6.4)	NS	10 (6.9)

*Fisher's exact test, NS=Not significantly different, * p-value <0.05, ** p-value <0.01, *** p-value <0.001*

Table 23 – Other side-effects specifically reported in the online survey & qualitative interviews

- Side-effects mentioned in the online survey:
  - Damage or sequelae of the lower ileum in the form of strictures causing problems with going to the toilet (1 to 2 hours a day +/-)
  - Benign skin cancer
  - Discomfort
  - Dizziness
  - Loss of strength
  - Adhesions
  - Hair loss
- Side-effects brought up during the qualitative interviews:
  - [name TNF inhibitor A]: poor view
  - [name TNF inhibitor A]: caused a lot of fatigue
  - [name TNF inhibitor A]: kidney problems
  - Perfusion treatment caused a lot of fatigue
  - Skin problems (e.g. dry skin, shingles, redness)
  - [name interleukin inhibitor]: constant muscle aches, aching back muscles and constant flu-like feeling
  - Joint problems, especially in the fingers
  - Gardia lamblia due to immunosuppressants
  - Nerve damage (neuropathy)
  - Physical transformation due to surgery (e.g. deformed belly)

Common side-effects reported in the survey were further contextualised by patients during interviews. Significant fatigue in the days following treatment was mentioned.

> *"I was also on the two for a few months, so both [name immunomodulator A] and [name TNF inhibitor A], but that turned out to be very heavy. I was very, very tired. The fatigue, both on [name immunomodulator A] and [name TNF inhibitor A], is actually the same" (3N1)[60]*

> *"Here with the treatment, the first performance didn't go very well so I was really knocked out for 2-3 days or more." (1F1)[61]*

Gastrointestinal problems and loss of appetite were also reported as side-effects of certain treatments. It seems that patients did not always tolerate the treatment and therefore had to stop it.

> *"No, the initial treatment was started with (especially immunomodulator A) and I couldn't really tolerate it. I took that for about a month and a half with complaints, so stomach ache, etc." (2N2) [62]*

> *"I was nauseous all the time, nothing was going through... I had a loss of appetite. I'm going to say, I was making myself food, I was like, "oh, that looks great," and then when I got to the front of the dish, it was impossible to eat." (1F1)[63]*

> *(name immunomodulator A), of those things, only half (name immunomodulator A) and I'm vomiting over the toilet. And then (name immunomodulator A), I've had that. But that was stopped every time, because I couldn't bear it. " (4N1)[64]"*

Dermatological problems noted and attributed by patients to treatment for CD (although not always proven) are dry skin, shingles, redness, and skin cancer.

"I don't have pimples, I don't have psoriasis, I don't have all these skin problems, except that I have dry skin, since the [name TNF inhibitor B]; Yes, I have dry skin." (4F2)[65]

" And then the [name immunomodulator A], if you think back to that, it's been a few years, I had skin rashes so quickly, so itchy, red skin and quick itching, especially when I came out of the shower like that, very dry skin too. " (3N1)[66]

" [...] Yes, I also have that as an additional consequence of taking that medication. So not Crohn's-related, but medication-related that I have skin cancer. This is partly due to [name immunomodulator A]. According to the dermatologist, the major cause is [name immunomodulator A]. But then, of course, it is maintained a bit by the immune-lowering infusions that I receive. That [name TNF inhibitor B] and all that. " (4N2)[67]

While joint pain was highlighted as an important symptom of CD, it was also attributed to treatment by the patients interviewed. Joint pain (particularly in the fingers) was reported, which tended to disappear when treatment is stopped.

"I've had problems with my joints, especially with my fingers, but now I'm not taking any more medication, I'm seeing that it's much better." (2F3)[68]

" I started to struggle with my hands, I have one finger here, which is very dull and painful, and all those other fingertips too, then I went to different neurologists for a year, found nothing, and then there was in a [region], which had discovered a study in [region] in America, that it could possibly be a side effect of the [name TNF inhibitor A], of the [name TNF inhibitor B], that has affected those nerve endings. " (4N1[69]

"The pain doesn't really go away, and so it's still regularly there, all the joint pain... Sorry, I come back regularly too. So at times I'm behind the wheel, and then I get cramps in my fingers. Well, it's not even really cramps, it's joint pain... and on the feet too. That's it, hands and feet." (3F2)[70]

While weight loss has been cited as a symptom of CD, interviewed patients reported weight gain following certain treatments. This weight gain could be significant since it was sometimes substantially more than 10kg. Patients noted that this bodily change was sometimes difficult to accept or induce other problems requiring to go to the physiotherapist for example.

"For a long time I didn't dare to leave the house, because you also have to know what treatments you're given, well, it's treatments too... At a certain point I gained 30 kilos, so the body changes, you have to integrate this disease." (2F1)[71]

" And the side effects, the [particularly corticosteroid], which is not a fun thing to take. I had to take 32 milligrams at one point for seven months. My face was a balloon, I had gained 10 kilos, I no longer had a feeling of satiety, so I was constantly eating, I really didn't feel well. " (3N1)[72]

"So I called a physiotherapist because there was a medication that had made me gain weight, 17 kilos in less than a year, back pain, so it had to be done." (5F2)[73]

Other side-effects not listed during the quantitative analysis were highlighted during the qualitative analysis. For example, dandruff was attributed as a treatment side-effect by one patient.

"I have much more dandruff in my hair and that's also part of the treatment." (1F1)[74]

"Significant allergic reactions to drugs have been reported, sometimes requiring hospitalisation, such as a doubling of the abdomen, dermatological reactions and even anaphylactic shock" And we know that from when she was 18, and she got [name TNF inhibitor] infusion, she had a [name TNF inhibitor] infusion twice, so the first time, and the second time she went alone, [...] so then I called that department in

[region], ah yes, sorry, but she did an anaphylactic shock, so it was gone, so it was allergic to the mouse protein that was in that [name TNF inhibitor]. " (4N1)[75]

"On the other hand, the induction went very well intravenously, but once I switched to a syringe, I couldn't stand it. I was having reactions to the injection site. Well, I tried a few times, but in fact it was super uncomfortable, my abdomen was doubling in size." (2F3)[76]

"Yes, because I had an allergic reaction to it. But to a very high degree. In that sense, if you're coming from a department store with a cart. And you load the car and you put your cart back. I already had the first stains on my hands from reaction. And by the time I got home, there was even a cup on it. Yes, I also have that as an additional consequence of taking that medication. [...] This is partly due to [name immunomodulator]. According to the dermatologist, the major cause is [name immunomodulator]. " (4N2)[77]

"And so he gave me a first treatment so [name immunomodulator] (it was pills) and cortisone... which I couldn't stand so I ended up in the hospital." (3F2)[78]

Kidney problems (notably kidney stones) have also been cited among other side-effects of treatment.

"[name TNF inhibitor] that I took for a few years to stabilize my Crohn's and which weakened my kidney a little bit too, all small consequences not because of Crohn's directly but it's because of the medication I took for that." (4F2)[79]

Patients reported that CD treatments have triggered autoimmune diseases, such as Verneuil's disease and spondyloarthritis.

"The treatments I've had, have actually developed other autoimmune diseases [...] The doctors confirmed it to me compared to the previous treatments I had, they were the ones who triggered, well, Verneuil's disease and ankylosing spondylitis." (2F1)[80]

Another side-effect reported specifically during interviews concerned the inflammation of the cornea, although the link between the treatment and the inflammation could not be formally established.

"A sharp inflammation of the cornea, well, the corneas of both eyes. Anyway, the ophthalmologist has always wondered if there could be a link... at the time it was [name TNF inhibitor]." (2F3)[81]

Beyond the side-effects attributable to drug treatments, side-effects (or complications) of surgical interventions were also reported. This was the case with the intestines which come out of the pouch placed during the surgical procedure.

"So I was going to work with my intestines on the outside if you will, I saw that in my pouch were all my intestines. Then when I got home, once I lay down they would go into my belly, and then during the day they would come out." (3F3)[82]

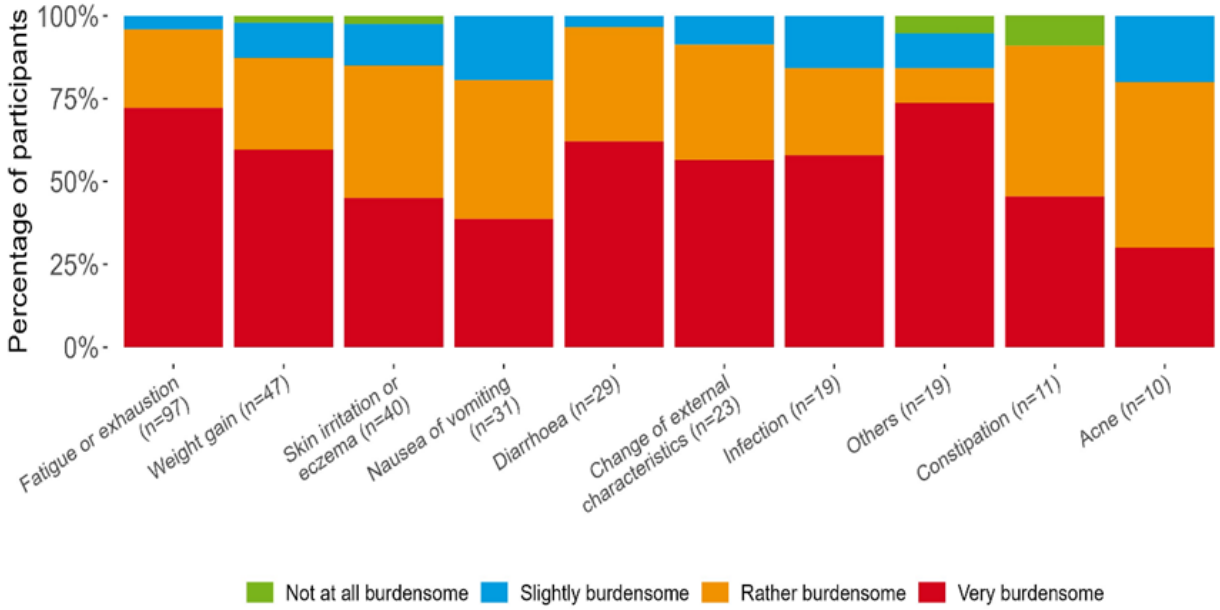
4.3.2.4 Experienced burden of side-effects

In the assessment of side-effects, respondents were asked to rate the burden caused by each reported side-effect (Table 24). The comprehensive list of symptom burdens can be found in the Appendix 4: Surveys. Among the ten most frequently reported side-effects, diarrhea, fatigue or exhaustion were identified as the most distressing by respondents. Specifically, survey participants who reported these side-effects, expressed that they were 'rather burdensome' (96.6%) or 'very' burdensome in (95.5%). A mere 10% of the respondents indicated that the ten most commonly reported side-effects were only 'slightly burdensome' or 'not burdensome at all'. Notably, given that 65% of the participants experienced fatigue or exhaustion as a side-effect, a significant 95.9% of them found this particular side-effect to be 'rather burdensome' or 'very' burdensome (Figure 13).

Table 24 – Distribution of reported side-effects by level of burden (n=150)

Side-effect	Reported burden n (% of respondents who reported this side effect)				Total n=150 n (%)
	Not at all burdensome	Slightly burdensome	Rather burdensome	Very burdensome	
Fatigue or exhaustion	0	4 (4.1)	23 (23.7)	70 (72.2)	97 (64.7)
Weight gain	1 (2.1)	5 (10.6)	13 (27.7)	28 (59.6)	47 (31.3)
Skin irritation or eczema	1 (2.5)	5 (12.5)	16 (40.0)	18 (45.0)	40 (26.7)
Nausea and/or vomiting	0	6 (19.4)	13 (41.9)	12 (38.7)	31 (20.7)
Diarrhoea	0	1 (3.4)	10 (34.5)	18 (62.1)	29 (19.3)
Change of external characteristics	0	2 (8.7)	8 (34.8)	13 (56.5)	23 (15.3)
Infection	0	3 (15.8)	5 (26.3)	11 (57.9)	19 (12.7)
Others	1 (5.3)	2 (10.5)	2 (10.5)	14 (73.7)	19 (12.7)
Constipation	1 (9.1)	0	5 (45.5)	5 (45.5)	11 (7.3)
Acne	0	2 (20.0)	5 (50.0)	3 (30.0)	10 (6.7)
Renal impairment	0	4 (40.0)	3 (30.0)	3 (30.0)	10 (6.7)
Infusion reactions	0	1 (14.3)	2 (28.6)	4 (57.1)	7 (4.7)
Surgical complications	0	0	1 (14.3)	6 (85.7)	7 (4.7)
Inflammation of the liver	1 (20.0)	2 (40.0)	2 (40.0)	0	5 (3.3)
Kidney stones	0	0	2 (50.0)	2 (50.0)	4 (2.7)
Inflammation of the pancreas	0	1 (25.0)	1 (25.0)	2 (50.0)	4 (2.7)

Figure 13 – Level of experienced burden of the 10 most frequently reported side-effects of CD treatment (n=150)[1]



[1]*The graph is ordered by frequency (left most highest frequency).*

Side-effects following surgery were also described as a burden during the individual interviews, for instance, a physical transformation due to the surgery (e.g. a deformed belly suggesting pregnancy) that is difficult to live with daily.

> *"I have a deformed belly, my belly button is not symmetrical, I have a hernia that will stay there because I was put in the mesh but now the hernia won't go away, so sometimes it feels like I'm pregnant, but just on one side when they see me in profile on the bus, they say to me 'you want to sit down, miss?" (3F3)[83]*

Given the constraints that medication can cause, patients even asked themselves whether it was worth continuing treatment.

> *"So in the end you say thank you to the package without asking too many questions, and it's only afterwards, when you read the list of side effects, that you say to yourself 'oh yes, anyway!' Was it a good thing in the end? But now, it's too late." (2F4)[84]*

> *"Really, I'm not interested in having treatments that are so old that in the end, yes, they work, but with so many side effects." (2F5)[85]*

" It takes a lot of self-discipline, especially being critical of medication, in the sense that you take it as you should. But if you see that after a while it's not working, you should discuss it. And in [region], I had the right professor with Professor (name). He said, 'Yes, I have never known anyone to get worse with that medication. But if I listen to you, that's the case. So I will follow up with you, we will stop this and try something else.' And then within a month, I suddenly got better. That's proof. You can react badly to medication. But we didn't know that. That the disease was breaking through instead of being stopped. So I remain critical of what I take. " (4N2)[86]

Patients expressed their wish to stop taking the drugs, either because they considered the side-effects too severe or because they saw it as a personal goal. Patients did not want to depend on medication for the rest of their lives. They saw stopping treatment as a sign of recovery (if they did not have symptoms anymore while not taking medication, they could consider themselves cured even if they were aware of the incurable aspect of the disease).

"I refuse, it's over, I don't want to take corticosteroids anymore and too bad if..." No, it's over, I don't want to anymore! [...] But I told him "whatever, I'd even be on my deathbed, I don't want [corticosteroid name] anymore, it's over" so he heard me, he listened to me, so that's it." (3F2)[87]

"Beginning medication I have [name immunomodulator] and immunosuppressants, aspirin, which was 10 pills a day. I think I've done that for 10 years. From one moment to the next I had had enough and very strange, I couldn't be compliant anymore, I was really tired of it. I also discussed this with the gastroenterologist and said " I actually want to stop" (2N1)[88]

"I see it, I'm often tempted to stop everything, because I know the side effects of medication [...]. And sometimes I say to myself, "Come on, I'm going to stop all these poisons" but here goes... Here I don't dare to do it anymore because I was really scolded by my new gastroenterologist so I don't stop my treatment anymore." (2F4)[89]

"I don't want to be addicted to medication for the rest of my life, and I want to... I want to try at least. And so he said, "Okay, we can stop, you're stabilized, everything's fine, we can stop." I stopped for a year, and so I had... Similarly, I have been very rigorous about my lifestyle." (2F5)[90]

The literature also mentions some side-effects associated with current medical treatment, including the potential of severe side-effects such as infection, malignancy, and hepatoxicity, especially associated with long-term treatment.[104, 105] An European patient survey showed that 42% of IBD patients had experienced side-effects from corticosteroid treatment and 49% were concerned about the long-term effects of corticosteroids.[42] Furthermore, according to some qualitative studies the changes in physical appearance (e.g. weight fluctuations, skin manifestations) due to medical treatment make patients feel insecure and may affect their social interactions.[101]

4.3.3 Quality of care

4.3.3.1 Experience with the organisation of care

Medical specialists, gastroenterologists in particular, were the most consulted healthcare professionals followed by general practitioners.

In the context of CD, medical specialists emerged as the most frequently consulted healthcare professionals, with 96.0% of survey respondents reporting having had consultations with specialists for their CD. General practitioners (GPs) were the second most commonly consulted healthcare providers, with 77.3% of respondents having consulted them for their CD. IBD nurses were consulted by 38.5% of respondents, while nurse consultations within hospital settings were utilised by 29.1%, and emergency services were accessed by 23.3% for problems related to CD.

The variety of consulted medical specialists illustrated that CD is a disease that is not solely limited to the gastrointestinal system. Among the participants who reported having consulted a medical specialist, the predominant consulted specialist was the gastroenterologist (96.6%). In approximately a third of cases, consultations also involved a surgeon (34.5%), a rheumatologist (33.8%), or a dermatologist (33.1%), specialists associated with the extra-intestinal manifestations mentioned above (Table 25).

A fourth of the respondents was unsatisfied with the care received

Patients indicated high levels of satisfaction, with over 75% expressing satisfaction across all consulted healthcare providers. The top three medical contacts that yielded the highest satisfaction scores (very satisfied or satisfied) were interactions with the IBD nurse (98.3%), gastroenterologists (96.5%), and consulting nurses in hospitals (95.4%). However, satisfaction scores were somewhat lower for emergency services (77.1%), rheumatologists (80.0%) and psychologists (81.8%) (Table 25).

Table 25 – Respondents' level of satisfaction by type of healthcare provider (n=148)

	Very satisfied n (%)*	Rather satisfied n (%)*	Rather unsatisfied n (%)*	Very unsatisfied n (%)*	Total n=148 n (%)
Specialist					
Gastroenterologist	100 (69.9)	38 (26.6)	3 (2.1)	2 (1.4)	143 (96.6)
Surgeon	35 (68.6)	11 (21.6)	5 (9.8)	0	51 (34.5)
Rheumatologist	24 (48.0)	16 (32.0)	7 (14.0)	0	50 (33.8)
Dermatologist	28 (57.1)	17 (34.7)	4 (8.2)	0	49 (33.1)
Ophthalmologist	18 (66.7)	6 (22.2)	3 (11.1)	3 (6.0)	27 (18.2)
Other	5 (45.5)	4 (36.4)	2 (18.2)	0	11 (7.4)
GP	71 (61.2)	34 (29.3)	7 (6.0)	4 (3.4)	116 (78.4)
Nurse specialised in IBD	42 (73.7)	14 (24.6)	1 (1.8)	0	57 (38.5)
Nurse on consultation in hospital	30 (69.8)	11 (25.6)	2 (4.7)	0	43 (29.1)
Emergency services	16 (45.7)	11 (31.4)	5 (14.3)	3 (8.6)	35 (23.6)
Psychologist	17 (51.5)	10 (30.3)	5 (15.2)	1 (3.0)	33 (22.3)
Physiotherapist	20 (69.0)	5 (17.2)	4 (13.8)	0	29 (19.6)
Dietitian	14 (50.0)	10 (35.7)	4 (14.3)	0	28 (18.9)
Home nurse	16 (76.2)	5 (23.8)	0	0	21 (14.2)
Social worker	2 (50.0)	2 (50.0)	0	0	4 (2.7)

Rehabilitation team	1 (100.0)	0	0	0	1 (0.7)
Other[1]	3 (33.3)	5 (55.6)	1 (11.1)	0	9 (6.1)

*[1]Other = "None", "Psychiatrist", "Alternative therapist (acupuncture)", "Pain specialist", "day care for infusion treatment", "IBD team", "surgeon", "gynaecologist" and one not specified; *Number and percentage of respondents who had a contact with this specific health care provider.*

Although patients stated that they were satisfied with their follow-up, some flaws have been highlighted. These concerned the perceived lack of competence of certain physicians and the limited availability of specialists.

When talking about the lack of competence, patients referred to post-operative complications, inappropriate medication (dosage) or a perceived lack of professionalism in general.

> *"I've had many hospitalizations giving many surgeries giving many complications, I almost went through it twice... for medical negligence." (3F3)[91]*

> *"Finally, it's rare to find a competent doctor, but I still went through several doctors to really find the rare pearl and who was able to put a good treatment in place." (2F1)[92]*

> *"I don't remember what doses I had, but I had brought back all my papers, and he said, 'But you've been completely overdosed, but what did that doctor do? What did he do? ". Well, I don't know anything about it, I'm given a treatment, I take it. He knows what the doctor is doing, I trust him... bah... I think that no, on the other hand, we are not sufficiently supervised, and there are doctors who are not professionals at all." (2F1)[93]*

Rotation in the physicians, between senior and junior staff, responsible for monitoring patient treatment has also been identified as a factor limiting the quality of follow-up care.

> *" It's fine as long as you can continue to see the same doctor, who knows your trajectory, who already has experience that you react or don't react to things in a special way and who doesn't want to invent the hot water every time. In the UZ [hospital] they are assistants. And every time different assistants, assistants who don't know my file. [...] And then it comes again. In the future, ma'am, you will have to say yourself that they should do [name artificial tears] in your eyes. And then I'm like, okay, the responsibility is put back on me. " (4N2)[94]*

Sometimes, patients condemned a lack of availability of the medical staff, who they considered to be increasingly busy due to a healthcare system under pressure. It was reported that doctors considered to be very knowledgeable in CD were often overwhelmed. As a result, patients had the feeling of being treated like a number. Respondents indicated that, in addition to doctors, all healthcare professionals (including nurses) seemed to lack availability for the patient.

> *"I'm being followed at [name of the hospital] by a very good doctor who saved my life, but I would say now he's even working too much, and we... I really feel the difference, he's been following me for 6 years now, I feel the difference, he has too much work, it's... I'm a number." (2F1)[95]*

> *"I know that there are some doctors who are very good, they are all full, but the disease is also not very recognized by other specialists. There are some who are not at all specialized in it, and I must admit that I don't want to go and see them at all. But hey, no, they're not present enough, even if they try to do their best, no, they're not present enough." (2F1)[96]*

> *"So you see, we feel that the medical system is under pressure, we feel that visits with the surgeon are 5 minutes, quickly quickly, we exchange but there is no examination, there is nothing in the end." (3F3)[97]*

"He's supposed to have a relay nurse, who handles a little bit of all the problems. What I don't know, if it's because of lack of means or... In short, she's not very approachable because I don't think she has a lot of hours to take care of that. There are a lot of Crohn's patients and so she's a bit overwhelmed. So not really follow up on a file, when you send questions you have to send messages to get answers, so it's a bit tiring." (4F1)[98]

" It is when you want to do a consultation with the gastrointestinal specialist yourself that you are confronted with these waiting times. I still have in the back of my mind, in the UZ [hospital] they also work with an IBD contact nurse. And that's where I think, if there's something really serious and I'm playing it through that person, I might be able to get to the professor in question faster. But I don't have any experience with that yet. " (4N2)[99]

The need for easier access to psychological care and reimbursement of this type of care was also identified. Interviewed patients expressed the need for psychological support, next to drug treatments and medical procedures. In addition to psychological support, other types of need were also mentioned, such as support from a dietician and a physiotherapist. Furthermore, therapeutic massages and even spa sessions were reported as being particularly important for patients' well-being.

"And a psychologist. That certainly has to be there, because it is important. " (4N1)[100]

"To have access, precisely, to be able to see a psychologist." (2F1)[101]

"At a younger age, psychological counselling would have been pleasant. Plus also someone who knows more about what support measures were in place. Although then there was almost nothing. " (4N2)[102]

"I think yes, maybe psychologist. Because yes, I went through this phase of denial. I come back to the three pillars, so dieticians, because I didn't, but I think that there are people for whom diet is a big factor. Psychologist, plus coach. I would say physical activity and what also comes to mind is physiotherapy, massage, that kind of thing." (2F3)[103]

"Therapeutic massages, even in a spa. Getting a massage in a spa also makes us feel good, even mentally, but it also does us good physically. Because I have a friend who studied that, so I was a bit of her guinea pig. It really feels good." (4F2)[104]

"I think it's a shame that gastroenterology doesn't focus on healthy nutritional advice in collaboration with dieticians. At least in the hospital where I am being treated, no attention is paid to this. " (Answer to online questionnaire)[105]

During the interviews, patients also reported some concerns when it came to their relationship with healthcare professionals. Some consultations were over in a matter of minutes, with a prescription for a blood test or medication, which could have saved the patient a lot of travel and time.

"So basically it boils down to: make an appointment on the internet, go to [name of the city] which is about twenty kilometres from my home, go and have a chat for a few minutes when frankly it wouldn't require you to see a doctor but hey, there you go. He lays me down for two seconds on his [...] stretcher. He palpates my large intestine for a few minutes to say he did something. And then he said, "Well, we're going to prescribe the medication." Frankly, sometimes it's laughable." (2F4)[106]

"But I also think in [region], if you ask a question like that, you will get an answer. But you have to ask the question yourself. Because if you say, everything okay, okay. But you've literally been in and out. The doctors prescribe the bloodtest. And that's it. And in the end, you've been inside for a maximum of five minutes. " (2N2)[107]

" I have also found in the meantime, nowadays, even if you want to get something done from a doctor, you have to drop the word inspection or give the feeling, in [region] anyway, that they could lose some of their money. And then, suddenly, everything goes. And then you notice, that mentality differs very much individually. " (2N2)[108]

Interviewed patients complained about the lack of a holistic approach. They criticised the over-specialisation of healthcare professionals, who did therefore not always consider all the factors of the disease. This led to the necessity of consulting several specialists and navigating through the different medical specialisations was not always easy for the patient. Nevertheless some patients benefit from such a multidisciplinary approach.

"I have six grandchildren. They all have bowel problems. But when they go to the paediatrician, not much attention is paid to the fact that their grandmother or aunt has Crohn's disease. [That's the big problem with doctors these days. They all look in boxes, only what interests them and the rest...] That's just like the gastroenterologist. He only looks at what he has to do. [...] Because the various departments don't talk to each other. Gastrointestinal sends you to Rheumatology. And Rheumatology says, 'what are you doing here? You are being treated by Gastrointestinal for your rheumatism. Yes, they send me here. But yeah, we can't do anything. Because you already take all the necessary baxters.'" (4N1)[109]

"And in hospitals, it's a consideration that isn't so much... uh... In any case, when you spend three hours in the day hospital for an infusion of [name TNF inhibitor], your blood pressure is taken before the perf is inserted, but you are never asked if you have any other symptoms." (2F4)[110]

"Often my case was discussed in a multidisciplinary team, so I think it was the difference compared to the follow-up of a simple gastroenterologist where there is no multidisciplinary approach, and I was also able to integrate a study to which I responded very well." (3F3)[111]

Patients regretted that they were not better guided through the various stages of their treatment, particularly with respect to the types of doctors they were expected to consult for follow-up. It was suggested that a real care pathway should be put in place, as for other types of pathology (e.g. diabetes or renal failure), with patient education and psychological support, or something similar to what has been put in place in France for patients with CD. This went beyond the purely medical care provided by a doctor to include other team members in the care continuum (e.g. nurses, social workers).

"That is to say, what would be interesting is to understand everything that is going on, to do a global treatment, that is to say, when you enter for a surgery where you have your pouch inserted, uh it's very nice that you have to go see a surgeon a month later or an ostoma therapist, but maybe see that you have to... Here I go to see a physiotherapist, because there is a relaxation of the abdominal wall, and it was my rheumatologist who told me today, several years later, that my abdomen is relaxed and that I need to work on it, I had not been told." (3F3)[112]

" In France, once a year, they are invited to go to the hospital where they are taken care of and have a comprehensive follow-up, meaning that they have a dermatologist follow-up, an ophthalmologist follow-up, a pulmonologist follow-up,... in short, all the related parts related to Crohn's disease. For example, a few years ago, I had erythema nodosum. I didn't even know it was due to my Crohn's disease. Nobody had told me about it. [...] So, compared to the hospital, having this more "360" vision on the different services that may be involved." (4F1)[113]

" And in the end, as a patient, you do indeed have to be at the helm, you have to take care of the care yourself, but you also have to be sufficiently substantiated, to be educated, to confirm and achieve that. " (2N2)[114]

" I will always come back to the same thing, of the collaboration that already exists, of doctor and nurse or perhaps also social worker. That has to be a collaboration. That's not just your doctor, there's so much more to it and I think when you start you need all those people and that needs to be offered. You have to be stimulated and followed up, that it shouldn't be I contact them, but they contact me even more. I have to say that this has improved over the last few years, but I think there is still room for improvement. And yes, forgetting it is not only medical and doing ultrasounds and blood tests and colonoscopies, but the ordinary conversation psychologically that I do miss. " (2N1)[115]

Several responses to the open-ended questions throughout the survey pointed in the same direction (Table 26):

Table 26 – Answers reported in the open text field of the survey related to patient's satisfaction with healthcare providers

- A more proactive multidisciplinary team - the disease was well treated but related problems/diseases were not always well managed
- Need for a more holistic care approach
- The overall management of the disease was inadequate. The GP said he was incompetent to manage the treatment, and the specialist showed no interest in the "other" aspects (vaccinations, skin, etc.). Lack of holistic care.
- Overall management of the patient, not specialty by specialty.

In the literature, **communication with the healthcare provider** was one the most important drivers of quality of care from the patients' perspective. However, only half of respondents from the IBD2020 survey, which was conducted during 2013 to 2014 and included patients from Finland, Italy, France, Canada, Germany, UK, Spain and Sweden, rated communication as excellent or very good.[36] In the European IMPACT survey, 54% of IBD patients indicated they **felt not being able to tell their physician something potentially important** about their illness and 64% felt their gastroenterologist did not ask good questions to better understand their disease status.[42]

Furthermore the treatment of CD (often) requires a **multidisciplinary approach**, which has been shown to improve outcomes and reduce hospital admissions and outpatient visits. However, an international patient survey showed that 41.5% of patients with IBD were not hospitalised in a specialist gastroenterology ward.[36] Furthermore, key members of such a multidisciplinary team: nutritionists, psychologists and IBD nurses, are not readily available at each gastroenterology department, due to logistics or financial constraints.[111-113] A survey in seven European countries and Canada showed that a third or fewer patients had access to a clinical nurse specialist, dietician, psychologist or social workers and significant differences were found between countries.[36] Those who did not have access to a certain professional, indicated an **unmet need for dieticians (47.5%), psychologists (33.1%), and clinical nurse specialists** (25.3%). Surprisingly, only a quarter of patients feel a need for a nurse specialist, while several studies show they are an important component of quality care[114] and also our findings suggest the importance of and satisfaction with care provided by a nurse specialised in IBD.

In the literature, a European survey in IBD patients (IBD2020) revealed that 50% of patients rated their care the coordination of their care as excellent or good and only 5.2% rated their care as poorly coordinated.[36]

Experience with the organisation of hospitals

The experience with the organisation of care was also influenced by the hospitals' organisation. In that respect, organisational changes in hospitals tend to dehumanise care facilities, using (patient) numbers instead of patient's name when calling patients in the waiting room, or scanning a ticket to signal waiting for a medical service instead of announcing presence to a secretary.

"It's very surprising, I think, because there's a lot of progress in human relations, and at the same time I find that the hospital, with all its protocols, is a little bit... it has other, less human sides. I take the example of blood tests, at the time there was a nurse who came out of

her little cubicle and called the person by name, the person would come to be shot, then she would call the next one. Now it's like at the butcher's, with numbers [...] Well, there you have it... the lanes now. Before, you had little arrows to indicate, look, this service is over there. Now it's lanes, you have to scan your ticket to know you've arrived safely. Before, you went to see the medical secretary to let them know that you were there. Well, it's small things but I think it's still quite dehumanizing." (4F1) [116]

When it comes to organisation of care within the hospital, interviewed participants shared thoughts about the presence of other patients in the treatment room. While some people appreciated receiving treatment in a hospital room shared with other patients (as it allowed for the exchange of experiences about the disease), others were uncomfortable with the presence of fellow patients and would have preferred facilities that offer more privacy.

"I explained to you the famous 3 hours I spent with the [name TNF inhibitor] at one time in the day hospital. Often we were next to someone else who had Crohn's disease, and I thought it was quite an interesting approach, because there was a lot of sharing of experience when we were a bit stuck in the hospital. [...] And frankly, I got a lot out of it at the time. This may be the only bright spot of the day hospital back when I had my [name TNF inhibitor]." (2F4)[117]

"And so they don't do anything with their day, and then when I see them eating their stuff... their sodas and... I'm a bit judgmental, but I'm like, "Come on!" There you go... No, I've never been able to talk to these people because... Yes, I'm probably a bit judgmental but I tell myself, if you were already doing all this, your illness would inevitably be a little better." (2F5)[118]

As already emphasised in the diagnosis and treatment, the perceived quality of care seemed better in university hospitals. Patients testified that they went to a university hospital to receive treatment that could not be provided elsewhere at the same level of quality, in their opinion. Sometimes this opinion is expressed when talking about "city hospitals" and "peripheral hospitals".

"So I think especially, in the process, and that's mainly the way, and also the completeness of information. Personally, I just see a discrepancy there, between university and university, to frame it objectively, without condemning institutions " (2N2)[119]

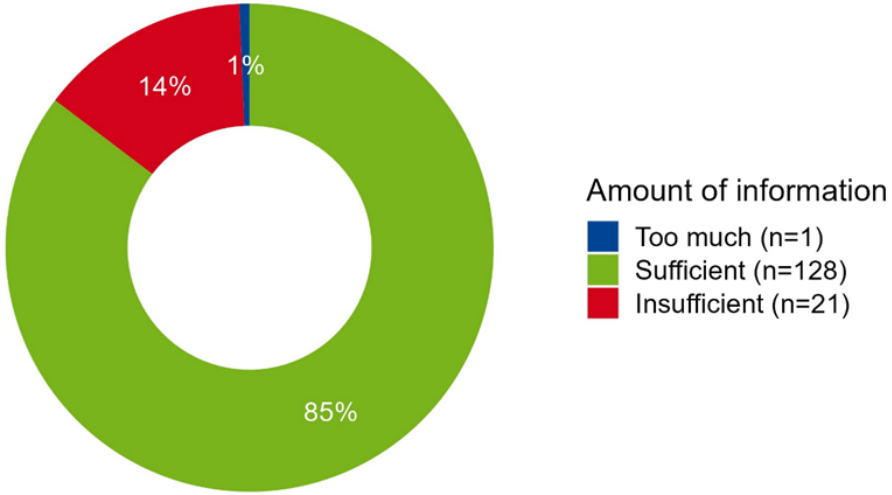
"If all hospitals were like [name university hospital], that would be wonderful, but obviously not all hospitals are academic, maybe not all gastroenterologists are as good as each other. So all of that put together, we won't necessarily have the same care I could say." (5F2)[120]

4.3.3.2 Quantity of information received

Healthcare professionals mostly provide sufficient information

Healthcare providers were generally effective in providing sufficient information, as reported by 85.3% of the respondents (n=128) whereas only 14.0% of the respondents (n=21) rated the amount of information received as insufficient (Figure 14). None of the respondents said they had not received any information.

Figure 14 – Amount of information obtained from healthcare providers (n=150)



Patients particularly appreciated extended, purposefully thorough consultations in which comprehensive information was given to them and in which they were given the opportunity to ask all their questions.

> *" So I went to the specialist, who explained to me that I'm going to get those biologicals, that it's with baxters. And then I went to the IBD nurse and then I don't remember exactly who told me what, but in the end everything was communicated to me well, with a cover, with a booklet, with everything you want. " (5N2)[121]*

> *" But now I have participated in IBD for the first time, the professor who is the whole group who gives support to Crohn's and also to colitis, so the whole group was once introduced on an afternoon from 5 to 8 or 9 at the UZ and that is the first time that I have participated in a group. So just listening, what is possible, what is happening and what we are all doing. [...] So there's a whole team behind that and they're basically putting that on those few hours, each individually explaining what their task and their job is. And that's why I'm also on Facebook, so I'm also in the IBD group." (5N1)[122]*

The information received may be perceived of better quality in a university hospital.

> *" Or indeed, being able to provide much more information to the patient. And then you see, for example, the contrast between, on the one hand, this [hospital], and on the other hand, the UZ [hospital]. The information you get as a patient is a world of difference. But ultimately, I think certain information contributes to the quality of care. And also the further follow-up of it. " (2N2)[123]*

Dissatisfaction was expressed because of a lack of proactive instructions (in relation to the patient's COVID vaccination status, for example), a lack of information on which doctors to consult, and the fact that information was shared too quickly and was sometimes difficult for patients to understand.

> *"Oh no, no, my doctor, uh... I'm telling you, sometimes I'm the one who has to ask for a vaccination: "Do you think I should get vaccinated, Doctor?" So "yes, obviously you have to get vaccinated, because you have low immunity." "Oh well, thank you for telling me!" "Do I have to go see the dermatologist Doctor?", "Oh yes yes, of course you..." ". But frankly no, it's not through my doctor that I found the info, no it's me." (2F4)[124]*

> *"Yes, because already in terms of information, what would have really helped me at the beginning was to say to myself, 'Well, there you go, make an appointment directly with a nutritionist or with someone specialized in food, because your illness is closely linked to that.' (3F2)[125]*

> *"What are the different types? Uh, what type I was in. The treatments, how it worked... Which I didn't have at my first gastroenterologist. Who made good diagnoses, who follows me up, but who in terms of dialogue*

with the patient... That's it, it's a bit... You don't spend a lot of time in his office. And so in terms of explanations it was a bit light." (2F2)[126]

Importance of how the diagnosis was communicated

Once the diagnosis of CD has been made, patients emphasised the importance of how the doctor communicates this news. They cited elements such as compassion, frankness and the time devoted to explaining the disease and its consequences as being crucial. Positive (thanks to these elements) and negative experiences with the announcement of the diagnosis were reported. Being able to ask questions, having a doctor who took the time to explain, listened and showed compassion are elements that were cited to contribute to an overall positive experience.

" "Do you want to see a nurse who will explain the disease to you at length, you can take someone from your family with you" and my mother had a hard time accepting the news – more than I did in the end – and telling herself that it was a disaster so I took my mother with me to the interview and so it was really a one-hour appointment where I was able to ask all my questions where I really I had all the information and then they all wrote booklets about the disease, I had all the services to which I was entitled. That's it, it was, I'm going to say this, it's nice." (1F1)[127]

"As someone who is in research etc., there is another dimension where I could ask all the questions I wanted. He knew all the literature, and so that side was really the right side for me. He knew how to answer my questions, being extremely rigorous about what he said, nuanced, [...] So yes, it's heavily influenced [the announcement of the diagnosis] by the way you're told and the person who tells you, so... It didn't feel like a big splash." (2F5)[128]

Conversely, negative experiences were also described in situations where the doctor did not show enough compassion, where the doctor did not take the time to give in-depth explanations or where the provided information was not clear enough.

"In my job, I have a lot of compassion and I find that sometimes, in fact, doctors don't put themselves in the patient's shoes. A modicum of compassion, I mean, it's not... It's not a flu that we have... It's an autoimmune disease that we're going to keep for life and we still have to deal with it; It's not easy." (2F1)[129]

"That was actually strange, after the colonoscopy, when I woke up, he would come and mention it and then he would say yes, we are going to make a follow-up appointment and then we will do an explanation, but that was so precise between one patient and the other who then had to come in for an examination, Yes, that it was said like that. " (3N1)[130]

"It's during that famous morning dorm with the head nurse, you have the titular doctor with his whole horde of assistants and then... They have results to communicate to you, and you are lying in bed, and you are told "oh yes indeed, the additional tests have confirmed the disease". I think that's how it happened, nothing more and nothing less." (2F4)[131]

" Nothing, but a book to take home and then they would have told me, come back to the consultation and then we will discuss it. I thought that was a bit of a shame actually. Well, maybe they said, of course because I'm a nurse they might think that I have a different background and that maybe you need less explanation. I don't know. But at the time, it's a shame that you get very little explanation. I personally think. " (2N1)[132]

"The time was not as attentive to the well-being of the patient as it is now. I find that it has really changed a lot. He didn't announce it to me in a good or bad way: he just announced it to me. What was really funny is that he had a young medical intern that day [...] who asked me questions that were not very smart, like 'Oh, you have Crohn's disease, how many times have you already had surgery?' I said 'never!' 'Oh, but it will happen soon!'" (4F1)[133]

" [...] Doing the cliché in the sense of okay, that it's a kind of band work, as it were. I was okay with it, we have a colon, we have a diagnosis and that's it. And we will do the further follow-up in further consultation with the GP or not. But I do think it is the way in which it is actually determined. Personally I think it could have been better in terms of communication, I think indeed the way it was worded. I can still remember very vaguely, but it is something that has also left an impact. Then you immediately think oops, such a stamp that you get on you. " (2N2)[134]

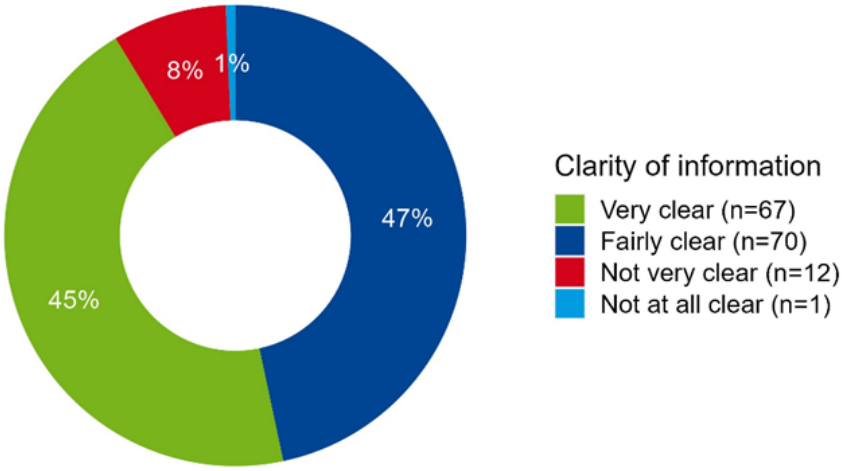
The literature showed that information needs varied according to age and disease severity. Qualitative research in Sweden showed that patients with a more severe, active IBD indicated a greater need for information, especially in the areas of work disability, stress management and treatment complications. In particular, they would have preferred to receive more information after their initial diagnosis and during periods of severe flares.[115] Furthermore, healthcare providers may need to incorporate family planning and discussion of possible pregnancy with IBD patients, when indicated, to mitigate the risk of misinformation regarding the genetic transmission of the disease.[116, 117] A survey in over 40 countries indicated that IBD patients have poor knowledge about the impact of IBD on fertility and pregnancy and healthcare providers do not sufficiently inform their patients on these topics.[116]

4.3.3.3 Clarity of information received

The majority of the respondents perceived the provided information as very or fairly clear

A total of 137 respondents (91.3%) found the provided information to be very or fairly clear, while 8.7% (n=13) reported that it was not very clear or not clear at all (Figure 15).

Figure 15 – Clarity of information provided about CD (n=150)



Patients were generally satisfied with the clarity of the information they received. However, some of them would have liked the consequences of the disease to be expressed more clearly (e.g., possible progression of the disease, severity and side-effects of treatments, the stages to expect and rationale behind).

"So no, the information wasn't... uh... No, the information was not clearly given and all the aspects of the disease, what was going to change, the heaviness of a treatment because in the end we are given pills, we don't realize what it is, in the end it is still a treatment that I consider quite heavy, with very significant side effects, And we don't talk about that." (3F2)[135]

" If I don't understand they have to make me, I waited until I understood it, so it's already difficult. It's because I've seen so many of them pass by, I don't take it from an assistant if he doesn't make the effort. I don't put any more energy into it. My wife thought that was weird too, and

when you have the professor and you explain that, they agree with you. You have to know what they're going to do and why they're going to do it. " (5N1)[136]

Type of additional information requested by respondents

The high number of requests for treatment information (n=127) highlighted the importance of addressing the therapeutical possibilities. Patients were keen to understand the range of treatments available, including pharmaceuticals, surgeries, dietary adjustments, and complementary therapies. This underscored the crucial role of healthcare providers in providing information to empower informed patient decision-making. Similarly, the substantial interest in understanding the condition itself (n=96) underscored the need to improve patient comprehension of CD. Additionally, the significant number of respondents interested in the disease's progression (n=83) highlighted CD's dynamic and unpredictable nature. This information provided patients with realistic expectations for managing their condition over time (Table 27).

Table 27 – Type of additional information requested concerning CD (n=150)

Kind of information	n (%)
Treatment options	99 (66.0)
Condition	96 (64.0)
Evolution of state of health	83 (55.3)
Clinical studies related patient's treatment	46 (30.7)
Patient associations	45 (30.0)
Support available	31 (20.7)
Costs of treatment and own expenses (not reimbursed by health insurance)	30 (20.0)
Access to own data	25 (16.7)
Accompaniment, psychological support, coaching	24 (16.0)
Establishing the condition or diagnosis	22 (14.7)
Patients' rights	19 (12.7)
Therapeutic education	18 (12.0)
Places where treatment is possible	16 (10.7)
The return home and possible arrangements (or alternative accommodation)	5 (3.3)
Rights of informal carers	5 (3.3)
Other[1]	5 (3.3)

[1]Other = "As much as possible", "Long term side-effects of treatment", "Benefits – parking card", "diapers", one empty answer

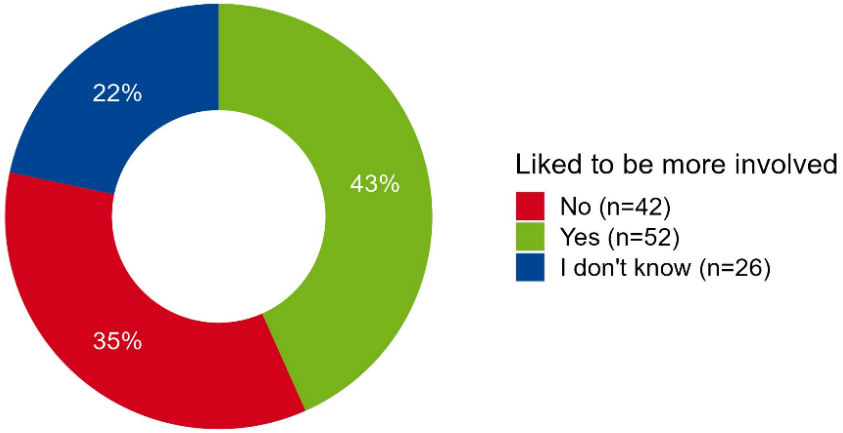
A survey among IBD patients from 2013-2014 in Europe showed that they felt inadequately informed, 3 months after their diagnosis, in the following categories: 24.4% had no discussion on IBD characteristics, 40.5% had not discussed the risks of treatment, 37.4% had not discussed the impact of smoking and lastly 27.3% had not discussed the impact of IBD on work/education.[36] Half of them (50.9%) rated the communication of their health care provides as very good or excellent.[36] Another survey (IBD GAPPS Survey) among CD patients, conducted in 2019, on the global assessment of patient and physicians unmet needs (n= 1 368) in North America and Europe revealed that almost half of the patients were well informed about new treatment options (46%).[118]

4.3.3.4 Involvement in treatment choice

One third of respondents expressed a desire to be more involved in decision-making about treatment

Among the participants for which this question was applicable[1], 43.3% (n=52) expressed a desire to be more involved in decisions regarding their treatment(s) for CD, 21.6% (n=26) responded "I don't know" and 35.0% (n=42) indicated that they do not want to be more involved in the decision-making (Figure 16).

Figure 16 – Involvement in treatment choices (n=150)[1]



[1]30 participants indicated that this question was "Not applicable" to their situation.

Examples of being listened to and involved in treatment choices were reported during the interviews: changing or not the treatment towards self-injection, the time between two infusions, collaboration with the doctor to choose the best treatment.

Different experiences were raised: in some settings patients were just invited to follow the prescription, in others they were well-informed about the different possibilities and had the last word on the final decision. They stressed, however, that they trusted their doctor, as they saw him or her as the specialist.

> *"I have to admit that I trusted, afterwards, when I got tired of taking the first treatment, with [name immunomodulator], I said... That's when we talked about it, we moved on to [name TNF inhibitor]. So there was still an exchange in relation to all of that." (2F2)[137]*

> *" But we decided that together. And afterwards, with the flare-up, it was also very well discussed with the gastroenterologist that they should keep in mind with the rheumatologist that we have to work together and look at it together. And what I have always emphasized is that if you mention other complaints to the gastroenterologist, they immediately refer you to someone else " (2N1)[138]*

> *"And here, for example, well, as it's getting better, the treatment is working, I was asked if I wanted to go for injections or not. And uh, I wasn't ready for the injection yet so I said "no, let's continue with the perf"." (1F1) [139]*

> *" The contrast is evident again between [hospital], for example, when you say okay, we're going to start with this, and it's like okay, this is it. While in [region], they literally had brochures, you name it, those and those options, that you can choose from that, that, that or that. So you did indeed have much more say, much more control. As it were, patients had the last word in [region]. Then you could really say. " (2N2)[140]*

> *"At one point he told me 'you absolutely have to take corticosteroids' again', I said 'no, I don't want to'. So basically we made a deal (laughs), ... It's laughable but that's the way it is." (3F2) [141]*

> *"And so there you have it, when I told him, 'I want to...' I prefer if it's possible to inject it myself", maybe he in his choice of treatment, maybe he has two identical treatments he will prefer one treatment or I can inject myself. Maybe, I don't know. In any case, he listens to all this." (3F2)[142]*

Examples of lack of listening or involvement were also reported, i.e. not having been listened to or not having sought to change the treatment prescribed. However, there seemed to be a fear of contradicting the doctor who was considered an expert, and who also held the keys to other elements impacting the patient's life such as the ability to give the patient sick leave or not.

"There, in fact, the gastroenterologist started increasing the doses of [name TNF inhibitor]. And the doses were getting bigger and bigger. And then there you go, in the support uh... I didn't feel listened to anymore." (2F3) [143]

" Yes, in [region] it was indeed a bit less. There was also less participation. That was like yes, look, we're going to give you that. No statement or no explanation was made. Look, there's all that. We'll start with that and then we'll see step by step what works. This is different at the UZ. That really gives you such a schedule of look, these are all possible treatments. You're sitting there now and it's ... Yes, the moment it is necessary, it will be discussed and then what the possible options are. " (3N1)[144]

"No, I think that...At least at the time when there were molecule switchovers... When you go to see a gastroenterologist, you are often in a situation... I'm going to say weakness, because you're going to see it because you're a little worse in terms of your symptoms, and so whatever he tells you, you take it at face value. Often this is accompanied by sick leave to be able to breathe. So in the end, you say thank you to the package without asking yourself too many questions." (2F4)[145]

" (...) I didn't actually dare to really contradict the doctors because I said to myself "they know what they're doing, it's their job" and I said to myself "well, okay, we change, we change, we change our treatment again". I trusted them. And hey, there's one I shouldn't have, after all." (2F1)[146]

A survey from 2019 among CD patients on the global assessment of patient and physicians unmet needs (n= 1368) in North America and Europe revealed that more than half of the patients were satisfied with their involvement in disease management (56%) and setting of treatment goals (51%).[118] Only 11% of patients felt that their physician did not consult them at all regarding treatment decisions. On the other hand, a survey among IBD patients in Europe (2013-2014) showed that 72.9% of patients (n= 4 987) were always or nearly always involved in treatment decisions.[36]

4.3.3.5 Diagnostic delay

Time between the first symptoms and the decision to consult

A majority of individuals decided to seek consultation with a healthcare provider more than one month after the first symptoms appeared.

Twenty-four percent of individuals waited less than a month from the onset of their symptoms before deciding to consult a healthcare professional (Table 28).

Table 28 – Distribution of participants by time between first symptoms of CD and decision to consult (n=150)

	n (%)
Less than 1 week	4 (2.7)
1 week to 1 month	32 (21.3)
1 to 3 months	41 (27.3)
More than 3 months	58 (38.7)
I don't know	15 (10.0)

It appears from the interviews that the decision to consult followed heavy symptoms. The intensity or the recurrence of the symptoms prompted consultation. In some cases, it is a specific event (e.g. uncontrolled need to go to the toilet) that made the patient realise that something was wrong. From the interviews, it appears that patients usually first turned to their GP or, in severe cases, to emergency care services.

"I asked for the car to be stopped, uh I was with my partner at the time, and I said we have to stop the car I have to go to the bathroom, and that I went to the bathroom on the side of the road. At that point, I said to myself "no, if I don't know how to hold back, if I don't know how to wait until I'm in a place where I can go to the bathroom, it's really weird,

especially on vacation. I tend not to have too many problems. So I thought it was weird. When I got home, I went to see my GP." (2F5)[147]

" I know I had symptoms at the time that I didn't know what that is. But I vomited a lot and I always had cramps and I'm not one to go straight to the doctor, so it just dragged on and on. I went to the doctor, got a referral, and suddenly I had Crohn's disease." (5N2)[148]

" [...] It had been a week I remember, so I sent for my GP. My GP told me "well, [patient's name], you're having a little gastro", uh a week off, and it still wasn't okay, the pain was getting worse and worse, I couldn't get up, I had a high fever, I lost more than 7 kilos in a week, and uh then I called my doctor back and I said "Listen, There's still something, it's not right" and from there he actually sent me to the emergency room." (2F2)[149]

Time between the decision to consult and the first consultation

One in three respondents had to wait more than one month to attend a first consultation, once the decision to consult was taken.

Table 29 illustrates that 22.0% of the respondents (n=33) successfully had a consultation within less than one week after deciding to consult a healthcare practitioner. However, 36.0% of the respondents (n=54) had to wait more than one month.

Table 29 – Distribution of participants by time between decision to consult and first consultation (n=150)

	n (%)
Less than 1 week	33 (22.0)
1 week to 1 month	42 (28.0)
1 to 3 months	36 (24.0)
More than 3 months	18 (12.0)
I don't know	21 (14.0)

A certain latency from the patient was reported in the interviews, which can also explain the time needed to get a consultation.

"That's my fault, in the sense that I am... It's not that I'm anti-doctor, but I've always considered, again it's a bit stupid of me being in the medical world, that the more I stay away from doctors, the better off I am. So that's it, so I'm the one who dragged things out a little bit as well." (3F1)[150]

Time between first consultation and diagnosis

One in five survey participants received the diagnosis more than a year after their initial consultation.

Nearly 20% of participants (n=29) received their diagnosis of CD within a timeframe of two months to one year. Conversely, the diagnosis for almost one in five participants extended beyond one year (19.3%) (Table 30).

Table 30 – Distribution of participants by time between first consultation and CD diagnosis (n=150)

	n (%)
Less than 2 weeks	36 (24.0)
2 weeks to 2 months	49 (32.7)
2 months to 1 year	29 (19.3)
More than 1 year	29 (19.3)
I don't know	7 (4.7)

Difficulties to diagnose CD

As stated above, the first contact with a health professional is usually a GP. Given the non-specific nature of symptoms, the first differential diagnoses that were considered concerned more common and less severe gastrointestinal pathologies, such as irritable bowel syndrome (IBS) or viral gastroenteritis. A certain frustration was sometimes expressed by the interviewed patients who even wonder if the GP knew about CD.

"So I went to see my GP and he said, 'Oh, it's not a big deal!' [...] I'm going to say it was more the attending physician who... even he finally wondered if he really knew what Crohn's disease was because finally I typed my symptoms on the internet and it came out, it was in the first stuff that came out." (1F1)[151]

"And I even think my GP wasn't quite aware of the disease, because when I came in with my abscess actually, so I actually had a fistula... That's how it happened, it was oozing and in fact my GP told me "oh yes, you have a small abscess, I'll give you a little antibiotic, it will pass"." (2F2)[152]

"Who told me, 'No, it's because you're eating too spicy, you're probably sick to your stomach, there's no problem', he gave me a little bit of vitamins. It's passed. I don't know why. I trusted what he told me anyway. Now it came back a week or two later too, with the same intensity." (3F1)[153]

" Yes yes, so, so I had painful diarrhoea and was treated for everything. And around 11-12 years old I get cramps in my abdomen, so yes, which is not illogical with that diarrhoea. And then there's a military doctor, because my dad was a gendarme. So that was a doctor who also came into the gendarmerie, an ordinary family doctor. And he said: " you have to go with that child, he certainly has appendicitis, you have to investigate that ""(5N1)[154]

" I know I had symptoms at the time that I didn't know what that is. But I vomited a lot and I always had cramps and I'm not one to go straight to the doctor, so it just dragged on and on. I went to the doctor, got a referral, and suddenly I had Crohn's disease." (5N2)[155]

Patients shared the impression that the doctor had not investigated the problem sufficiently and had made a diagnosis that subsequently proved to be incorrect.

"I've been to the doctor, I've been to him two or three times. I went to a theoretically specialized doctor. I don't remember which hospital it was at... So that was the first symptoms, in August. I was at the doctor's office until November. I had an appointment with a specialist in December. Who hasn't... Nothing found. Who hasn't explored masses either." (3F1)[156]

"He did a mini colonoscopy; I was just asleep for a few minutes. I came out of there being told that I had nothing, that it was just a little bit irritable bowel, and that I needed to stop certain foods." (2F5)[157]

However, the diagnostic process could be accelerated thanks to specific experience/background of the GP with regard to CD.

"When I got home, I went to see my GP, who immediately ... She actually worked... She did her internship as an intern in the gastroenterology department and that's where I had the chance, uh I think in my career that's what made things easier, was that she asked for an appointment for me." (2F5)[158]

Sometimes, patients only received the correct diagnosis when they went to a university hospital.

"I first consulted in small polyclinics, uh... neighborhood. I was a student so I didn't know Brussels very, very well at the time [...] well, it was a bit of a bit of a blurb, and then I was lucky at some point, as I was being sent from one to the other, to have a friend whose brother was a very young paediatrician and who worked at [name of university hospital], and who said, "Look, she absolutely has to go to a university hospital, whatever it is," that's it. [Name of university hospital] was the closest, and I ended up at [name of university hospital], and there it was diagnosed very quickly." (4F1)[159]

"We fiddled a little bit with the diagnosis, I have to admit that..." I even went as far as [Name of University Hospital] in an ambulance to see a specialist at the time, to confirm the disease. I remember being hospitalized for a long time, I think I stayed in the hospital for a month

and a half, on an empty stomach, with a central channel – which had to be changed twice by the way – well... I think that, at the moment, compared to that, it's a little bit simpler. But that's the memory I have of it, a long diagnosis, a long hospitalization, and a trip to the university hospital to confirm the diagnosis." (2F4)[160]

" Yes. A university hospital at that time is further away. Especially in terms of research. And the rest will follow. Yes, those are smaller hospitals. I think now, yes, right a study like the doctor has, I don't think they do that in small hospitals. " (4N1)[161]

"I've always kept the same gastroenterologist, we just went to see another gastroenterologist at [university hospital] ... Just to have a... Because hey, it's still chronic diseases and everything so we wanted to have a second opinion to confirm the first diagnosis." (2F2)[162]

However, going to a university hospital represented a certain obstacle, either because of the distance, or because it is an unfamiliar environment.

"And it's true that for me, I don't always want to travel so much to be taken care of. But I also have to accept that I don't have the health professionals who are perhaps... I know that in university hospitals, for example, they have a nurse who is dedicated to this... On the periphery, there is no such thing. [...] Because the day hospital in the university hospitals you have to park, to pay for a parking space that is sometimes expensive. You have to go that far, it's an environment I don't know, the university hospitals." (2F4)[163]

According to interviewed patients, the diagnosis of CD was sometimes delayed because of a compartmentalisation of medical specialisation, each doctor being concerned only in his or her specific domain.

"What I often notice with doctors is that they have their specialty, so he looked at the gynaecological aspects. My baby was fine, so he made me understand that the rest was in my head. But it wasn't in my head, I was really not well. " [...] Because it wasn't related to the baby, and finally the first gastroenterologist I saw, well after him he only saw my intestine." (2F3)[164]

" I mean, I've been admitted to the emergency room once. And then I'm hospitalized. Then assistants found that I was suffering from lupus. That I had a tumour in the uterus. And that my intestine was so constricted that I had to have surgery. Rheumatology afterwards, to which I was referred as an ambulatory patient, they said, 'what are you doing here, lupus, you just have rosacea and a little red cheeks, but that's not lupus'. The gynaecologist who laughed it off like, what, 'what's that here? Tumour in your uterus, you have a small tilted uterus.' So that was gone too. And the presumed severe narrowing for which I had to be operated on, that was also gone. But those were all assistants who did their very best, but who immediately think of the worst, because a UZ is also a referral hospital, if the others don't know anymore, you go to the UZ. " (4N2)[165]

The diagnosis of CD has often been made following several types of examinations, depending on the case: ultrasound, biopsy, blood test, stool analysis, gastroscopy, colonoscopy, entero-MRI. These analyses could be perceived as long and burdensome.

"But it went on for a long time and at the time we were doing... The whole series: colonoscopy certainly, we made colomba... We were doing a whole series of exams but extremely... Well, I was 18 years old and didn't know anything about it, so it was extremely difficult to live with." (2F4)[166]

The long time that often elapsed between the first consultation and the diagnosis of CD was, amongst others, attributed to the time required to get appointments to carry out the diagnostic tests. Some patients felt that this period of time was too long, while others felt that the process was rather quick.

"So I had tests and was finally diagnosed in 2013. [...] I waited almost two... I'm going to say at least a year and a half between the time I said to myself "hey, there's something wrong" and doing the process. [...]

Yes, I think it was towards the end of 2012 that he sent me to a specialist and uh, well the time to get the appointments etc., I had the final diagnosis in... I think it was early 2013." (3F2)[167]

" That was then in 1976. And the diagnosis was made in 1994, thus that is 18 years later. Yes, 18 years later yes. " (4N1)[168]

" It took about ten years to make the diagnosis. And after ten years when people said 'it's Crohn's disease', I had already read about it myself. " (4N2)[169]

"Well, it was quick... Yes, I think it was quick, it lasted two or three months... And I did a CT scan, I think there wasn't an MRI yet, an ultrasound, and then, stool analysis and then we saw that it was Crohn's disease. Yes, that's right. It was very fast." (4F2)[170]

Patients who considered the waiting time too long reported that the delays were particularly long due to the time needed to obtain an appointment for a magnetic resonance imaging.

"And then I had to wait [...] 2 and a half months before having a first appointment with the gastroenterologist. " [...] "So on the other hand, I had called the same day of the colonoscopy to do it on February 15, and when I called to have the entero-MRI, I was told that I didn't have an appointment before July 17 and so that's a very long waiting time. [...] And that's quite challenging to think that you have to wait months and months before you have all the exams." (1F1)[171]

"On the other hand, there are very long delays for MRIs, for CT scans, well that's absurd, you have to contact... I had to contact several hospitals to get my MRI done at the request of the rheumatologist. It was three months huh, for the MRI huh. Finally I tried at another hospital and there was a place that had become available and it was a month of waiting, but for the psychiatrist it was the same thing, you had to wait more than a month before seeing the psychiatrist. So still it's.. Yes, there are long... longer and longer waiting times." (3F3)[172]

Certain patient characteristics conferred an advantage in terms of obtaining timely appointments. For instance, patients who were themselves healthcare professionals, who had a relative who was a doctor or who had been followed-up for a long time in the same hospital were able to secure medical appointments more quickly. Taking part in clinical trials also enabled patients to have a medical appointment more quickly.

"Well, I think maybe it's also because I work there, so since I'm a colleague, he may have taken things a little bit quicker" (2F1)[173]

"I'm lucky to have a dad who is a pulmonologist and who also did some research and so very quickly, we thought about Crohn's disease. Finally, given the symptoms, he discussed it with gastroenterologist colleagues so I was seen, uh... I don't know exactly anymore but maybe 2 or 3 weeks after the onset of symptoms by a gastroenterologist at [name of hospital]." (2F3)[174]

" That's the downside of me. I've been there for so long now, I've never had to wait. So also, I mean, yes. I always try, so with that I have the phone number of the prof as well. " (5N1)[175]

"And then afterwards, well [name of doctor] contacted me to see if I wanted to enter the study [name of clinical study] I accepted and there she managed to find me a slot. What was it like a week after she called me, I had an appointment for the enteric MRI so I had it." (1F1)[176]

Also in the literature, the delay in diagnosis of CD was an often reported problem, mainly attributed to a lack of awareness, non-specific symptoms, and limited access to specialised care.[119] A comprehensive survey in 25 European countries was conducted from 2010-2011. This survey noted that only 54% of IBD patients received a definitive diagnosis within a year from symptom onset. However, in 45% of IBD patients the search for a definitive diagnosis took longer than a year and in 17% even longer than five years.[42] A significant proportion of patients (56.7%) resorted to emergency care before obtaining a formal diagnosis and 12.3% of patients had to resort to emergency care at least five times before the diagnosis was made.[36] A

timely diagnosis is considered very important since research has shown that a delay in diagnosis is associated with an increased risk of surgery, intestinal obstruction, a more complex disease and a lower quality of life.[120-123]

Time between diagnosis and first treatment

A large majority of respondents (80%) began initial treatment within one month of diagnosis

About a third of respondents (38.7%) received a first treatment less than one week after diagnosis. For almost 15% of respondents, treatment was initiated more than one month after diagnosis (n=20) (Table 31).

Table 31 – Distribution of participants by time between diagnosis and first treatment (n=150)

	n (%)
Less than 1 week	58 (38.7)
1 to 2 weeks	30 (20.0)
2 weeks to 1 month	30 (20.0)
More than 1 month	20 (13.3)
I don't know	12 (8.0)

4.3.4

4.3.5 Accessibility

4.3.5.1 Treatment availability

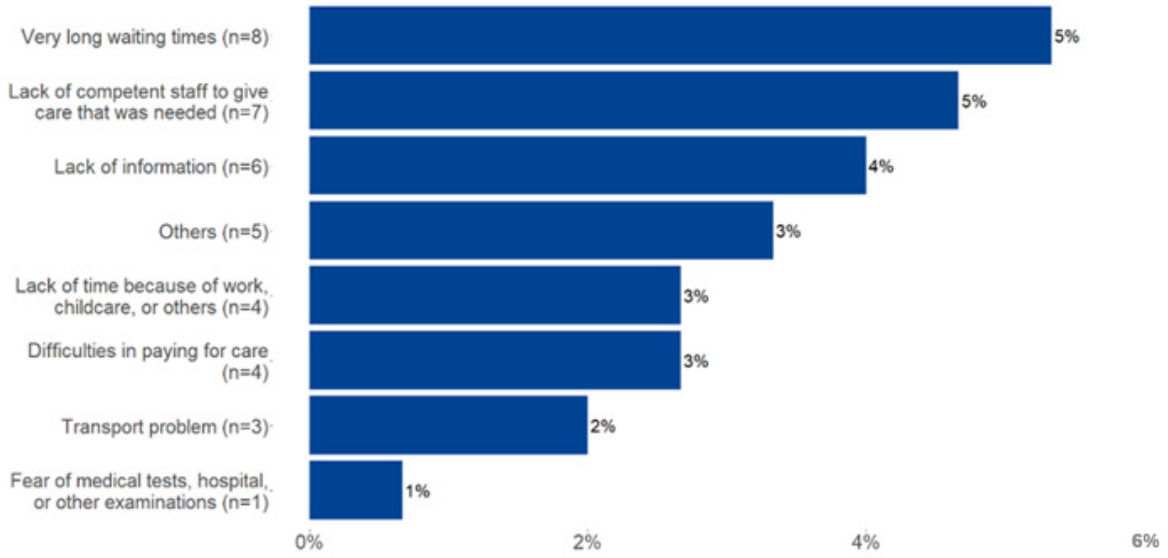
No data found.

4.3.5.2 Forgone care

Care perceived as needed but not received

To the question *'Is there care for CD that you did not get when you needed it?'* 13.3% of the respondents (n=20) answered 'Yes'. The most common reported reasons for forgone care were the very long waiting times to get access to care (5.3%), the lack of competent staff to give care that was needed (4.7%), and the lack of information (4.0%) (Figure 17).

Figure 17 – Causes of forgone care mentioned by survey participants (n=20)



The IMPACT survey (2010-2011) across 25 pan-European countries showed that access to specialist care for patients with IBD was good, as most respondents saw a specialist within a year from the onset of symptoms.[42] However, patients felt that the **access to their IBD professional was inadequate** and could be improved.[42]

Forgone care due to geographical barriers

During the interviews, patients also highlighted geographical barriers to receiving the care they need.

"Same thing, [name immunomodulator A], I had to do an intravenous induction, so I still had frequently... In addition, I live in [Place of Residence], well that's my choice to be followed to [Place of Care], but so there was the road so it was a day when I wasn't working." (2F3)[177]

" Especially if you want to go to specialized care, in my case you have to bridge a certain distance, [region-region]. Indeed, that is not next-door. Then they say, for example, to colonoscopy, where you have been put to sleep with what is it called again [name general anaesthetic A] and [name general anaesthetic B] so that you officially cannot drive the car. " (2N2)[178]

Key points

- One of the most important unmet healthcare need expressed by patients, is the need for improved treatment or management of gastrointestinal symptoms. These gastrointestinal symptoms profoundly impact patients' HRQoL, psychological well-being and social life.
- Current medical treatment is associated with a range of potential safety concerns (e.g. increased risk of infection, malignancy or hepatoxicity) and a high experienced burden of side effects, especially with long-term treatment.
- An accurate assessment of disease activity relies on invasive procedures to potentially identify early treatment failure. However, such procedures are inconvenient for patients and may negatively affect compliance with their monitoring strategy and thus ultimately clinical outcomes.
- Almost half (48.7%) of the respondents postponed their decision to seek medical attention until a period exceeding three months following the onset of symptoms. Once the decision to consult a healthcare professional was made, half of the respondents (50.0%) were able to find medical attention within a month. Almost 60% (56.7%) of the respondents to the survey received the CD diagnosis in less than two months, while 19.3% received the diagnosis more than a year after their initial consultation.
- A comprehensive survey in 25 European countries (2010-2011) noted that only 54% of IBD patients received a definitive diagnosis within a year from symptom onset. However, in 45% of IBD patients the search for a definitive diagnosis took longer than a year and in 17% even longer than 5 years.
- The most common treatments for CD were drugs, nutritional support and surgical procedures. A quarter of respondents (24.8%) received surgery. More than 85% of the participants expressed being "very satisfied" or "satisfied" with the treatment they received, despite the fact that 17.9% of them considered the treatment "very burdensome" or "rather burdensome". The most prevalent reason was attributed to side-effects (84.6%). Additional barriers or obstacles following a treatment include: time consuming treatment or distance to the place of care.
- The most reported side-effects of the CD treatment were fatigue or exhaustion (66.9%), weight gain (32.4%), skin irritation or eczema (27.6%), nausea and/or vomiting (21.4%), diarrhoea (20.0%). Among the ten most frequently reported side-effects, diarrhoea, and fatigue or exhaustion were identified as the most burdensome by respondents. Given the constraints they could cause, some patients doubted whether it is worth continuing treatments. It was often unclear, however, whether diarrhoea and fatigue or exhaustion were symptoms of the disease or side-effects of the treatment.
- Patients indicated high levels of satisfaction regarding the consulted healthcare providers, with over 75% expressing satisfaction. They emphasised the importance of the doctor's announcement of the CD diagnosis: elements such as compassion, frankness and the time devoted to explaining the disease and its consequences were all cited as being important. When unsatisfied, the main issues identified during the interviews included the limited availability of practitioners, lack of competences in case of post-operative complications, inappropriate medication (dosage) or a perceived lack of professionalism in general. The lack of an holistic approach was also highlighted: patients criticised an over-specialisation of healthcare professionals, who consequently did not always consider all the factors of the disease.
- Although the quantity and clarity of information provided was deemed sufficient by respondents (85.3% and 91.3%,

respectively), a more effective communication by healthcare professionals would be appreciated. Dissatisfaction was expressed because of a lack of proactive instructions, a lack of information on which specialists to consult, and the fact that information was shared too quickly and was sometimes difficult for patients to understand.

- **In the literature, communication with the healthcare provider has been identified as one the most important drivers of quality of care from the patients' perspective. However only half of respondents from the IBD2020 survey rated communication as excellent or very good.**
- **Patients expressed a desire to be better informed about the consequences of the disease. In addition, 34.7% of the survey participants expressed a desire to be more involved in decisions regarding their treatment(s) for CD.**
- **The treatment of CD (often) requires a multidisciplinary approach, which has been shown to improve outcomes and reduce hospital admissions and outpatient visits. Key members of a multidisciplinary team include nutritionists, psychologists and IBD nurses.**

4.4 Unmet social needs

4.4.1 Impact on social life

Daily lives and social activities impacted by CD

During the individual interviews, patients said they think twice before accepting social activities. It is not uncommon for them to refuse activities out of fear of finding themselves in embarrassing situations, particularly if access to the toilet is not easy.

> *"From a social point of view etc., uh... Sometimes when I go out and all that, people say to me, "Hey, don't you have a drink, and don't you do this?" yes, but I'm careful because I know that when I have one drink, one too many drinks well, it takes me 2-3 days to get over it, or I have more easily... gastroenteric problems and so there you have it. And so it's not always great... I'm not always super cheerful, especially since I have to say "oh yes, I'm sick" so it tends to ruin the atmosphere! (2F2)[179]*

> *" The thing that bothers me psychologically is always so when you go somewhere that you always think 'ah, maybe I should go to the toilet.' That does play a role and that's in social life, for example going to concerts or something, that's something I don't do. Because in such a portable toilet, and then there might be a long queue, so I just rule that out. Going into town at an event or something, I usually don't do it with the thought of " am I going to be able to go to the toilet there? " " (5N2)[180]*

> *"Sometimes we're afraid to go to people's houses, for example to sleep in people's homes, I don't dare to sleep too much. Because sometimes the consequences are a little embarrassing, but if after a while, to have said I don't do all this, you end up getting used to it and you live well with it." (5F2)[181]*

Refusing social activities can lead to isolation. In the open-ended questions of the online survey, difficulties in remaining available and involved in family life were mentioned. The disease can cause patients to withdraw into themselves. Changes in physical appearance due to illness or treatment can also increase the desire to isolate from social activities.

> *"For a long time I didn't dare to leave the house, because you also have to know what treatments you're given, well, it's treatments too... At a certain point I gained 30 kilos, so the body changes, you have to integrate this disease. I didn't dare to leave my house at all for fear that I would have an accident, I didn't want to see my friends anymore because I wasn't well. At one point, I actually really cut myself off from the world... And a lot, yes a lot of judgment, a lot of judgment and then also physically." (2F1)[182]*

" There are things I can eat, but yes, you're at home, I've been home since 1983, 1984, so that's also 40 years. You get used to that too. I can be here all week without seeing anyone else. " (4N1)[183]

Impact on leisure activities

Leisure activities (e.g. sports, exercise) have also been highlighted as a part of everyday life that needed some adjustments or restrictions. Either because patients no longer had the energy to participate in sports, or because sporting activities were not always adapted to their new needs. Again, embarrassing aspects of the disease was also reported as being an obstacle to exercise and participate in sports.

" I'm now going to play billiards once every Friday evening. So that's normally going to go from seven o'clock to nine and a half. I go from eight o'clock to ten o'clock/half past eleven. I then play two matches and my lights are off. [...]. But your energy that you put in just to be able to play your points. Takes a lot of energy for me. You can't explain that to someone else. I come home, my light is off. In fact, you've only been away for two and a half hours. " (5N1)[184]

"Maybe socially, yes I actually I never stopped exercising even in crisis I never stopped going out, I'm just – how can I tell you – adapted a little bit to the situation what I mean, to exercise, I was next to the door for if I ever had to go to the toilet. [...] With regard to excercise, for example, I had to cut back. I used to exercise 6 times a week, I had to reduce it to 3 because physically it wasn't possible. [...] So I actually do indoor exercises; I do spinning, and Zumba where I also did circuit trainings but that's no longer possible to carry weights etc., that doesn't. I didn't do it again either." (1F1)[185]

" I've already said that to my partner, I would really like to do yoga, but I sometimes don't dare because I think, suppose I have gas in the intestine or air in the intestines and that flies out unwillingly, because that happens sometimes, then it's not so nice, So yes, but yes. " (3N1)[186]

"And here is the sports club where I had taken over, well I stopped recently because I was really not well but it's done by a physiotherapist, and in fact she does groups with people with various pathologies. So we know when we go there that there's no discomfort, we're not well, we're not well, we're in pain, but we stop. She adapts the exercises, but sports clubs like that are not everywhere." (3F2)[187]

" But right away, they go cycling quite a lot, cycling, that, I can't sit on my butt for long, it hurts. I don't have a lot of social contacts. My family and my children, and that's it. And my husband. " (4N1)[188]

On the other hand, patients see exercise and participating in sports as an opportunity to feel better (reduction in symptoms observed) and have stepped up their sporting activities since their diagnosis.

"I've learned to be much more in tune with my body, uh... There you have it, in the three pillars there is the sport pillar, so I started exercising and finally I am in better shape today than before I was sick." (2F3)[189]

Patients suffering from CD identified travelling as another difficulty. Three factors are mainly targeted: the restriction of possible destination countries (due to quality of healthcare or vaccination requirements), the difficulty of transporting certain medicines in good conditions (need to be stored in the fridge) or the severity of the symptoms which makes the trip complex or unpleasant.

"Let's say that Crohn's disease, we also have to say to ourselves that we have to forget that we may want to travel far, go to a foreign country and live there, knowing that the care may not be the same, perhaps not as good as in Belgium. I'm not criticizing anyone, but I don't know." (5F2)[190]

" In 94 we went out by plane, but there was a lot of trouble with me. And then we said in 95 we bought a mobile home in Malmedy, in the middle of nature. And that's our holiday. So that's not far from home, I don't have to sit in the car for so long, I know everything there. " (4N1)[191]

"It's saying ok "what are the live vaccines?", "what can I do?", ok it's okay I won't be able to go to such and such a country anymore because I can no longer get vaccinated against yellow fever, these are important decisions to be made obviously, then when you're sick and you're unwell you only wait for one thing, it's to have a treatment so I'm going to say it's missing out and then when you talk about it with your family you say to yourself "well yes, in the end it's better that I'm fine" and they don't care if I don't go to Africa." (1F1)[192]

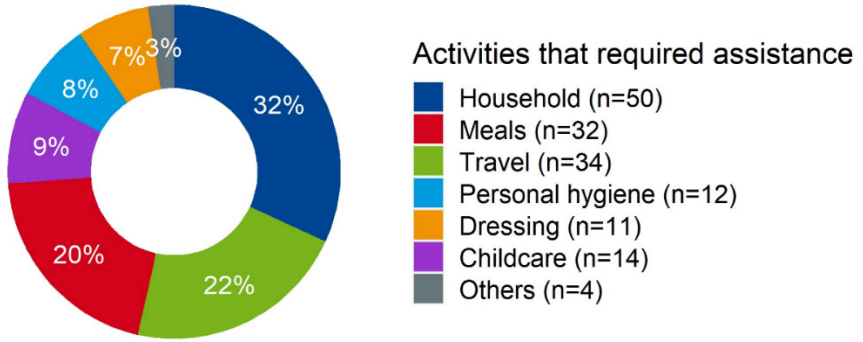
"All that's restrictive is that it's a product that has to stay in the fridge, so when we go on holiday I have to calculate, to know when I'm coming back... When my injection arrive, can I take my injection with me or not, it's also a whole logistics uh... that needs to be set aside. I remember at the time when I had [name immunomodulator], I remember the syringe also had to stay in the fridge, and we went skiing, and the doctor told me "well you just have to buy some kind of fridge box just for all the insulin and all that, but he completely forgot to tell me that..." I hadn't thought about it either, but that... Well, when you go skiing, you're at altitude. So when I opened the syringe, half of the product came out." (2F1)[193]

" I go on a trip with a friend, she knows that and sometimes I have to, I've been vomiting there for nights, it's very unpleasant for them. " (2N1)[194]

Informal caregivers play an important role when additional support is needed

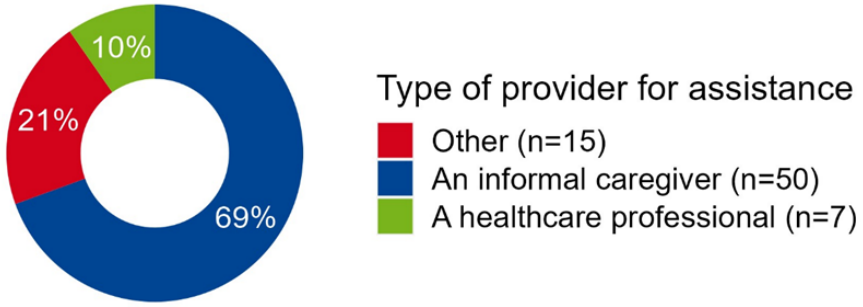
More than 40% (n=64) of the participants reported that they needed (or had needed) assistance with activities of daily living due to CD. Among these participants, the most prevalent areas in which assistance was needed included: household tasks (78.1%; 50/64), travel (53.1%; 34/64) and meal preparation (50.0%; 32/64). In all instances where assistance with daily living activities was necessary due to CD, the primary source of support was an informal caregiver, accounting for 78.1% (50/64) of cases. This underscores the essential role played by caregivers in helping individuals with CD in managing their daily challenges and maintaining their HRQoL.

Figure 18 – Activities for which survey respondents required assistance (n=64)



To note: the denominator used was the total number of answers (and not the number of participants answering this question)

Figure 19 – Type of provider helping the patient, when assistance is required (n=64)

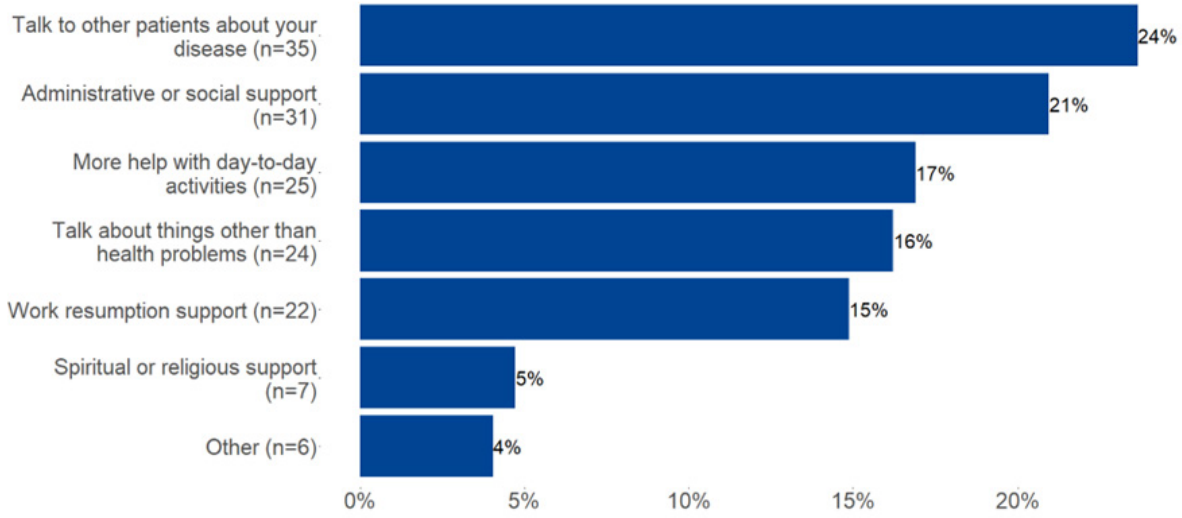


To note: the denominator used was the total number of answers (and not the number of participants answering this question)

Slightly more than half of participants had unmet social support needs

A bit more than half of respondents (54%) reported that they (had) needed social support in at least one area but did not receive it (Figure 20). The social support needs that were most frequently reported by participants as unmet were: talking to other patients about their disease (23.6%), administrative or social support (20.1%), more help with day-to-day activities than they are currently receiving (16.9%) and talking about things other than health problems (16.2%). In addition, 34.2% of participants reported that they faced difficulties finding someone who can be trusted to talk to about their disease.

Figure 20 – Reported types of social support needed, but not received



Social support of loved ones is important

Going to a medical appointment to receive the treatment might require being accompanied by a third party because a severe flare can make driving impossible or simply because there was a need for support. This could also constitute an obstacle, or at least a constraint, to treatment.

> *"Well, I've always been extremely independent, but my husband has often accompanied me because it's true that when you're in a crisis, you don't actually know how to do anything." (2F1)[195]*

> *" Yes, for example, but I'll just say, to the pharmacist if I need something, or yes... She also usually accompanies me to the hospital. Just in general, support. " (2N1)[196]*

The support of loved ones (family and friends) was reported to be important to help patients to cope with their illness. Caring attitudes that were particularly appreciated were described (ex: supporting tasks of daily life to relieve the sick person, inquiring about the presence of toilets in public places, or simply being available and showing empathy).

> *"Well folks, it's funny the last time I went to a restaurant, I was the last one to arrive, and the first thing they said to me after saying hello was 'the toilet is here if you need it'. So there you have it, it's funny but it's also a form of support. Or the people who exercise with me too, sometimes they tell me "yes no wait [name of the patient], don't force yourself too much, you're not in great shape", or "oh well, go for it, you can do better" and that's it, that's how it regulates itself but I think that the entourage has a big role to play." (1F1)[197]*

" Just the understanding he has when I don't feel well, when I know I don't feel well and there's someone next to me who knows that when I'm somewhere and I say it's not going well, that really hits me and then I almost faint and that person knows that and I don't need any more words, someone like that next to you, I still have people, girlfriends who know that too and that gives a support and a feeling of safety when I don't feel well, those people know that." (2N1)[198]

"And I think it was rather fortunate because indeed, the announcement of the diagnosis, the operations, etc., etc., it already takes a toll on you and if you have to have the administrative follow-up on top of that, it must not be easy. I was fortunate to have an entourage that supported me and was available at the time." (2F2) [199]

" Fortunately, I have a good partner who supports me enormously in this and is very understanding in that area. That makes a difference. For example, he will do the cleaning and cooking. He's going to take a lot off your hands. The moments when I have to lie down on the couch or sleep longer or something, for example, he actually takes on a lot. " (3N1)[200]

" The choice of me, I was lucky to be an only child, in hindsight, I had my brother, in the sense that my parents then, they couldn't drive the car, but they came from [region] to [region] to do my laundry, to do my ironing, to clean. " (4N2)[201]

However, patients sometimes complained about a lack of understanding on the part of their loved ones. Besides the support they could provide, recognition and understanding seemed to be key factors.

"Even in relation to the family, it's been very complicated because people don't actually understand what it is. Yes, we say "Crohn's disease", "Crohn's disease" yes, but they don't actually know what it is, and all the suffering it is, and I confess to you, and my husband knows it, and my son knows it, if they weren't here, I'd already be in heaven." (2F1)[202]

Support from other individuals with Crohn's Disease is beneficial

The interviewees assessed relationships with other patients with CD as beneficial. They valued the exchange of experiences and best practices and the fact that patients could encourage each other in times of difficulty. Patient support groups were also considered useful sources of information. Interactions between patients could take place in virtual groups (e.g. social media), interactions at places of care or through activities/events organised by patient associations.

"And then on Facebook as well I found... so I don't know how I came across this at the time, a group in fact that was set up by a lady I think who is followed in Liège, in collaboration I think with the gastroenterology services, and in fact all people suffering from either aractelite or Crohn's disease can exchange, Asking questions, uh, throwing out their overflow of emotions, well, it's really a group where you can ask anything, and so if you ask a question, well, you have the feedback from some people. Well, you have to sort it out too but I mean; This allows you to get feedback from other people and to position yourself a little bit." (3F2)[203]

"At [name of the hospital], they have a Facebook group called [name of the group], and it's super cool because there are all activities [...]. It's great because you can see that it's a positive group. And finally [...], there's never anyone who shows up and says "I have Crohn's" or "I have ulcerative colitis", we never talk about treatments or anything, it's more like "ah, did you go to the nutritionists, was it great?" or give each other little tips "oh well, I did that, it was good." (1F1)[204]

"I say it, the people at the hospital themselves who give a lot of support, also know that there is an association where you can always ask questions or meet fellows. The fact that you are not alone. I am well surrounded. I have a lot of people who understand me and are going to assist me. " (3N1)[205]

"I recommend it, because when we have low morale or whatever, we're all... Finally everyone is really lovely and healthy with others. And that's really nice, and if you have questions, well, in general, you can still find an answer. We have a drop in morale, we cheer each other up so no, that's anyway... It's still important to be part of a group like that, I think." (2F1)[206]

Sometimes these interactions with other patients were perceived as counterproductive, when the patient groups tends to be very negative. It is also reported that there was a lot of misinformation circulating through these channels. The desire not to be around other patients too often was also expressed, because it reminded them that they themselves were ill, while others simply did not feel the desire or the need to interact with other patients.

"My first instinct was also to see, for example, on Facebook if there were groups of people who were suffering from the disease because we had just been diagnosed but we don't necessarily have all the information, we haven't had an appointment with the doctor yet, and so I put myself in a group where people were all depressed and I said to myself it's not going to be okay, where I fell, where they all say that it cost them a fortune, that this treatment is wrong." (1F1)[207]

"I don't actually see myself as a patient in the patient association. Because I have the impression that they are more sick associations than patient associations. [...] The image I have of it is associations of patients who are sick, and who suffer from this disease, who deposit through this association of patients a suffering that can live because of the disease. If I can compare it with a forum. Finally on a forum, where people who give their opinion on the internet or in a restaurant, we will have ten customers who are not going to be satisfied who will put their opinion on it, but the 100 customers who are next door and who have had a good time are not going to give their opinion on the restaurant. That's a little bit of the feeling I have about patient associations." (2F2)[208]

"Sometimes there is still false information. I had read on a forum that talked about fecal transplantation from a healthy carrier to an unhealthy carrier. And I said to myself, "Oh well, that's cool." Because they were saying, "yes, this is the future," all that. So I said to myself at the end of the day, if I could be given the fecal matter of a healthy person and I'd be better... And I talked to my doctor about it and he said, 'Oh yes, listen, [name of the patient], if you want to die, I'll do it tomorrow!'" (2F1)[209]

" So you can, and if you have a problem with something, but you don't want to be confronted with the most negative thing, you don't read it. That's still your own choice. " (4N2)[210]

"Every year, in fact, they organise meetings, well, it's all over Belgium, there's Liège, Mons, this year I don't know where it is, but this year it's more information meetings precisely in relation to Crohn's disease. I have to admit that I never wanted to participate because psychologically, I only want to be with people who have this disease. And I need something else, because it reminds me too much that I'm sick." (2F1)[211]

Navigating through administrative formalities

In Belgium, to obtain reimbursement for certain drugs such as biologicals, patients must receive a reimbursement certificate from their sickness fund, which must be requested by the prescribing physician. Patients complained about the fact that the authorisation for reimbursement of these medicines must be renewed every year, despite CD being a chronic disease requiring long-term treatment. Moreover, patients mentioned a risk of treatment interruption if the renewal is not granted in a timely manner. This represented a source of stress, especially since the patients were not in control of this procedure; the specialist doctors were responsible for completing and signing the document and they were not all diligent with these administrative procedures. Additionally, the rest of the procedure involving the sickness funds was considered unnecessarily burdensome for the patients.

" What I find difficult is that you, you are chronically ill and then, I have an e-number for the physiotherapist and then get it, that is first for a year, then for two years, then I think. I'm not going to heal, so why do you have to prove that you have that every time. Those are special certificates, that medication ok, that's about a lot of money, that's every time and every time that has to be applied for and then you have to see that that's in order and well, those intermediate steps in between, then I think, if I don't keep an eye on that, replace that certificate, expires then that's no longer in order, None of that can be done directly, I find that a bit cumbersome. " (2N1)[212]

"The second administrative step, and one that could sometimes be problematic, is that you have to ask the medical advisor of the mutual insurance company for the authorization to reimburse the current treatment. Since it's super expensive, it's between 1500 and 2000€ for boxes of 6 injections so depending on the frequency it costs a lot of money. We only pay €12 for example to give you an idea [due to reimbursement from the sickness fund], €12.5, and I'm still reimbursed for this €12.5 by the critical illness extension. But this extension of the medical advisor, to be sure to have it on time, to receive the mail etc., at least 2 months in advance. So we have to go back to the gastro, I think even last time they were the ones who sent it directly to the health insurance I think. The treatment is proposed, and therefore the agreement must be sought from the medical advisor. And we get an agreement for x injections per year." (3F2)[213]

" For the medication still has to go through an advising physician from the health insurance company, that is indeed some paperwork, which is involved and if you are not good at that, you have to see that it has been sent on time, that you get your approval, that is always only for a year, It also has to be renewed every year. [...] For example, with [private insurance company], I had joined privately at the time and that was outside the employer and I was actually completely excluded from everything from the gastrointestinal system. I thought that was terribly bad. So I knew, suppose I have appendicitis for example, something that anyone can get regardless of whether you have Crohn's disease or not, I was going to have to pay for everything myself while that can be separate, anyone can get that. I thought that was very bad. " (3N1)[214]

" It's a points system, it's every two years that they come. So I've had that informal care every time and now it's, at [private insurance company] there's someone young who came, who took that up and who, yes I was half a point short, but yes half a point is half a point, so I didn't get it this year. That boy can only record what he observes the moment he comes. When I get out of the hospital, I don't do anything. I mean, the dirty thing about Crohn's is, always has been in all these years, you look good, yes on the outside you look good, but you don't have any energy. So the slightest thing you do a little too much is enough to get you. " (5N1)[215]

"So that means that I have in my memos the date on which I got my report from the medical officer, and so in addition to managing my stock of syringes, I have to have a document filled out by my specialist before the fateful date, that this document arrives at the mutual insurance company so that I can obtain my medical advisor's agreement, to be able to continue to be delivered to me at a price of 13€ because... I don't want to spend 500€ every time I go to pick up my syringes so yes, I have to have the agreement of the medical officer and it's a document that I have to give to my pharmacist." (2F4)[216]

In general, patients complained about having to spend time on administrative formalities with the sickness funds, the pharmaceutical firms, the private insurance or other institution to make their illness recognized, when their illness is taking its toll on their time, both professionally and personally. Moreover communication channels are multiple (e-mail, post…) and it takes a long time to receive an answer, either by phone or e-mail. Patients would sometimes like more support with these adminsitrative procedures.

"And then if my costs exceed €400 I'm also entitled to 50% of the coverage, it requires administrative procedures etc., which are a bit uh... That depends. When you're a worker, it still requires a bit of management. When you're not doing anything all day, it's for sure, it's not too complicated to do these documents." (2F5)[217]

"And then, of course, well, well, I understand – at the price of the drug – they don't advance the injections, so you have to contact companies that donate... But these are steps. It's only happened to me once since I've had injections. And then the administrative support that may exist but in any case that I don't know about. Maybe a permanent office or a contact person precisely for all the procedures at the level of the AVIQ, at the level of things that could relieve us on a daily basis but for which we have to do administrative procedures." (3F2)[218]

" So if you want to get extra information, for example, it's much, much harder to get in touch with that person. While someone from your health insurance fund can get in much more easily for additional information, but you usually don't know either, and they refer you to the payment agency, where you have to ring the doorbell anyway. And if you really want to know something, you're going to have to hang up on the phone, because an email takes an average of a month or two to reply. " (2N2)[219]

" That's a general problem I think, sometimes it's in the e-box, other times it's in your things from the health insurance company. Other times, they send it in the mail. I can't follow those papers from the health insurance company. I always think it's weird all those, I have insurance, why can't it all go directly? You already have an 'app' for medication and that scanning is all automatic, but all the rest then you still have to enter your costs and you have to be able and willing to do that, otherwise you won't get that money, of course." (2N1)[220]

Patients highlighted the fact that pharmacists can help them to navigate through the administrative procedure for reimbursement. They also pointed out that pharmacists are sometimes very dedicated to find available medicines and avoid interrupting treatment.

"I think there should still be a place, and I think that for all diseases, where we can direct people on all the practicalities... Once again, this medication story with the doctor at the health insurance company. If the pharmacist hadn't taken some of her time to explain the process to me, no one had. It wasn't her job to do that." (4F1)[221]

"My pharmacist struggled a little bit, but after that... I didn't have a break in treatment, but it was just barely. So I really have to be very careful to have stock." (2F4)[222]

" No, the pharmacy will send it on, if there is other medication for the heart, they just say, this is not related to your disease, to your condition. That's a whole list forwarded, but there's one drug in between. If they have to approve a medication the first time, then you have to have a report from the doctor. But once that's in the file, it's doable. " (4N1)[223]

"In general, my regular pharmacist knew that every 6 weeks I came back to get a box, so I didn't understand where the failure had been, and I had always been at her pharmacy, so every 6 weeks I buy a box all year round, so there had been a "stuut" and so we had to act in a hurry. I don't remember where the pharmacist got the box, if it was from another pharmacy where she worked or if it was... Anyway, she helped me out." (3F2)[224]

4.4.2 Impact on education

No information found in the literature. Importantly, this research has focused on the adult population (> 18 years), but literature exists on children or adolescents and the impact of CD on their education, however this was not the focus of this report. It should be noted that 32% of the participants were students just before their diagnosis of CD, so the educational impact cannot be underestimated. No specific mentions were made throughout the survey and/or qualitative interviews on the impact of CD on education.

4.4.3 *Impact on work*

Around two thirds (68.8%) of respondents that were employed just before their CD diagnosis had an incapacity to work that was linked to the disease, more than a fourth were still not back to work.

From the 93 individuals employed just before the diagnosis of CD, a significant majority, comprising two-thirds of this group (64/93), reported experiencing work incapacity due to CD (Table 32).

Table 32 – Work incapacity due to CD (n=93)

		n (%)
Paid work before CD diagnosis		93 (100.0)
	Incapacity	64 (68.8)
	No incapacity	29 (31.2)

In summary, 42.2% of respondents were able to return to work as before, while 28.1% reduced their number of working hours. For 17.2%, their health condition prevented them from resuming work. It is worth noting that a higher percentage of respondents (12.5%) indicated that they could not return to their job for reasons other than their health status (Table 33).

Table 33 – Return to work status, by age

Age (years)	18-49 n=35 n (%)	≥50 n=29 n (%)	p-value	Total n=64 n (%)
			NS	
Yes, as before	15 (42.9)	12 (41.4)	NS	27 (42.2)
Yes, less than before	10 (28.6)	8 (27.6)	NS	18 (28.1)
No, due to current state of health	8 (22.9)	3 (10.3)	NS	11 (17.2)
No, due to other reasons	2 (5.7)	6 (20.7)	NS	8 (12.5)

*Fisher's exact test, NS=Not significantly different, * p-value <0.05, ** p-value <0.01, *** p-value <0.001*

Interviews confirmed these quantitative results: CD led to work absenteeism of varying lengths, due to flare-ups, poor health condition (physical or psychological) or hospitalisations. In addition to (possible) long-term absences, patients reported being forced to reduce their working hours because their health condition no longer allowed them to work full-time. These work time reductions can have a significant financial impact.

> *" But I continued to do my other shifts. But I did of course, I only worked 75% and fortunately, because I don't think, if I had worked 100% in that regimen, I wouldn't have been able to I think. " (2N1)[225]*

> *"They hospitalized me for a week, but I was at home for more than a year before I could go back to work. [...] Well, I actually started again just before the pandemic, and when the pandemic happened, I was directly dismissed, and then it's been more than 2 years that I've been in a big spondyloarthritis crisis and uh... Well, I can't work anymore at the moment, anyway. [...] Finally I took it back, let's say, I started again... Then, uh, I'd hold out for a month, then I'd stop again for a month, and then I'd start again for a month. It's been quite complicated. Just before the pandemic, with the health insurance company, I made the decision to ask for a medical part-time job." (2F1)[226]*

"That is to say, I will have to consider a 4/5ths because I accept the fact that I will never be able to work full-time again, that I have to preserve my health. But that means that again for my pension, for etc., well... I will have done a part-time job, even though I would like nothing better than to work full-time." (3F3)[227]

" Also at the department where I was and they made me a proposal to go on long-term sick leave. So because since I'm going on long-term sick leave, instead of your 100% salary, you only have 60% of your salary, but until your retirement age. So I did, that was the deal of [name of the company] then to me. " (5N1)[228]

Because CD is a chronic disease, it leads to chronic treatment, which can eventually lead to chronic absenteeism. CD required regular medical monitoring and some treatments require regular day hospitalisation. This means that employed patients have to be absent from work on a regular basis. Patients with a flexible work schedule could more easily combine work and such medical appointments, while others find it difficult to fit these appointments into their work schedules.

" (...) So professionally it was a little bit annoying because it was quite regular and (...) there is nothing to do, day hospital the time to go there, to do the IV and to come back we lose half a day of work." (3F2)[229]

" Yes, the difficulty then is those overtime hours and trying to plan like that. I have to say, for example, I also like the system of progressive employment. I also had to do it once after a flare-up, that I worked a little less for a while. That is also something that does help to actually go back to work. [...] I experience it mainly when I go to work, the consultations are always during the day. I normally worked full-time until my son was born, so it's not easy to plan things then, always have to try to do outside your hours or take time off for that, that's sometimes a bit crazy, I have to go a few times a year to add days off to that. " (3N1)[230]

" Yes, we have a flex schedule, so we can start when we want and stop when we want, so if you have to go to the hospital, yes that's in my own time, then I'll stop working and I'll go to the hospital and then I'll go back to work or I'll come for a few hours, or I'll not come. That is actually very flexible, nothing has ever been said about it. " (5N2)[231]

Repeated absences and loss of productivity could make patients feel guilty. The professional environment is not always accommodating or tolerant of the health problems of patients with CD. Patients expressed a deep sense of injustice when faced with such situations, for example, criticism from colleagues or disciplinary action for repeated absences that are beyond their control. Others are distraught by the inability to benefit from medical leave when they feel they need it.

"It was very, very complicated actually when I had to tell my bosses that... I was sick, and they didn't have any compassion at all, they didn't even tell me... Because well, I apologized a little bit, I said "sorry to be away all the time, uh... I can't do anything about it" and my employer still told me, "Look, [name of workplace] is not charity." Well, you fall a little bit of a stunt like that, and then you know when colleagues are finally talking to you... They're talking about you behind your back... Well, it comes up to my ears, then, yes, a lot of thoughts, a lot of remarks uh... At first it hurts." (2F1)[232]

"In the company I work for, absences are monitored. And that, as a result, it was one of my bosses who was kind enough to tell me, that in fact I have... The witness was flashing for me because I had repeated absences and so she went to human resources and said "look, this person we know that he has a chronic illness, so can't it be notified somewhere so that..." There isn't one type... she is not flagged in the end as someone who is frequently absent" and the answer was no. And honestly, it made me... Anyway, I didn't make a big deal out of it, but I think it's unfair. Because I don't cheat! (2F3)[233]

"And an impact on my work as well because it's not nice to be the girl who gets hospitalized at least twice a year and... Anyway, we don't feel legitimate and it's true that this period I'm going through right now has been particularly difficult for me. " [...] "There's a lot of guilt. Uh, there you go, because we don't feel legitimate, huh, we say to ourselves, well, I say to myself, colleagues don't say it, they know the disease I have, they understand and... But I feel guilty, I tell myself I'm not legitimate, I can't be counted on." (3F3)[234]

"I think that for all these patients, again, whoever they are, it's profoundly unfair. I'm telling you, I think that... so maybe there are Crohn's patients who have had more absences than me, but I, honestly, have been much less absent than many of my colleagues. I have colleagues who have fallen into burnout, I have.. Finally... And that's okay in itself, I'm not saying that I'm doing better than everyone else, and just that I'm saying to myself "but come on, it's not fair"." (4F1)[235]

Absence from work did not only mean absence from the company, but could also encompass situations where an employee is at work yet absent from duties due to an urgent need. However, access to the toilet at all times was not always easy in all types of work (e.g., assembly line work). The tolerance of the management was a key factor here.

"There are some who don't understand when they say listen... When you have to run to the bathroom, people uh... Someone who works in the factory, on the assembly line, can't leave his job like that. We're not going to say "yes but wait, the break can go to the toilet", no it's impossible, it's impossible." (4F2)[236]

However, the picture was more nuanced when it came to responding to patients' needs in a professional context: cases of compassion, flexibility, tolerance and mutual support to get the work done were also reported.

" And if you had that, then you can't help but say to a colleague that I don't feel good here, especially after my first outburst, coming back that has been a difficult process, but yes, then they said 'sit down' or 'I'll take over', well, yes, they all did, so." (2N1)[237]

" But I was actually lucky, that she did it then, I still had shifts, that I didn't have to do night shifts for a long time, that they said we're not going to let you do that. Otherwise I think I would have had to look for another job. [...] And now I have to do my day job and do more desk work. Yes, I think you always get over that. " (2N1)[238]

" At work, they know about my condition and then, they take it very much into account. I also work in a residential care centre, healthcare, it's an ideal place. [...] So they're not going to say anything about it if I have to go to the toilet several times a day or something. They are already happy that I can come to work. " (3N1)[239]

"Now, apart from the appointments with the gastroenterologist which unfortunately were during working hours, I have always made sure that it does not impact my work, I have never been absent very often either but as I tell you I have a fairly high tolerance threshold. Well I explained to him, now it's someone who accepted, why because his dad had had problems too and I think he realized what... I think his dad had colon cancer, something like that, so he was well aware of what the disease was. Now I'm not sure it's the same everywhere, in the same way." (3F2)[240]

" I did my job well at work, I told not my immediate boss, but the highest of them, I did explain what my situation was, because I was hospitalized several times, so that I was out for about three months. [...] No questions were asked about it either. [...] So at a certain moment I was at my drawing board and I did indeed have another flare-up, and I indeed had no energy left. So the boss comes to me and says [Name of the participant] better go home because I see that things are not going well. [...] I then opened up with him and then the social services came to me to talk about it because I had said that it was Crohn's. " (5N1)[241]

Patients with CD sometimes needed to adapt their working environment, in terms of working hours or of infrastructure. In this respect, not everyone was equal: differences were observed between sectors and between types of

profession. Sometimes when it was not possible to do otherwise, patients adapted their eating habits to avoid using the restroom. Patients shared their impression of not always being understood regarding their needs (ex: possibility of taking naps during the day, easy access to the restroom, tailor-made work schedule), including by the work physician.

"Officially no, but unofficially yes with my boss, now he's a one-way boss... uh "Chief, it's not going too well this week uh, I can do a part-time I come from 10am to 3pm", even if I stayed later, but it allowed me to sleep a little later in the morning, but that's what. For 15 days, but otherwise it's 15 days at home and I'm under certificate, so we worked it out like that, and it was fine, and it was better that way. There were days when things weren't going too well, and sometimes I wasn't going too well and I stayed at home, and that's what. What was that... minimum 15 days I'm home for my Crohn's." (4F1)[242]

"And same thing, well, I work in administration and there are quite a few things that are put in place for staff who may have chronic diseases or... Anyway, there's a lot of stuff, I don't... I feel comfortable talking about it as well. There you go. There is no... I imagine maybe in a company where there would be a lot of pressure, a lot of work, where you would have to follow up etc., maybe in the private sector." (2F2)[243]

" Now, one of the consequences of years, because it is very difficult for an employer, especially as a civil servant, if someone is chronically ill, to find good solutions for this. [...] Because at one point I worked in the government and in the government there are few opportunities to work less. " (4N2)[244]

"For example, I had to ask my school, because we have 4 toilets for 300 students. And I know that during recess breaks, [...] the toilets are really taken by storm and so... For me, sometimes there's a big problem with that. I had to ask for a key, to be able to use a toilet on another floor, and I find it not easy." (2F4)[245]

" Once you're at home, I've actually signed at home for work for 6 months. I was allowed to work from work, which was also one of the proposals, I was allowed to work from home. So my drawing board was brought home, so I did my job at home. " (5N1)[246]

"Having to leave a meeting because you have to go to the bathroom, but in fact there's only one toilet in the building for 10 people and there are people waiting outside the door. So what I've gotten into as a habit is when I had meetings or company visits, or... Well, I wasn't actually eating. I didn't eat, I didn't drink before, if I knew I had to go on the road, because at least that way I avoided everything, any potential problem so the first impact is that, you change your way of doing things and you adapt because you know that... In the event of an incident... I've had incidents before." (3F2)[247]

"So, in occupational medicine, I once asked for an adaptation of the position after my colostomy, I think, for a medical part-time which was strongly recommended by my gastroenterologist, because I had to learn to live with it. [...] And the same goes for occupational medicine, they don't really understand, so it's not easy because they're going to say the regulation provides for a medical part-time, but you have to come to work every morning. So every morning you have to commute, come to work, even though you haven't slept all night. And he'll tell you, "Well, you just have to rest in the afternoon," while my doctor was advising, "You work two or three days a week, and then you recover." But it was all over again, and I had to fight for people to understand my need, if you will. I don't think it's very, very well understood in the workplace either." (3F3)[248]

As mentioned before, CD could be socially embarrassing. It is a disease that is sometimes difficult to talk about because it affects a person's intimacy. This embarrassment could be even greater in a professional context. For example, inappropriate questions from colleagues about the disease, the need to go to the toilet frequently or flatulate. These were all obstacles to doing one's job, which can limit one's opportunities, particularly when travelling for work or professional purposes.

"What's very embarrassing is in society having a cramp, and not being able to uh... flatulate the way I want, go to the bathroom when I want, where I want, the way I want. And so, yes, in society it's not easy, not with my friends because everyone knows, and I don't have a lot of dignity so I don't care. I am as I am and never mind. What is more troublesome is in the workplace, for example. When I go to the toilet it's always very, very noisy, and so that's extremely annoying." (2F5)[249]

" The diarrhoea has become the biggest problem, yes. It limits your professional life, your choice of where you will work, what kind of work you can do. A job, previously, I gave lectures on the move. Yes, that was simply no longer possible, that was also far too heavy. I once had an offer to be asked to work in journalism, which I also had to turn down, because I thought, the combination with my illness, that just doesn't work. So you want a job where you can sit close to a toilet and where your travel route is also limited. So that creates, that gives limitations. " (4N2)[250]

"Yes, sometimes to refuse business trips. Because it wasn't going too well. There is also a risk of dismissal because he is too often absent. I've been made to change departments a lot because of that, for example. And, maybe because of that, I'm maybe a little less sociable." (5F2)[251]

Despite constraints, patients expressed their desire to continue working as if they were not ill.

" What you miss when you are someone who always goes on and on, I work, I love my job, so working and for me working and doing it is a thing of not being sick because I want to be sick at all costs, I would rather walk around sick than have to say 'I don't come to work'. Because that's very, then you're confronted with being sick and I have a very hard time with that and I can't set boundaries, but no one is going to cross your boundaries with you. Because that's always when you say 'are you okay?' 'Yes, yes', no one will ask any questions. So you're not always protected from yourself. And yes, I really have to, people often have to say to me 'it's been good, you have to stop' and luckily I have people around me who say that. I really need that. " (2N1)[252]

" But I wasn't told that and I didn't get a sick note or anything, so I just kept doing the job, the number 1 job. Because that's the most important thing when you're single, which I was at the time, that you have an income. If you end up on the health insurance fund, then you are down on the statistics. And a lot has had to make way for that all my life to be able to keep that job and to be able to continue working full-time. " (4N2)[253]

"Because, well, I could stop working, but I don't want to stop working, so I always keep working. Uh, until the moment when I can't anymore, well, I won't be able to anymore." (5F1)[254]

Several studies in the literature reported on the impact of IBD on work. A Dutch study reported that IBD patients are as likely to be employed as the general population, but fewer of them work fulltime.[124] A European survey showed that 40% of the respondents made adjustments in their working life (e.g. flexible hours, part-time), 25% of patients were more than 25 days absent from work and 31% even lost or quit their job due to IBD, which poses a financial burden on the patient and their family.[42, 125, 126] These figures are similar to the results of the current patient survey in Belgium.

4.4.4 Financial consequences

Two-thirds of respondents reported experiencing a financial impact directly linked to CD

Sixty-five percent (n=98) of respondents indicated that their health condition has (had) a financial impact on their households.

A substantial majority (85.7%, 84/98) of those affected reported increased financial burden due to medical costs associated with managing their CD. Nearly half (45.9%, 45/98) of respondents cited the reduction or absence of income as a contributor to the financial impact arising from their health condition.

In the individual interviews, patients stated that medical care and treatment were generally well covered. However, CD has financial consequences, sometimes direct (reduced working hours resulting in a loss of income), sometimes indirect (increased insurance premiums). Patients also highlighted the financial impact of the accumulation of small expenses that may seem trivial but which, in the long run, add up to a significant sum.

Loss of income

Firstly, as mentioned above, patients who had to stop working generally had a loss of income. A longer period of work incapacity, would result in a greater financial impact. Moreover, the replacement income paid by the sickness fund was only 60% of the basic salary.

> *"For someone who works full-time, who is hospitalized twice a year, well, you very quickly come across a salary of 60% and so on. And there are other fees... That's a lot. Excessively." (3F3)[255]*

> *" The disadvantage of a medical pension, if you compare it with the other statuses, the status of self-employed and salaried employee, is also not so interesting. An employee or self-employed person who falls ill accrues his pension until the statutory retirement age. A civil servant does not. So my pension rights as an employee, I can only get them paid out at the age of 65. And all those years before that, I only have the limited career that I had as a civil servant. " (4N2)[256]*

4.4.4.1 Out-of-pocket healthcare costs

It appeared from the interviews that patients believed that the main drugs related to CD were well reimbursed, especially given their high price excluding reimbursement. However, there were a whole series of costs linked to related treatments or examinations which were not, or only minimally, reimbursed. Food supplements (probiotics, vitamins, etc.) for example were not reimbursed at all. Over time, the accumulation of these costs could have a significant financial impact. Having a private insurance limited some of the costs.

> *" [...] But I still find that taking 60€ out of your pocket is still a lot, I think. I think it should actually be free. Well, I know it never will be, but... [...] It was for the [name interleukin inhibitor], my pharmacy actually charged me 60€ every time, now I only pay 10€ because I am in the "BIM" status. [...] And that, ok, it's nothing compared to the 3,000€. But I still think it should be free. Well I want to say especially now, I think that the cost of living has increased for everyone, I tell myself people who don't have the means, well 60€ is 60€ what." (2F1)[257]*

> *"Calprotectin, calprotectin, I have a hard time getting reimbursed. Stool analysis, we are entitled to two reimbursements per year but they are put on uh... There are dates to be respected, I had never been told. And in fact, every time I came to take my 40€ calprotectin, I was there... Finally... That's expensive." (2F5) [258]*

> *"Magnesium, Calcium when I was taking Cortisone etc., well all that, it's still quite expensive, probiotics etc., well these are things that you have to take as a supplement in the end, but uh... So all this is not reimbursed, but on the other hand all the medical appointments related to the disease, so all the blood tests, additional analyses, the little that is still at our expense is still reimbursed by the mutual insurance company. But here's the thing, not everything that's a treatment add-on is. And so sometimes I get it for uh... The months when I have to recharge, bad luck everything falls at the same time, I have enough for uh... Yes, 150€ per month some months." (3F2)[259]*

> *"Yes, that's... Luckily, I have my hospitalisation insurance which covers everything, 100%. Otherwise it's every 6 weeks, it's 60€ huh. At my expense. Because hey, that's the cost too. There are some who don't work, it's quite expensive 60.5€, 60€ every six weeks. [...] It's still a budget. " [...] "(Name Proton Pump Inhibitor) which is not reimbursed, before I took (Name immunomodulator) it was reimbursed, and then after we had to pay 3€, you will say 3€ is cheap for a box of 100... But in the long run, if you take 3 a day it's 3€ a month, but hey, in the long run... Before it was free, why it became paid, we don't know. " [...] "The (name proton pump inhibitor) I take 20 mg but I take 40 and I cut it in*

half because it's cheaper, and I take the big boxes [...] That's more, that's more, that's more, that's more... And then we don't just have Crohn's, there are some who have tranquilizing spondyloarthritis, there are some who have psoriasis, there are some who have this, there are some who have a, plus the drugs of other pathologies we can get to... 100€ easily, huh. Even if the reimbursement of the health insurance, we arrive between 50 and 100€ per month." (4F2)[260]

" And then I only took the codeine, because everything else was superfluous anyway. That is very expensive, because it is all manual work. So I decided to abandon that track. [...] I have an average of 130€ per month of medication. Yes, once you're retired, that adds up quite a bit. " (4N2)[261]

"When you do a stool analysis... um, blood, there are some elements that are not reimbursed, I'm going to take for example vitamin B12. However, in Crohn's disease, when we have had resections, there is a whole part of the intestine that can no longer absorb B vitamins or iron, etc. And it's still due to the disease, so why are these vitamins, for example vitamin B12 analysis, not reimbursed? (5F2)[262]

Other reported healthcare costs included appointments with various health care practitioners for symptoms arising from CD.

"But on top of that, I have to pay for my care, because I have to pay for a physiotherapist, because I have to pay for my gastro consultations, my colonoscopy examination, so the health insurance company intervenes, of course, but there is still a lot of personal part that has to intervene." (3F3)[263]

" He then referred me to a dietician who did the rotation diet, with whom he cooperated. So that was independent of the hospitals actually, that was through a blood test that I had to do. That was sent to Germany, because it was quite expensive and cost 500€ or so. " (3N1)[264]

"Well, at some point the psychologist is necessary, but it's at your expense. Because it's not included in the Crohn's package, if you will. "We think that the Crohn's is a gastroenterologist, that's all, but not a Crohn's, it can go to the physiotherapist, to the rheumatologist since I went to do tests with a rheumatologist, it can... It's several blood tests. [...] Yes, it counts." (3F3)[265]

European studies highlighted the high geographical variability of out-of-pocket costs for patients with CD.[127-132]. These differences emphasised certain needs regarding the accessibility to care (e.g. financial access) in certain regions of Europe.

4.4.4.2 Non-healthcare costs

Next to the cost of treatment, patients identified a series of indirect costs such as cost of parking, household help,... Taken together, these costs could also have a significant financial impact for some patients, especially if they were needed for life.

" The car park is always a day visit. Tomorrow it will be about 6 euros again. But then we have to take it. On an annual basis, this does increase. There are people who have worse things going on. " (4N1)[266]

"I went to the CHU on Friday, so I went to see a doctor, follow my treatment etc., it's stupid but I go to the parking lot it's 5€. When you add up everything over the month etc., it's true that I work but it's still a little less than I due to my illnesses." (5F1)[267]

"We also have a cleaning lady at home, so that's also a big help when I'm tired"." (3N1)[268]

"But I'm just 65 from February, so I was two months late. Then I got more subsidy for that stairlift to be put in. So the family doctor should have informed me more about that. I didn't know. You're too late. If we have it installed now, I will miss out on a 6,000 €. So that's a lot of money. But for the time being, it won't happen." (4N1)[269]

Increase in insurance premiums

Patients have expressed their frustration at life insurance premiums rising because of their CD. Private health insurance or other insurance exclude CD from their financial coverage.

> *"And the problem is that the insurances are becoming so expensive. They don't get accident insurance. She has an expensive hospitalization insurance. She has a more expensive mortgage on her house. And that insurance... She has always filled everything out honestly.[…] That's all an extra cost " (4N1)[270]*

> *"The fact that I had illness, for example, I had an increase in my life insurance. After the operation, I had surgery in 2012 I think, I asked the [name of the specialist] to write me a report saying that there was a remission at that level, to see if there was any way to reduce that insurance. That's what he did to me, and on the paper it said "total clinical remission." Since the operation, I really don't have anything left. And even with that, insurance doesn't want to diminish." (3F1)[271]*

> *"I was asked to fill out a medical file, and as a chronically ill person, everything was going up very, very strongly, I said to myself, well no, I'm only going to use my own funds. And once again, I'm lucky enough to be a little older and therefore to have my own house – knock on wood – and so I'm not too concerned anymore, but I think young people are sick, well, it's complicated." (4F1)[272]*

> *" For example, with [insurance company], I had joined privately at the time and that was outside the employer and I was basically completely excluded from everything from the gastrointestinal system. I thought that was terribly bad. So I knew, suppose I have appendicitis for example, something that anyone can get regardless of whether you have Crohn's disease or not, I was going to have to pay for everything myself while that can be separate, anyone can get that. I thought that was very bad. " (3N1)[273]*

Table 34 – Other indirect costs reported in the open text field by survey respondents or mentioned in the qualitative interviews

- Household help costs
- Cost of nappies and toilet paper
- Toilet flushing cost
- Cervical smear recommended 1x/year, but reimbursed every 3 years

Additional needs in terms of financial support have also been identified (Table 34). For example, support for domestic help (and fair compensation if it is provided by a relative), free access to toilets everywhere, or the provision of nappies in the event of flare-ups. In this respect, emphasis was placed on the fact that patients are not responsible for the illness that affects them (the causes of which are not known with certainty) and they should not be the victim of their chronic illness financially (e.g. chronic statute, reimbursements for chronic condition).

> *"Because people don't actually realize the cost it has. It actually has an impact, really. Yes actually, I would say disability status actually, for all people with Crohn's disease." (2F1) [274]*

> *"As soon as the person has a file, when he is hospitalized very regularly, and very regularly he becomes unavailable, I think that help, for me, is normal. I mean... to participate in the life of society, to contribute, to pay taxes, to pay for care like everyone else... Whereas, we don't entertain like everyone else. Our daily lives are impacted." (3F3)[275]*

> *"We didn't ask to be sick either. Especially since it's not a disease that we don't know how we caught it either. It should be like in France I think, free for the chronically ill. I know enough is enough, that's what. But there are a lot of countries where chronically ill people like IBD and so on, it's free." (4F2)[276]*

"That patients also in the event of a crisis, when they are really facing it or when they have had surgery, that they don't know how to clean their homes, that the government can provide help, from the point of view of domestic helpers. Not paying the full fare but still a reduced fare." (2F1)[277]

"Why am I going to go and ask for a nurse to come here, so my wife is going to sit in the chair watching TV etcetera, or my daughter or anything when they can help me? But then the problem is that you need recognition. If we pay a nurse, I'm going to say, I don't know... 400 euros a week to come and help me, well they already give 200 and everyone would be happy I'll say. The state wins, the people win.... Well, it's a win-win. I'm going to say, I think it's help with household chores, that there's a recognition that isn't abused." (5F1)[278]

"That we can go to the toilet for free. Establish... I know that there are – it's in progress or that it's done, or that it's going to be done – new cards, but it's not clear that stores know the card to let us go to the bathroom. Make a campaign for the shops, send I don't know me, a mailing list saying here is this card authorizes all the sick to go to the toilet, "let them pass". [...] I would try to make patients have less financial worries about getting treatment." (4F2)[279]

Key points

- **Informal caregivers play an important role when support for activities of daily living is needed. The most prevalent areas in which assistance is needed include household tasks (78.1%), transportation and journeys (53.1%) and meal preparation (50.0%).**
- **A bit more than half of respondents (54%) reported needing social support in at least one area without receiving it. The most frequently reported unmet social support needs included talking to other patients about the disease (23.6%), administrative or social support (20.1%), more help with day-to-day activities (16.9%) and talking about things other than health problems (16.2%).**
- **Patients have to change their habits to take into account CD: travel and sport habits are changed; it is not uncommon for patients to refuse activities out of fear for finding themselves in embarrassing situations. CD also has an impact on the emotional and sexual life.**
- **Crohn's disease has a great impact on respondents' ability to work. Two thirds (68.8%) of respondents employed just before their CD diagnosis had to interrupt for at least one month. Only 42.2% of respondents were able to return to work as before the onset of CD, 28.1% transitioned to part-time employment and 17.2% did not resume work because of their health.**
- **Patients expressed their desire to continue working. To overcome the constraints, patients sometimes needed to adapt their working environment, whether in terms of working hours or infrastructure.**
- **A European survey (2010-2011) showed that 40% of respondents made adjustments in their working life (e.g. flexible hours, part-time), 25% of patients were more than 25 days absent from work and 31% even lost or quit their job due to IBD, which poses a financial burden on the patient and their family.**
- **Patients are financially affected in two ways: the medical costs associated with managing their CD and the accumulation of many small non-healthcare expenses.**
- **Patients have expressed their frustration about private insurance premiums rising because of their CD.**

4.5 Other unmet patient needs

This section describes other needs that were expressed by patients, during the interviews or the online survey (in the open text fields), but are not directly covered by the current methodological framework.

Firstly, interviewed patients expressed the need for more research related to autoimmune diseases. More research to give hope in the face of a lifelong disease, to improve the daily lives of future generations, and to increase recognition of the disease in general. Besides the scarcity of scientific research, according to patients, the type of research was highlighted as important, in particular the need to support clinical research alongside fundamental research.

> *"Really, yes, to be able to advance this research. Because I say to myself, people who learn it like they do today, well, they must be in the same state as me. It's really a hammer blow when we announce it. [...] In fact, I really want research to advance on all autoimmune diseases, not especially Crohn's, because already, there aren't many [...] It would really be for future generations. Frankly, if they could really find something and get a little bit more recognition of this disease." (2F1)[280]*

> *"I don't find it very complicated to conduct studies. Here we are for the moment, we are really in much more fundamental studies... a little too fundamental and not clinical enough. We don't really consider the clinical role and how the patient feels, which is ultimately the main thing. [...] I think the medical world really needs to make more connections. Or there should be more studies. I don't think there are enough studies on mental health." (2F5)[281]*

Finally, the need for more innovation (digital health) in the treatment and monitoring of CD was raised. In this respect, the feeling that Belgium is lagging behind other countries was shared.

> *" I mainly think, gosh these days, we all have apps, you name it, don't we? And I certainly think that we in Belgium are a bit behind the rest of the world. And certainly with medical technology, additional tools that exist. And certainly also with care pathways. And I think, right away, does it exist, okay, you have [name application], you have [name application], you have different applications on the market, which can give you as a patient a push in the right direction, in that process of care. And I also think that you just have to push that much harder from policy, from the NIHDI, to accelerate that innovation. " (2N2)[282]*

5 RESULTS – UNMET SOCIETAL NEEDS

5.1 Unmet health needs

5.1.1 Frequency

The incidence and prevalence of CD varies significantly between countries and regions, with the highest incidence in industrialised regions, such as Northern Europe (e.g. France, the UK, Sweden and Germany) and North America.[5, 6] A recent literature review estimated the incidence of CD in Europe to be 0.4-22.8 per 100 000 person-years.[2] In 1998, a prospective study in the area of Liège, Belgium, estimated an incidence to of 4.5 per 100 000 person-years.[7] The prevalence of CD in Europe varies from 1.5 to 213 cases per 100 000 persons.[5] In 2019, the GBD study estimated a prevalence of 153.4 to 199.8 per 100 000 for all ages in Belgium.[6]

5.1.2 Transmissibility (contagiousness)

Not relevant.

5.1.3 Antimicrobial resistance

Not relevant.

5.1.4 Burden on informal caregivers

The burden on informal caregivers is described as the emotional, physical, practical, and/or financial burden associated with taking care of a patient with CD. The survey showed that the role of an informal caregiver is pivotal in the support of CD patients . However this care role poses an additional burden. A prospective study in the Netherlands of IBD patients and their respective caregivers revealed that IBD caregivers were impacted because they felt stressed (41%), experienced fear for the future of the care recipient (73%) or felt that their care recipient was dependent of them (55%).[133]

5.2 Unmet healthcare needs

5.2.1 Value for money of standard care

The treatment landscape of CD is complex, with multiple strategies to induce and maintain remission, while avoiding long-term complications. In Europe, the direct healthcare costs per CD patient are estimated at an average of €3 500 per year.[128, 134] The most important driver of (direct) healthcare costs is medication, in particular biologic therapy.[135] Biologic therapy was expected to improve disease control and reduce hospitalisations and inpatient costs. However, since the introduction of biologic therapy the healthcare costs have only increased and the reduction of other medical costs (e.g. surgery, hospital admission) have never materialised.[136] Therefore the cost-effectiveness of biologicals for IBD treatment might depend on their effect on productivity costs, but more research is needed on this effect.[135]

A systematic review showed that infliximab and adalimumab induction and maintenance treatments were cost-effective compared to standard care in patients with moderate or severe CD. However in European (e.g. UK, Italy), American and Canadian healthcare settings, the ICER of these treatments was above the cost-effectiveness thresholds in patients with conventional-drug refractory CD, fistulising CD and for maintenance of surgically-induced remission.[137]

In general, biologic therapy is costly, but helps to improve outcomes and are therefore found to be not cost-effective, particularly in the case of maintenance therapy. In the future, the cost-effectiveness of biologics may improve as market prices fall and with the introduction of biosimilars.[137]

5.2.2 Preventability

Population-based studies have revealed some early life risk factors that may contribute to the susceptibility to IBD development, such as: tobacco smoke, antibiotics and infections (e.g. otitis media).[138]

To date no prevention strategy exists, however several initiatives have been undertaken, mainly focused on diet and healthy lifestyle interventions. A large prospective cohort study in industrialised countries, examined a

number of the dietary and lifestyle factors known to be associated with the risk of developing CD.[139] They concluded that a significant number of cases could be prevented by adopting a healthy diet and lifestyle. An important limitation of this cohort study is, however, that it assumes a direct causal relationship between lifestyle, dietary factors and the risk of CD. Further research is needed to confirm this causal relationship and the effectiveness of preventive strategies.

5.3 Unmet social needs

5.3.1 Productivity losses

CD is a chronic disease with a significant impact on work of the affected individuals, patients are also mostly diagnosed in the most productive years of their life. In Europe, the average indirect cost due to loss of work productivity is estimated at €1 900 per patient yearly.[140] Several country-specific studies report more detailed average costs related to absenteeism, presenteeism and disability due to CD. A national study in Poland (n=200) reported the total indirect costs associated with CD, based on a self-reported questionnaire. These costs were estimated at €462.47 per patient per month (24.0%, absenteeism; 35.0%, work disability; 30.4%, presenteeism; 0.4%, productivity loss at unpaid work; and 10.4%, informal care).[127] When adjusting for disease activity (e.g. only consider patients with disease in remission) the total indirect costs were reduced by 60% to €234.44 per patient per month.[127]

The cost of informal care was strongly correlated with disease severity.[127] A successful induction and maintenance of remission in patients with active disease might reduce the total indirect cost of CD informal carers by at least 41%.[127] A French survey noted that 36% of informal caregivers needed a working arrangement to take care of their relative with IBD.[141] A study in the Netherlands revealed significant productivity losses associated with caregiving, with absenteeism rates as high as 38%.[133] This shows that productivity losses are not limited to the patient itself, but also impact the informal caregivers. Literature showed that IBD caregivers retire early, change from working schedule or even face work loss due to their caregiving responsibilities.

5.3.2 Environmental impact of standard of care

No information found in the literature. Nevertheless, as reported in the patient survey and interviews, the management of CD necessitates consistent medical monitoring, and certain treatments involve regular day hospitalisation. This may lead to potential environmental impacts of standard of care due to frequent patient travel to the hospital and associated carbon emissions, which will vary by modes of transportation and travel distances.

Key points

- **In 2019, the global burden of disease study (GBD) estimated a prevalence of 153.4 to 199.8 per 100 000 inhabitants for all ages in Belgium.**
- **Informal caregivers are important for patients with CD, but they experience a high burden because of their caregiving tasks.**
- **A number of preventable dietary and lifestyle factors, which are known to be associated with the risk of developing CD, are investigated but further research is needed.**
- **CD leads to productivity losses and unemployment in individuals with CD and also causes productivity losses for their informal caregivers.**

6 RESULTS – UNMET FUTURE NEEDS

6.1 Future health needs

6.1.1 Burden of disease

In industrialised countries, the incidence rate of IBD is stabilising or even decreasing compared to the previous decade.[142] However, the **prevalence continues to increase** due to the young age of onset, lack of curative treatment and low mortality.[142] There is a decreasing trend in age-standardised DALYs and mortality rates, likely the result from improved treatment strategies (e.g. biological agents, more awareness, patient support programmes).[6] The global prevalence of IBD is expected to continue to rise, so there is a need to anticipate the future burden and challenges that health systems will face due to a growing patient load and a prolonged disease course.[143]

6.2 Future healthcare and social needs

6.2.1 Economic burden

CD poses a heavy and increasing burden on societies and healthcare systems, as incidence remains high in the industrialised world and is rising in newly industrialised nations. In recent years, the healthcare **costs associated with CD have risen** and have shifted from hospitalisation and surgery costs to mainly drug related costs.[135] In Europe, the direct healthcare costs per patient are expected to continue to rise due the chronic nature of the disease, the life-long care and the increasing incidence.[128, 134] The cost of medication and in particular biological therapy has become the most important cost driver and should be further investigated (see section 5.2.1. Value for money of standard of care).[135-137, 144]

Key points

- **The global prevalence of IBD is expected to continue to rise, so there is a need to anticipate the future burden and challenges that health systems will face due to a growing patient load and a prolonged disease course.**
- **Due to the chronic nature of the disease and the life-long care, it is expected that the economic burden of CD will continue to grow in the future.**

7 INEQUITIES

From a societal perspective, some health and healthcare inequalities concerning IBD and CD were reported in the literature. However, the relationship between socioeconomic status (SES), ethnicity and the prevalence of IBD remains controversial.[145]

The literature has reported some disparities in the healthcare use and clinical outcomes of IBD-related healthcare for both minority patients (e.g. more surgery in Caucasian patients) and those with lower SES.[146, 147] Additionally, patients with low SES, particularly those with CD, had higher rates of hospitalisation, increased healthcare use (e.g. outpatient physician visits, emergency care admissions) and increased mortality rates.[145, 148, 149] Further research is needed to better understand the reasons for these outcomes, so that IBD healthcare can be improved for all patients.

Currently, there is a lack of studies on new therapies (e.g. biologicals) that enroll patients with lower SES or ethnic minorities. As a result, the evidence is mainly applicable to patients with high SES and Caucasian populations, which limits the generalisability of study results, hinders our understanding of IBD pathogenesis and clinical course among diverse patient populations.

Lastly, disadvantaged IBD populations often have misconceptions and understanding of IBD, which leads to early hospital leave and/or poor treatment adherence. Attention should be paid to educate and support those patients to improve their HRQoL and correct their (potential) disease misperceptions.[147]

8 DISCUSSION

8.1 Summary of results

The patient survey offers a comprehensive insight into the experiences and perceived (unmet) needs of people with CD in Belgium. The responses of 150 participants were analysed of whom the majority was aged between 25 and 64 years, identified as female and French-speaking. Additionally, 20 individual, semi-structured interviews were conducted with CD patients, who completed the patient survey and expressed an interest in participating in an individual interview. From those who expressed interest, a final selection was made to ensure a representative sample based on language, age, time since diagnosis and type of treatment received. The goal of these interviews was to enrich our comprehension of the reasons behind patients' unmet needs and to shed light on the impact of CD on their lives. In addition to these data collection methods, a literature review was initiated to collect data on patient and societal unmet needs not covered through primary data collection (e.g. patient survey and interviews).

Patient unmet health needs

Both physical and psychological symptoms were reported by respondents of the patient survey. The three most frequently reported physical symptoms were diarrhoea, fatigue or exhaustion and cramps, while the three most frequently reported psychological symptoms were stress, fear or anxiety and feeling down, depressed, or sad. The literature review also revealed that psychological symptoms (e.g. anxiety, depression) are common in individuals with CD and patients experience a lack of psychological support.[101, 102]

The symptoms related to CD led to an increase of the proportion of the self-reported problems compared to before the onset of the disease, especially for the following self-reported EQ-5D-5L dimensions: difficulties to perform usual activities (+55.3% points), pain/discomfort (+46.0% points), mobility (+34.7% points) and anxiety/depression (+30.0% points).

Symptoms of CD imposed a significant burden on patients (e.g. prolonged periods spent in the restroom, permanent state of weakness, fear/anxiousness for embarrassing social situations). Notably, continuous abdominal pain emerged as the most burdensome physical symptom with 98.6% of the respondents reporting this symptom, rate it as rather or very burdensome. Stress is considered the most burdensome psychological symptom with 93.4% of the respondents, who report this symptom, rate it as rather or very burdensome. It is noteworthy that all psychological symptoms were rated as "very" or "rather" burdensome by at least 75% of the respondents. Additionally, the fact that CD is not always visible leads to feelings of illegitimacy within society, where patients may not always be considered as being ill by their family, employer or colleagues.

Patient unmet healthcare needs

Once the decision to consult a healthcare professional was made, half of the respondents managed to find medical attention within a month. Nearly 60% of the respondents in the patient survey obtained their diagnosis within less than two months, whereas 19.3% received the diagnosis more than a year after their initial consultation. The individual interviews shed light on several reasons contributing to diagnostic delays: difficulties to diagnose CD at first sight, long waiting times to obtain medical imaging (e.g. MRI) and the compartmentalisation of medical specialisation(s). Respondents expressed a need for better training and education of healthcare professionals to improve timely diagnosis, especially for the first line health actors.

Prescribed drugs (95.9%), nutritional support (23.4%) and surgical procedures (24.8%) emerged as the most commonly used treatments in patients with CD. More than 85% of the participants expressed being very satisfied or satisfied with the treatment they received. However, a significant proportion of patients (19.7%) considered their treatment very or rather burdensome because of side-effects, even though it is not always easy to distinguish CD symptoms from treatment side-effects. The most frequently reported side-effects were fatigue or exhaustion, weight gain, skin irritation or eczema, nausea and/or vomiting and diarrhoea. The literature review revealed that patients mostly expressed a need for improved treatment of gastro-intestinal symptoms, as they have a high impact on their HRQoL and (general) well-being.[101] Patients also expressed concerns regarding the safety and long-term effects of their treatment.[101]

Respondents participating in the patient survey indicated high levels of satisfaction with their consulted healthcare providers, with over 75% expressing satisfaction. During the interviews, they emphasised the importance of the doctor's communication of the CD diagnosis. Attributes such as compassion, transparency and time devoted to explain the disease and its consequences were cited as crucial. Respondents who were unsatisfied, identified as main issues during the interviews the limited availability and lack of expertise in addressing post-operative complications, inappropriate medication (dosage) or a perceived lack of professionalism. Additionally, respondents highlighted the need for healthcare professionals to have more time during consultations for clear information (e.g. practical tips, on-going research), meaningful interactions and empathy. The literature also confirmed the importance of clear and good communication, as communication with the healthcare providers has been identified as one the most important drivers of quality of care from the patients' perspective.[36]

Lastly, concerning the accessibility and organisation of care, interviewed patients expressed a need for improved access to specialised care, the need for having specialised therapies available at more hospitals and a desire for fewer hospital visits.

Patient unmet social needs

Respondents highlighted that CD had a significant impact on several aspects of their life, patients had to change their diet, leisure activities, their sexual and social habits due to CD. In general, the main reasons why respondents adapted their lives are twofold: 1) because of severe and burdensome symptoms or 2) because of the fear of experiencing socially awkward or embarrassing situations.

CD also has a significant impact on work, around two thirds (67.5%) of employed respondents had to interrupt work for at least one month since their CD diagnosis. Only 49.3% of the respondents were able to return to work as before the onset of the disease, 25.3% transitioned to part-time employment and 8.9% did not resume work. In the interviews, patients

expressed a desire to continue working, but report a need to adapt their working environment (e.g. working hours, infrastructure). These adaptations are not always possible which led more stress/anxiety at work or even unemployment. A European survey (2010-2011) showed that 40% of respondents made adjustments in their working life (e.g. flexible hours, part-time), 25% of patients were more than 25 days absent from work and 31% even lost or quit their job due to IBD, which poses a financial burden on the patient and their family.[42]

Besides the significant impact on work, which can eventually lead to a loss of income, CD poses an additional financial burden. Several costs were identified as a consequence of CD, these costs were directly (e.g. medication) or indirectly related (e.g. hospital parking costs, home help) to CD. Additionally, respondents also suggested a regulation to prevent discrimination in health insurance, particularly in terms of rising private insurance premiums because of their CD.

Finally, the need for more administrative support was shared. The respondents were in need of more guidance on what to do and of easier administrative procedures, when it comes to the attestation renewal for chronic disease and the treatment reimbursement, for instance.

Informal caregivers are pivotal part to the social and medical support of CD patients, as shown by the survey and literature. However their experienced burden cannot be underestimated and should be taken into account. Importantly, giving support to a patient with CD does not only pose a psychological burden to informal caregivers, but also to productivity losses.

Unmet societal needs

The prevalence and incidence of CD is variable across different countries (e.g. north-south gradient in Europe) and ranges from 1.5 to 213 cases per 100 000 persons in Europe.[5] In 2019, the GBD study estimated a prevalence of 153.4 to 199.8 per 100 000 for all ages in Belgium.[6]

The treatment landscape of CD is complex with direct health care costs per CD patient estimated at an average of €3 500 per year, with as most important cost drivers the medication, in particular biologic therapy.[128, 135] Since the introduction of biologic therapy the healthcare costs have only increased and the expected reduction of other medical costs (e.g. surgery, hospital admission) has never materialised.[136]

CD is a chronic disease with a significant impact on work of the affected individuals, patients are also mostly diagnosed in the most productive years of their life. In Europe, the average indirect cost due to loss of work productivity is estimated at €1 900 per patient yearly.[140] However these costs are highly country dependent.

Unmet future needs

The prevalence is expected to rise in the near future.[142] The incidence in industrialised countries is stabilising, but remains high, in comparison to the previous decade, while continuing to rise in newly industrialised countries.[142]

Due to the chronic nature of the disease and the life-long care, it is expected that the economic burden of CD will also continue to grow in the future.

8.2 Limitations

Some limitations should be accounted for when interpreting the findings of this study.

8.2.1 Primary data collection

Recruitment

The recruitment was mainly done through patient organisations, medical professionals and hospitals (e.g. posters in waiting room). In other words, the study relied heavily on the healthcare system. Therefore, individuals at the margins of healthcare with specific (or higher) unmet needs could potentially have been excluded.

Survey sample

The limited sample size (n=150) and the strict inclusion criteria may have implications for the generalisability of the findings to the broader population

of individuals with CD. The small sample size increases the risk of type II errors and can lead to undetected potential associations.

Regarding the inclusion criteria, patients younger than 18 years old were not included, which excludes an important subpopulation of young CD patients (e.g. pediatric onset CD). This subpopulation may express other health-related unmet needs, which are hence not captured by the current study.

While an online survey is a convenient and accessible method for the general population, it comes with some disadvantages. Limited access to internet or a lack of technological knowledge may exclude certain (vulnerable) subpopulations and should be taken into account when interpreting the results of this study.

It was noted that many respondents initiated the survey but subsequently closed it (103 out of 253), which may have introduced selection bias into the sample. Those who eventually did not completed the survey might have had different characteristics or experiences than those who did complete the survey, potentially affecting the generalisability of the study's results.

Interviews

In the interview phase of the study, a challenge was encountered related to the limited number of participants available to cover all predefined selection criteria adequately. To address this limitation, participants from adjacent groups were included as replacements.

Interpretation of data

Another challenge, which is particularly important in the context of chronic diseases, concerns temporality. A significant proportion of included CD patients, had been diagnosed more than ten years ago. In the survey we evaluate HRQoL before the onset of the disease and after. This long-time span between onset of first CD symptoms and survey participation may lead to recall bias. Moreover, information on past unmet needs might be irrelevant today because treatment(s) and healthcare organisation might have changed in the meantime. Additionally, in this survey and interviews, respondents provide a snapshot that summarises their disease and unmet needs at that moment. However, most chronic diseases like CD are heterogenous, progress over time, have different subtypes, different treatments and fluctuating symptoms (e.g. flare-ups). These factors make it very challenging to assess the (life-long) unmet health-related needs.

Another limitation revolves around multimorbidity, it is essential to acknowledge that some diseases are frequently associated with others sharing common pathophysiology, and significantly impacting individuals' lives. This was made explicitly clear during the interviews as patients expressed difficulty to differentiate between symptoms directly related to CD or symptoms related to other inflammatory diseases frequently associated with CD (e.g. arthritis) and treatment side-effects in their survey responses. Such symptoms or associated diseases pose an added burden on these individuals, but this is very difficult to quantify. This complicates the interpretation of the data (e.g. symptoms of CD, symptoms of co-morbidities, treatment side-effects).

8.2.2 Secondary data collection

Through a pragmatic literature review, secondary data was collected. Ideally, up-to-date high-quality evidence identified through a thorough systematic review should be linked to each criterion of the NEED framework. However, due to time constraints, the secondary data was collected through pragmatic searches for each criterion and no quality appraisal was performed. The research team is aware that by utilising this method we may have missed important sources of evidence or included low-quality evidence.

For some criteria in the NEED framework different sources of evidence were found. For other criteria it was not easy to find specific data on CD, especially for the societal needs criteria (e.g. environmental impact, financial impact). There is currently no methodology on how we should deal with missing data in these criteria.

Most studies report (survey) data on IBD, without making the distinction between the inflammatory diseases (e.g. aggregated data of CD and ulcerative colitis (UC), certainly for Belgium there is a current lack of epidemiological data on CD. Different methodologies, definitions and/or

measurement units further complicate the data to be comparable across different studies.

Information on criteria or indicators in the NEED framework that required database analyses (e.g. YLL, YLD, co-payments) was not yet available at the time of report publication.

8.3 Lessons learned

Throughout the study, valuable insights were gained regarding the development of the (online) survey. Initially, the aim was to utilise the EQ-5D-5L and integrate it into a survey platform ("Qualtrics"). The survey was incorporated on the platform in two languages (Dutch and French) and with the addition of specific questions related to the period before the onset of first symptoms. However, challenges were encountered when modifying the survey within Qualtrics, as the platform had limited options for customisation. Consequently, we had to rely on JavaScript to implement the necessary modifications, which made the incorporation on the survey platform more difficult and time-consuming. Such delays were not anticipated from the start, in the future this should be taken into account and more time should be assigned to the development survey and its implementation.

Throughout the case study the researchers were able to identify additional potential unmet needs, that could be incorporated when developing future questionnaires. The case study allowed us to improve the clarity, coherence and importance of survey questions and answer options. These insights can help in the development of future questionnaires for other case studies.

The recruitment phase of the study also presented several noteworthy challenges, particularly in engaging patient organisations and (medical) specialists for patient recruitment. This proved difficult due to frustration related to their limited involvement in the questionnaire development stage. In the future attention should be paid to contacting them earlier in the development process of the survey to avoid this issue. It is important to strive for maximal transparency to all involved partners, and the inclusion of disclaimers for the involvement of subcontractors in the survey process emerged as essential considerations. Secondly, some hospitals required ethical committee (EC) approvals specific to their institutions, in addition to the general approval of the ethical committee for the project, these demands were not anticipated and caused some delay in the recruitment process. Furthermore, several stakeholders mentioned timing as a critical factor, as they only have limited windows of opportunity available to actively participate in the study and disseminate the information within their respective networks. To ensure maximal participation of health care providers, organisations and patients a longer recruitment period and/or an earlier involvement in the survey development process can be suggested. This should enable us to reach more patients and a more representative sample.

It is of the utmost importance to obtain a sample that is sufficiently large and representative of the population (e.g. vulnerable population, age) with the disease. This is crucial to provide accurate estimates on the unmet needs, to make comparisons between diseases and make relevant statistical analysis. Therefore we suggest to have specific initiatives or attention to reach individuals at the margins of healthcare in future case studies.

Future case studies should adapt or think about how to modify the current methodology to include children and/or adolescents, as the study of health-related unmet patient and societal needs should take them into account. This report only covered an adult population (> 18 years) so some of the current methods are not applicable in a younger population.

To be comprehensive, a systematic review of the literature should be done and the quality of evidence (e.g. GRADE) should be taken into account, in the current case study a more pragmatic literature review was conducted. Furthermore, a transparent methodology should be developed on how to deal with criteria for which no data were found in the literature.

8.4 Added value of the study

The added value of this "unmet needs" case study on CD lies in the following aspects:

1. It serves as **a test for the NEED assessment framework**. The current study offers the opportunity to verify the relevance and applicability of the methodological NEED framework by applying it to CD. It integrates various sources of evidence—such as literature, the evaluation of patient unmet needs through a specifically developed survey, semi-structured interviews and expert opinions—we believe that in this way a broad spectrum of unmet needs is measured at the patient and societal level. The case study shows that the framework is adaptable (e.g. by adjusting indicators in the framework or measurement methods), comprehensive and usable to assess the unmet needs of patients and society .
2. The added value of the overall NEED project is the creation of a database that captures information on patient and societal unmet health-related needs across several health conditions, highlights the most pressing unmet needs and allows comparisons across different diseases. The current study is an important milestone in the development of such an extensive database.
3. The case study intends to provide **guidance for policy-makers, healthcare stakeholders, researchers and the industry** to incorporate patients' needs into their decision-making processes regarding CD. Thereby hopefully contributing to the paradigm shift from supply-driven healthcare to a more needs-driven healthcare innovation and policy system for CD.
4. The case study uses a **patient-centred approach**, which aims to directly evaluate and improve the patients' HRQoL by using their perspective and specific needs.

8.5 Potential suggestions to tackle unmet needs in patients with Crohn's disease

Identifying and describing the unmet needs that are associated with CD can guide the development of relevant solutions. Although the design and assessment of the most efficient and cost-effective strategies require a separate process, we can outline some suggestions to improve the overall management of CD, enhance the quality of life of affected individuals and reduce the economic burden on healthcare systems and patients. The suggestions proposed below are derived from the unmet needs identified in the literature, the patient survey and the interviews.

1. Improve the awareness and education among first-line actors, especially GP's (e.g. early recognition of red flags that warrant referral to a gastroenterologist), in order to reduce significant diagnostic delays.
2. Continue the search for medical treatments that reduce the burden of gastrointestinal symptoms in patients with CD. The gastrointestinal symptoms are deemed most burdensome following our patient survey, alleviating these symptoms should be targeted by future research and development.
3. Improve the access to psychological support for patients with CD (e.g. reimbursement) and encourage physicians to pro-actively refer patients to a psychologist and/or talk with CD patients about (possible) psychological support.
4. Support employers to tailor work to the specific needs of employees with CD (e.g. adapt the working environment, flexible working schedule). Such measures should enable employers to create an inclusive workplace for individuals with CD.
5. Address the financial burden and discrimination in insurance premiums that is associated with CD. Introduce regulations to prevent discrimination in health insurance, particularly regarding raising private insurance premiums for patients with Crohn's.
6. Simplify and streamline the administrative processes patients need to go through because of their disease (e.g. attestation renewal for chronic

disease status (NIDHI) and treatment reimbursement). Additionally, provide clear guidance and support to patients navigating the administrative aspects of managing their condition.

7. Manage the healthcare costs associated with CD. Considering the current burden and potential future burden of the disease, strategies to manage the complex treatment landscape efficiently and contain healthcare costs, should be set-up.

REFERENCES

1. Maertens de Noordhout C, Levy M, Claerman R, De Jaeger M, De Pauw R, Kohn L, et al. Needs Examination, Evaluation and Dissemination (NEED): assessment framework. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Center (KCE); 2024 03/2024. KCE Reports 377C1 (377C1) Available from: https://doi.org/10.57598/R377C1
2. Zhao M, Gonczi L, Lakatos PL, Burisch J. The Burden of Inflammatory Bowel Disease in Europe in 2020. J Crohns Colitis. 2021;15(9):1573-87.
3. Actis GC, Pellicano R, Fagoonee S, Ribaldone DG. History of Inflammatory Bowel Diseases. J Clin Med. 2019;8(11).
4. Baumgart DC, Carding SR. Inflammatory bowel disease: cause and immunobiology. Lancet. 2007;369(9573):1627-40.
5. Burisch J, Jess T, Martinato M, Lakatos PL, EpiCom E. The burden of inflammatory bowel disease in Europe. J Crohns Colitis. 2013;7(4):322-37.
6. Wang R, Li Z, Liu S, Zhang D. Global, regional and national burden of inflammatory bowel disease in 204 countries and territories from 1990 to 2019: a systematic analysis based on the Global Burden of Disease Study 2019. BMJ Open. 2023;13(3):e065186.
7. Latour P, Louis E, Belaiche J. Incidence of inflammatory bowel disease in the area of Liege: a 3 years prospective study (1993-1996). Acta Gastroenterol Belg. 1998;61(4):410-3.
8. Carriere J, Darfeuille-Michaud A, Nguyen HT. Infectious etiopathogenesis of Crohn's disease. World J Gastroenterol. 2014;20(34):12102-17.
9. Guan Q. A Comprehensive Review and Update on the Pathogenesis of Inflammatory Bowel Disease. J Immunol Res. 2019;2019:7247238.

10. McGovern DP, Kugathasan S, Cho JH. Genetics of Inflammatory Bowel Diseases. Gastroenterology. 2015;149(5):1163-76 e2.

11. Petagna L, Antonelli A, Ganini C, Bellato V, Campanelli M, Divizia A, et al. Pathophysiology of Crohn's disease inflammation and recurrence. Biol Direct. 2020;15(1):23.

12. Jostins L, Ripke S, Weersma RK, Duerr RH, McGovern DP, Hui KY, et al. Host-microbe interactions have shaped the genetic architecture of inflammatory bowel disease. Nature. 2012;491(7422):119-24.

13. Liu JZ, van Sommeren S, Huang H, Ng SC, Alberts R, Takahashi A, et al. Association analyses identify 38 susceptibility loci for inflammatory bowel disease and highlight shared genetic risk across populations. Nat Genet. 2015;47(9):979-86.

14. Gaya DR, Russell RK, Nimmo ER, Satsangi J. New genes in inflammatory bowel disease: lessons for complex diseases? Lancet. 2006;367(9518):1271-84.

15. Borowitz SM. The epidemiology of inflammatory bowel disease: Clues to pathogenesis? Front Pediatr. 2022;10:1103713.

16. Vieujean S, Caron B, Haghnejad V, Jouzeau JY, Netter P, Heba AC, et al. Impact of the Exposome on the Epigenome in Inflammatory Bowel Disease Patients and Animal Models. Int J Mol Sci. 2022;23(14).

17. Halfvarson J, Brislawn CJ, Lamendella R, Vazquez-Baeza Y, Walters WA, Bramer LM, et al. Dynamics of the human gut microbiome in inflammatory bowel disease. Nat Microbiol. 2017;2:17004.

18. Aldars-Garcia L, Chaparro M, Gisbert JP. Systematic Review: The Gut Microbiome and Its Potential Clinical Application in Inflammatory Bowel Disease. Microorganisms. 2021;9(5).

19. van der Heide F, Dijkstra A, Weersma RK, Albersnagel FA, van der Logt EM, Faber KN, et al. Effects of active and passive smoking on disease course of Crohn's disease and ulcerative colitis. Inflamm Bowel Dis. 2009;15(8):1199-207.

20. Mahid SS, Minor KS, Soto RE, Hornung CA, Galandiuk S. Smoking and inflammatory bowel disease: a meta-analysis. Mayo Clin Proc. 2006;81(11):1462-71.

21. To N, Gracie DJ, Ford AC. Systematic review with meta-analysis: the adverse effects of tobacco smoking on the natural history of Crohn's disease. Aliment Pharmacol Ther. 2016;43(5):549-61.

22. Hou JK, Abraham B, El-Serag H. Dietary intake and risk of developing inflammatory bowel disease: a systematic review of the literature. Am J Gastroenterol. 2011;106(4):563-73.

23. Khalili H, Chan SSM, Lochhead P, Ananthakrishnan AN, Hart AR, Chan AT. The role of diet in the aetiopathogenesis of inflammatory bowel disease. Nat Rev Gastroenterol Hepatol. 2018;15(9):525-35.

24. Ananthakrishnan AN, Khalili H, Konijeti GG, Higuchi LM, de Silva P, Fuchs CS, et al. Long-term intake of dietary fat and risk of ulcerative colitis and Crohn's disease. Gut. 2014;63(5):776-84.

25. Ananthakrishnan AN, Khalili H, Konijeti GG, Higuchi LM, de Silva P, Korzenik JR, et al. A prospective study of long-term intake of dietary fiber and risk of Crohn's disease and ulcerative colitis. Gastroenterology. 2013;145(5):970-7.

26. Lambert K, Pappas D, Miglioretto C, Javadpour A, Reveley H, Frank L, et al. Systematic review with meta-analysis: dietary intake in adults with inflammatory bowel disease. Aliment Pharmacol Ther. 2021;54(6):742-54.

27. Cornish JA, Tan E, Simillis C, Clark SK, Teare J, Tekkis PP. The risk of oral contraceptives in the etiology of inflammatory bowel disease: a meta-analysis. Am J Gastroenterol. 2008;103(9):2394-400.

28. Torres J, Mehandru S, Colombel JF, Peyrin-Biroulet L. Crohn's disease. Lancet. 2017;389(10080):1741-55.

29. Ananthakrishnan AN, Higuchi LM, Huang ES, Khalili H, Richter JM, Fuchs CS, et al. Aspirin, nonsteroidal anti-inflammatory drug use, and risk for Crohn disease and ulcerative colitis: a cohort study. Ann Intern Med. 2012;156(5):350-9.

30. Abraham BP, Mehta S, El-Serag HB. Natural history of pediatric-onset inflammatory bowel disease: a systematic review. J Clin Gastroenterol. 2012;46(7):581-9.

31. Feuerstein JD, Cheifetz AS. Crohn Disease: Epidemiology, Diagnosis, and Management. Mayo Clin Proc. 2017;92(7):1088-103.

32. Cushing K, Higgins PDR. Management of Crohn Disease: A Review. Jama. 2021;325(1):69-80.

33. Kamp K, Dudley-Brown S, Heitkemper M, Wyatt G, Given B. Symptoms among emerging adults with inflammatory bowel disease: a descriptive study. Res Nurs Health. 2020;43(1):48-55.

34. Conley S, Proctor DD, Jeon S, Sandler RS, Redeker NS. Symptom clusters in adults with inflammatory bowel disease. Res Nurs Health. 2017;40(5):424-34.

35. Hulme K, Safari R, Thomas S, Mercer T, White C, Van der Linden M, et al. Fatigue interventions in long term, physical health conditions: A scoping review of systematic reviews. PLoS One. 2018;13(10):e0203367.

36. Irving P, Burisch J, Driscoll R, Olsson M, Fullarton JR, Rodgers-Gray BS, et al. IBD2020 global forum: results of an international patient survey on quality of care. Intest Res. 2018;16(4):537-45.

37. Cohen BL, Zoega H, Shah SA, Leleiko N, Lidofsky S, Bright R, et al. Fatigue is highly associated with poor health-related quality of life, disability and depression in newly-diagnosed patients with inflammatory bowel disease, independent of disease activity. Aliment Pharmacol Ther. 2014;39(8):811-22.

38. Włodarczyk M, Makaro A, Prusisz M, Włodarczyk J, Nowocień M, Maryńczak K, et al. The Role of Chronic Fatigue in Patients with Crohn's Disease. Life (Basel). 2023;13(8).

39. Czuber-Dochan W, Dibley LB, Terry H, Ream E, Norton C. The experience of fatigue in people with inflammatory bowel disease: an exploratory study. J Adv Nurs. 2013;69(9):1987-99.

40. Graff LA, Clara I, Walker JR, Lix L, Carr R, Miller N, et al. Changes in fatigue over 2 years are associated with activity of inflammatory bowel disease and psychological factors. Clin Gastroenterol Hepatol. 2013;11(9):1140-6.

41. Vavricka SR, Schoepfer A, Scharl M, Lakatos PL, Navarini A, Rogler G. Extraintestinal Manifestations of Inflammatory Bowel Disease. Inflamm Bowel Dis. 2015;21(8):1982-92.

42. Lonnfors S, Vermeire S, Greco M, Hommes D, Bell C, Avedano L. IBD and health-related quality of life -- discovering the true impact. J Crohns Colitis. 2014;8(10):1281-6.

43. Jess T, Gamborg M, Matzen P, Munkholm P, Sørensen TI. Increased risk of intestinal cancer in Crohn's disease: a meta-analysis of population-based cohort studies. Am J Gastroenterol. 2005;100(12):2724-9.

44. Satsangi J, Silverberg MS, Vermeire S, Colombel JF. The Montreal classification of inflammatory bowel disease: controversies, consensus, and implications. Gut. 2006;55(6):749-53.

45. Silverberg MS, Satsangi J, Ahmad T, Arnott ID, Bernstein CN, Brant SR, et al. Toward an integrated clinical, molecular and serological classification of inflammatory bowel disease: report of a Working Party of the 2005 Montreal World Congress of Gastroenterology. Can J Gastroenterol. 2005;19 Suppl A:5A-36A.

46. Tarrant KM, Barclay ML, Frampton CM, Gearry RB. Perianal disease predicts changes in Crohn's disease phenotype-results of a population-based study of inflammatory bowel disease phenotype. Am J Gastroenterol. 2008;103(12):3082-93.

47. Thia KT, Sandborn WJ, Harmsen WS, Zinsmeister AR, Loftus EV, Jr. Risk factors associated with progression to intestinal complications of Crohn's disease in a population-based cohort. Gastroenterology. 2010;139(4):1147-55.

48. Best WR, Becktel JM, Singleton JW, Kern F, Jr. Development of a Crohn's disease activity index. National Cooperative Crohn's Disease Study. Gastroenterology. 1976;70(3):439-44.

49. Gade AK, Douthit NT, Townsley E. Medical Management of Crohn's Disease. Cureus. 2020;12(5):e8351.

50. Gajendran M, Loganathan P, Catinella AP, Hashash JG. A comprehensive review and update on Crohn's disease. Dis Mon. 2018;64(2):20-57.

51. Irvine EJ, Feagan B, Rochon J, Archambault A, Fedorak RN, Groll A, et al. Quality of life: a valid and reliable measure of therapeutic efficacy in the treatment of inflammatory bowel disease. Canadian Crohn's Relapse Prevention Trial Study Group. Gastroenterology. 1994;106(2):287-96.

52. Bewtra M, Kaiser LM, TenHave T, Lewis JD. Crohn's disease and ulcerative colitis are associated with elevated standardized mortality ratios: a meta-analysis. Inflamm Bowel Dis. 2013;19(3):599-613.

53. Baumgart DC, Sandborn WJ. Crohn's disease. Lancet. 2012;380(9853):1590-605.

54. Cheifetz AS. Management of active Crohn disease. JAMA. 2013;309(20):2150-8.

55. Maaser C, Sturm A, Vavricka SR, Kucharzik T, Fiorino G, Annese V, et al. ECCO-ESGAR Guideline for Diagnostic Assessment in IBD Part 1: Initial diagnosis, monitoring of known IBD, detection of complications. J Crohns Colitis. 2019;13(2):144-64.

56. Turner D, Ricciuto A, Lewis A, D'Amico F, Dhaliwal J, Griffiths AM, et al. STRIDE-II: An Update on the Selecting Therapeutic Targets in Inflammatory Bowel Disease (STRIDE) Initiative of the International Organization for the Study of IBD (IOIBD): Determining Therapeutic Goals for Treat-to-Target strategies in IBD. Gastroenterology. 2021;160(5):1570-83.

57. Talley NJ, Abreu MT, Achkar JP, Bernstein CN, Dubinsky MC, Hanauer SB, et al. An evidence-based systematic review on medical therapies for inflammatory bowel disease. Am J Gastroenterol. 2011;106 Suppl 1:S2-25; quiz S6.

58. Torres J, Bonovas S, Doherty G, Kucharzik T, Gisbert JP, Raine T, et al. ECCO Guidelines on Therapeutics in Crohn's Disease: Medical Treatment. J Crohns Colitis. 2020;14(1):4-22.

59. Kumar A, Cole A, Segal J, Smith P, Limdi JK. A review of the therapeutic management of Crohn's disease. Therap Adv Gastroenterol. 2022;15:17562848221078456.

60. Benchimol EI, Seow CH, Steinhart AH, Griffiths AM. Traditional corticosteroids for induction of remission in Crohn's disease. Cochrane Database Syst Rev. 2008;2008(2):CD006792.

61. Davies SC, Nguyen TM, Parker CE, MacDonald JK, Jairath V, Khanna R. Anti-IL-12/23p40 antibodies for maintenance of remission in Crohn's disease. Cochrane Database Syst Rev. 2019;12(12):CD012804.

62. Hazlewood GS, Rezaie A, Borman M, Panaccione R, Ghosh S, Seow CH, et al. Comparative effectiveness of immunosuppressants and biologics for inducing and maintaining remission in Crohn's disease: a network meta-analysis. Gastroenterology. 2015;148(2):344-54 e5; quiz e14-5.

63. MacDonald JK, Nguyen TM, Khanna R, Timmer A. Anti-IL-12/23p40 antibodies for induction of remission in Crohn's disease. Cochrane Database Syst Rev. 2016;11(11):CD007572.

64. Engel T, Yung DE, Ma C, Pariente B, P WI, Eliakim R, et al. Effectiveness and safety of Ustekinumab for Crohn's disease; systematic review and pooled analysis of real-world evidence. Dig Liver Dis. 2019;51(9):1232-40.

65. Ford AC, Sandborn WJ, Khan KJ, Hanauer SB, Talley NJ, Moayyedi P. Efficacy of biological therapies in inflammatory bowel disease: systematic review and meta-analysis. Am J Gastroenterol. 2011;106(4):644-59, quiz 60.

66. Vieujean S, D'Amico F, Netter P, Danese S, Peyrin-Biroulet L. Landscape of new drugs and targets in inflammatory bowel disease. United European Gastroenterol J. 2022;10(10):1129-66.

67. Chande N, Patton PH, Tsoulis DJ, Thomas BS, MacDonald JK. Azathioprine or 6-mercaptopurine for maintenance of remission in Crohn's disease. Cochrane Database Syst Rev. 2015;2015(10):CD000067.

68. Chenna VSH, Nagi TK, Suarez ZK, Hernandez OL, Nageye ME, Reyaz N, et al. Comparison of Effectiveness and Safety of Ustekinumab and Adalimumab As Induction or Maintenance Therapy in Patients With Moderate to Severe Crohn's Disease: A Systematic Review and Meta-Analysis. Cureus. 2023;15(4):e38277.

69. Stidham RW, Lee TC, Higgins PD, Deshpande AR, Sussman DA, Singal AG, et al. Systematic review with network meta-analysis: the efficacy of anti-TNF agents for the treatment of Crohn's disease. Aliment Pharmacol Ther. 2014;39(12):1349-62.

70. Chande N, Townsend CM, Parker CE, MacDonald JK. Azathioprine or 6-mercaptopurine for induction of remission in Crohn's disease. Cochrane Database Syst Rev. 2016;10(10):Cd000545.

71. French H, Mark Dalzell A, Srinivasan R, El-Matary W. Relapse rate following azathioprine withdrawal in maintaining remission for Crohn's disease: a meta-analysis. Dig Dis Sci. 2011;56(7):1929-36.

72. Gisbert JP, Marín AC, Chaparro M. The Risk of Relapse after Anti-TNF Discontinuation in Inflammatory Bowel Disease: Systematic Review and Meta-Analysis. Am J Gastroenterol. 2016;111(5):632-47.

73. Bemelman WA, Warusavitarne J, Sampietro GM, Serclova Z, Zmora O, Luglio G, et al. ECCO-ESCP Consensus on Surgery for Crohn's Disease. J Crohns Colitis. 2018;12(1):1-16.

74. Stevens TW, Haasnoot ML, D'Haens GR, Buskens CJ, de Groof EJ, Eshuis EJ, et al. Laparoscopic ileocaecal resection versus infliximab for terminal ileitis in Crohn's disease: retrospective long-term follow-up of the LIR!C trial. Lancet Gastroenterol Hepatol. 2020;5(10):900-7.

75. Costa J, Magro F, Caldeira D, Alarcao J, Sousa R, Vaz-Carneiro A. Infliximab reduces hospitalizations and surgery interventions in patients with inflammatory bowel disease: a systematic review and meta-analysis. Inflamm Bowel Dis. 2013;19(10):2098-110.

76. Tsai L, Ma C, Dulai PS, Prokop LJ, Eisenstein S, Ramamoorthy SL, et al. Contemporary Risk of Surgery in Patients With Ulcerative Colitis and Crohn's Disease: A Meta-Analysis of Population-Based Cohorts. Clin Gastroenterol Hepatol. 2021;19(10):2031-45 e11.

77. Danese S, Allez M, van Bodegraven AA, Dotan I, Gisbert JP, Hart A, et al. Unmet Medical Needs in Ulcerative Colitis: An Expert Group Consensus. Dig Dis. 2019;37(4):266-83.

78. Adamina M, Bonovas S, Raine T, Spinelli A, Warusavitarne J, Armuzzi A, et al. ECCO Guidelines on Therapeutics in Crohn's Disease: Surgical Treatment. J Crohns Colitis. 2020;14(2):155-68.

79. Gionchetti P, Dignass A, Danese S, Magro Dias FJ, Rogler G, Lakatos PL, et al. 3rd European Evidence-based Consensus on the

Diagnosis and Management of Crohn's Disease 2016: Part 2: Surgical Management and Special Situations. J Crohns Colitis. 2017;11(2):135-49.

80. Berg DF, Bahadursingh AM, Kaminski DL, Longo WE. Acute surgical emergencies in inflammatory bowel disease. Am J Surg. 2002;184(1):45-51.

81. Campbell L, Ambe R, Weaver J, Marcus SM, Cagir B. Comparison of conventional and nonconventional strictureplasties in Crohn's disease: a systematic review and meta-analysis. Dis Colon Rectum. 2012;55(6):714-26.

82. Lightner AL. Segmental Resection versus Total Proctocolectomy for Crohn's Colitis: What is the Best Operation in the Setting of Medically Refractory Disease or Dysplasia? Inflamm Bowel Dis. 2018;24(3):532-8.

83. Andersson P, Olaison G, Hallbook O, Sjodahl R. Segmental resection or subtotal colectomy in Crohn's colitis? Dis Colon Rectum. 2002;45(1):47-53.

84. Jones PD, Kappelman MD, Martin CF, Chen W, Sandler RS, Long MD. Exercise decreases risk of future active disease in patients with inflammatory bowel disease in remission. Inflamm Bowel Dis. 2015;21(5):1063-71.

85. Eckert KG, Abbasi-Neureither I, Koppel M, Huber G. Structured physical activity interventions as a complementary therapy for patients with inflammatory bowel disease - a scoping review and practical implications. BMC Gastroenterol. 2019;19(1):115.

86. Scaldaferri F, Pizzoferrato M, Lopetuso LR, Musca T, Ingravalle F, Sicignano LL, et al. Nutrition and IBD: Malnutrition and/or Sarcopenia? A Practical Guide. Gastroenterol Res Pract. 2017;2017:8646495.

87. Holt DQ, Strauss BJ, Moore GT. Patients with inflammatory bowel disease and their treating clinicians have different views regarding diet. J Hum Nutr Diet. 2017;30(1):66-72.

88. de Vries JHM, Dijkhuizen M, Tap P, Witteman BJM. Patient's Dietary Beliefs and Behaviours in Inflammatory Bowel Disease. Dig Dis. 2019;37(2):131-9.

89. Zimmerman J, Fisher M. Avoidant/Restrictive Food Intake Disorder (ARFID). Curr Probl Pediatr Adolesc Health Care. 2017;47(4):95-103.

90. Parkes GC, Whelan K, Lindsay JO. Smoking in inflammatory bowel disease: impact on disease course and insights into the aetiology of its effect. J Crohns Colitis. 2014;8(8):717-25.

91. Biedermann L, Fournier N, Misselwitz B, Frei P, Zeitz J, Manser CN, et al. High Rates of Smoking Especially in Female Crohn's Disease Patients and Low Use of Supportive Measures to Achieve Smoking Cessation--Data from the Swiss IBD Cohort Study. J Crohns Colitis. 2015;9(10):819-29.

92. Nunes T, Etchevers MJ, Merino O, Gallego S, Garcia-Sanchez V, Marin-Jimenez I, et al. High smoking cessation rate in Crohn's disease patients after physician advice--the TABACROHN Study. J Crohns Colitis. 2013;7(3):202-7.

93. Colombel JF, D'Haens G, Lee WJ, Petersson J, Panaccione R. Outcomes and Strategies to Support a Treat-to-target Approach in Inflammatory Bowel Disease: A Systematic Review. J Crohns Colitis. 2020;14(2):254-66.

94. Colombel JF, Panaccione R, Bossuyt P, Lukas M, Baert F, Vaňásek T, et al. Effect of tight control management on Crohn's disease (CALM): a multicentre, randomised, controlled phase 3 trial. Lancet. 2017;390(10114):2779-89.

95. Maertens de Noordhout C, Detollenaere J, Primus-de Jong C, Kohn L, Devleesschauwer B, Charafeddine R, et al. Identifying Patient

needs in Belgium: methodological approach and application. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE); 2022. KCE Reports (348) Available from: https://kce.fgov.be/en/identifying-patient-needs-methodological-approach-and-application

96. Bouckaert N, Gerkens S, Devriese S, Cleemput I. An EQ-5D-5L value set for Belgium – How to value health-related quality of life? Health Services Research (HSR). Brussel: Belgian Health Care Knowledge Centre (KCE); 2021 07/2021. KCE Reports 342 Available from: https://kce.fgov.be/sites/default/files/atoms/files/KCE_342_EQ-5D-5L_value_set_for_Belgium_Report_1.pdf

97. Castanares-Zapatero D, Kohn L, Dauvrin M, Detollenaere J, Maertens de Noordhout C, Primus C, et al. Long COVID: Pathophysiology – epidemiology and patient needs. Health Services Research (HSR). Brussels: Belgian Health Care Knowledge Centre (KCE); 2021. KCE Reports (344) Available from: https://kce.fgov.be/sites/default/files/atoms/files/KCE_344_Long_Covid_scientific_report.pdf

98. Hvidberg MF, Petersen KD, Davidsen M, Witt Udsen F, Frolich A, Ehlers L, et al. Catalog of EQ-5D-3L Health-Related Quality-of-Life Scores for 199 Chronic Conditions and Health Risks in Denmark. MDM Policy Pract. 2023;8(1):23814683231159023.

99. Saarni SI, Harkanen T, Sintonen H, Suvisaari J, Koskinen S, Aromaa A, et al. The impact of 29 chronic conditions on health-related quality of life: a general population survey in Finland using 15D and EQ-5D. Qual Life Res. 2006;15(8):1403-14.

100. Salomon JA, Haagsma A, Davis A, Maertens de Noordhout C, Polinder S, Havelaar AH, et al. Disability weights for the Global Burden of Disease 2013 Study. Lancet Glob Health. 2015;3(11):e712-23.

101. Schoefs E, Vermeire S, Ferrante M, Sabino J, Lambrechts T, Avedano L, et al. What are the unmet needs and most relevant treatment outcomes according to patients with inflammatory bowel disease? A qualitative patient preference study. J Crohns Colitis. 2022.

102. Neuendorf R, Harding A, Stello N, Hanes D, Wahbeh H. Depression and anxiety in patients with Inflammatory Bowel Disease: A systematic review. J Psychosom Res. 2016;87:70-80.

103. Villoria A, Garcia V, Dosal A, Moreno L, Montserrat A, Figuerola A, et al. Fatigue in out-patients with inflammatory bowel disease: Prevalence and predictive factors. PLoS One. 2017;12(7):e0181435.

104. Hindryckx P, Novak G, Vande Casteele N, Khanna R, Laukens D, Jairath V, et al. Incidence, Prevention and Management of Anti-Drug Antibodies Against Therapeutic Antibodies in Inflammatory Bowel Disease: A Practical Overview. Drugs. 2017;77(4):363-77.

105. Rutgeerts P, Gasink C, Chan D, Lang Y, Pollack P, Colombel JF, et al. Efficacy of Ustekinumab for Inducing Endoscopic Healing in Patients With Crohn's Disease. Gastroenterology. 2018;155(4):1045-58.

106. Peyrin-Biroulet L, Rahier JF, Kirchgesner J, Abitbol V, Shaji S, Armuzzi A, et al. I-CARE, a European Prospective Cohort Study Assessing Safety and Effectiveness of Biologics in Inflammatory Bowel Disease. Clin Gastroenterol Hepatol. 2023;21(3):771-88.e10.

107. Roda G, Jharap B, Neeraj N, Colombel JF. Loss of Response to Anti-TNFs: Definition, Epidemiology, and Management. Clin Transl Gastroenterol. 2016;7(1):e135.

108. Bjorlykke KH, Jahnsen J, Brynskov J, Molander P, Eberhardson M, Davidsdottir LG, et al. Therapeutic drug monitoring in inflammatory bowel disease: implementation, utilization, and barriers in clinical practice in Scandinavia. Scand J Gastroenterol. 2023;58(1):25-33.

109. Papamichael K, Afif W, Drobne D, Dubinsky MC, Ferrante M, Irving PM, et al. Therapeutic drug monitoring of biologics in inflammatory bowel disease: unmet needs and future perspectives. Lancet Gastroenterol Hepatol. 2022;7(2):171-85.

110. Verstockt B, Noor NM, Marigorta UM, Pavlidis P, Deepak P, Ungaro RC, et al. Results of the Seventh Scientific Workshop of ECCO: Precision Medicine in IBD-Disease Outcome and Response to Therapy. J Crohns Colitis. 2021;15(9):1431-42.

111. Jackson BD, De Cruz P. Quality of Care in Patients With Inflammatory Bowel Disease. Inflamm Bowel Dis. 2019;25(3):479-89.

112. Melmed GY, Oliver B, Hou JK, Lum D, Singh S, Crate D, et al. Quality of Care Program Reduces Unplanned Health Care Utilization in Patients With Inflammatory Bowel Disease. Am J Gastroenterol. 2021;116(12):2410-8.

113. Molander P, Jussila A, Toivonen T, Makkeli P, Alho A, Kolho KL. The impacts of an inflammatory bowel disease nurse specialist on the quality of care and costs in Finland. Scand J Gastroenterol. 2018;53(12):1463-8.

114. Hernández-Sampelayo P, Seoane M, Oltra L, Marín L, Torrejón A, Vera MI, et al. Contribution of nurses to the quality of care in management of inflammatory bowel disease: a synthesis of the evidence. J Crohns Colitis. 2010;4(6):611-22.

115. Lesnovska KP, Borjeson S, Hjortswang H, Frisman GH. What do patients need to know? Living with inflammatory bowel disease. J Clin Nurs. 2014;23(11-12):1718-25.

116. Vieujean S, De Vos M, D'Amico F, Paridaens K, Daftary G, Dudkowiak R, et al. Inflammatory bowel disease meets fertility: A physician and patient survey. Dig Liver Dis. 2023;55(7):888-98.

117. Mountifield R, Bampton P, Prosser R, Muller K, Andrews JM. Fear and fertility in inflammatory bowel disease: a mismatch of perception and reality affects family planning decisions. Inflamm Bowel Dis. 2009;15(5):720-5.

118. Rubin DT, Sninsky C, Siegmund B, Sans M, Hart A, Bressler B, et al. International Perspectives on Management of Inflammatory Bowel Disease: Opinion Differences and Similarities Between Patients and Physicians From the IBD GAPPS Survey. Inflamm Bowel Dis. 2021;27(12):1942-53.

119. Nene S, Gonczi L, Kurti Z, Morin I, Chavez K, Verdon C, et al. Benefits of implementing a rapid access clinic in a high-volume inflammatory bowel disease center: Access, resource utilization and outcomes. World J Gastroenterol. 2020;26(7):759-69.

120. Nguyen VQ, Jiang D, Hoffman SN, Guntaka S, Mays JL, Wang A, et al. Impact of Diagnostic Delay and Associated Factors on Clinical Outcomes in a U.S. Inflammatory Bowel Disease Cohort. Inflamm Bowel Dis. 2017;23(10):1825-31.

121. Vavricka SR, Spigaglia SM, Rogler G, Pittet V, Michetti P, Felley C, et al. Systematic evaluation of risk factors for diagnostic delay in inflammatory bowel disease. Inflamm Bowel Dis. 2012;18(3):496-505.

122. Lee DW, Koo JS, Choe JW, Suh SJ, Kim SY, Hyun JJ, et al. Diagnostic delay in inflammatory bowel disease increases the risk of intestinal surgery. World J Gastroenterol. 2017;23(35):6474-81.

123. Khanna R, Bressler B, Levesque BG, Zou G, Stitt LW, Greenberg GR, et al. Early combined immunosuppression for the management of Crohn's disease (REACT): a cluster randomised controlled trial. Lancet. 2015;386(10006):1825-34.

124. Netjes JE, Rijken M. Labor participation among patients with inflammatory bowel disease. Inflamm Bowel Dis. 2013;19(1):81-91.

125. Santiago M, Dias CC, Alves C, Ministro P, Goncalves R, Carvalho D, et al. The Magnitude of Crohn's Disease Direct Costs in Health

Care Systems (from Different Perspectives): A Systematic Review. Inflamm Bowel Dis. 2022;28(10):1527-36.

126. Park EY, Baek DH, Kim GH, Kim C, Kim H, Lee JW, et al. Longitudinal trends in direct costs and healthcare utilization ascribable to inflammatory bowel disease in the biologic era: a nationwide, population-based study. J Gastroenterol Hepatol. 2023.

127. Holko P, Kawalec P, Sajak-Szczerba M, Avedano L, Mossakowska M. Indirect Costs of Inflammatory Bowel Diseases: A Comparison of Patient-Reported Outcomes Across 12 European Countries. Inflamm Bowel Dis. 2023;29(5):752-62.

128. van der Valk ME, Mangen MJ, Leenders M, Dijkstra G, van Bodegraven AA, Fidder HH, et al. Healthcare costs of inflammatory bowel disease have shifted from hospitalisation and surgery towards anti-TNFalpha therapy: results from the COIN study. Gut. 2014;63(1):72-9.

129. Mesterton J, Jonsson L, Almer SH, Befrits R, Friis-Liby I, Lindgren S. Resource use and societal costs for Crohn's disease in Sweden. Inflamm Bowel Dis. 2009;15(12):1882-90.

130. Mandel MD, Balint A, Lovasz BD, Gulacsi L, Strbak B, Golovics PA, et al. Work disability and productivity loss in patients with inflammatory bowel diseases in Hungary in the era of biologics. Eur J Health Econ. 2014;15 Suppl 1:S121-8.

131. Kawalec P. Indirect costs of inflammatory bowel diseases: Crohn's disease and ulcerative colitis. A systematic review. Arch Med Sci. 2016;12(2):295-302.

132. Stark R, Konig HH, Leidl R. Costs of inflammatory bowel disease in Germany. Pharmacoeconomics. 2006;24(8):797-814.

133. Zand A, Kim BJ, van Deen WK, Stokes Z, Platt A, O'Hara S, et al. The effects of inflammatory bowel disease on caregivers: significant burden and loss of productivity. BMC Health Serv Res. 2020;20(1):556.

134. AlRuthia Y, Almadi M, Aljebreen A, Azzam N, Alsharif W, Alrasheed H, et al. The cost-effectiveness of biologic versus non-biologic treatments and the health-related quality of life among a sample of patients with inflammatory bowel disease in a tertiary care center in Saudi Arabia. J Med Econ. 2020;23(10):1102-10.

135. van Linschoten RCA, Visser E, Niehot CD, van der Woude CJ, Hazelzet JA, van Noord D, et al. Systematic review: societal cost of illness of inflammatory bowel disease is increasing due to biologics and varies between continents. Aliment Pharmacol Ther. 2021;54(3):234-48.

136. Pillai N, Dusheiko M, Maillard MH, Rogler G, Brungger B, Bahler C, et al. The Evolution of Health Care Utilisation and Costs for Inflammatory Bowel Disease Over Ten Years. J Crohns Colitis. 2019;13(6):744-54.

137. Pillai N, Dusheiko M, Burnand B, Pittet V. A systematic review of cost-effectiveness studies comparing conventional, biological and surgical interventions for inflammatory bowel disease. PLoS One. 2017;12(10):e0185500.

138. Agrawal M, Sabino J, Frias-Gomes C, Hillenbrand CM, Soudant C, Axelrad JE, et al. Early life exposures and the risk of inflammatory bowel disease: Systematic review and meta-analyses. EClinicalMedicine. 2021;36:100884.

139. Lopes EW, Chan SSM, Song M, Ludvigsson JF, Hakansson N, Lochhead P, et al. Lifestyle factors for the prevention of inflammatory bowel disease. Gut. 2022.

140. Burisch J, Zammit SC, Ellul P, Turcan S, Duricova D, Bortlik M, et al. Disease course of inflammatory bowel disease unclassified in a European population-based inception cohort: An Epi-IBD study. J Gastroenterol Hepatol. 2019;34(6):996-1003.

141. El Hajj W, Buisson A, Olympie A, Ravel MH, Devos C, Trang-Poisson C, et al. Impact of Inflammatory Bowel Disease on Patients'

Caregivers: Results From a French Survey. Inflammatory Bowel Diseases. 2023.

142. Windsor JW, Kaplan GG. Evolving Epidemiology of IBD. Curr Gastroenterol Rep. 2019;21(8):40.

143. Parian A, Ha CY. Older age and steroid use are associated with increasing polypharmacy and potential medication interactions among patients with inflammatory bowel disease. Inflamm Bowel Dis. 2015;21(6):1392-400.

144. Alulis S, Vadstrup K, Olsen J, Jorgensen TR, Qvist N, Munkholm P, et al. The cost burden of Crohn's disease and ulcerative colitis depending on biologic treatment status - a Danish register-based study. BMC Health Serv Res. 2021;21(1):836.

145. Wardle RA, Wardle AJ, Charadva C, Ghosh S, Moran GW. Literature review: impacts of socioeconomic status on the risk of inflammatory bowel disease and its outcomes. Eur J Gastroenterol Hepatol. 2017;29(8):879-84.

146. Lin KK, Sewell JL. The effects of race and socioeconomic status on immunomodulator and anti-tumor necrosis factor use among ambulatory patients with inflammatory bowel disease in the United States. Am J Gastroenterol. 2013;108(12):1824-30.

147. Sewell JL, Inadomi JM, Yee HF, Jr. Race and inflammatory bowel disease in an urban healthcare system. Dig Dis Sci. 2010;55(12):3479-87.

148. Bernstein CN, Walld R, Marrie RA. Social Determinants of Outcomes in Inflammatory Bowel Disease. Am J Gastroenterol. 2020;115(12):2036-46.

149. Nguyen GC, Bayless TM, Powe NR, Laveist TA, Brant SR. Race and health insurance are predictors of hospitalized Crohn's disease patients undergoing bowel resection. Inflamm Bowel Dis. 2007;13(11):1408-16.

APPENDICES

APPENDIX 1. SUMMARY TABLES

Appendix 1.1. Summary table - Unmet health needs

Quality of life		
EQ-5D average utility-score		
	Before	0.85
	Today	0.70
	Delta	-0.15***
Physical		
Frequency of physical symptoms reported related to CD		n (%)
	Diarrhoea	131 (87.3)
	Fatigue or exhaustion	121 (80.7)
	Cramps	113 (75.3)
	Lack of energy	107 (71.3)
	Urgency or stool urge	105 (70.0)
	Joint pain or inflammation	88 (58.7)
	Continuous abdominal pain	74 (49.3)
	Dry, painful or itchy skin or rash	68 (45.3)
	Anal pain	66 (44.0)
	Weight loss	64 (42.7)
	Nausea or vomiting	63 (42.0)
	Headache	62 (41.3)
	Blood loss during bowel movements	50 (33.3)
	Loss of appetite	50 (33.3)
	Weight gain	47 (31.3)
	Libido problems	45 (30.0)
	Constipation	42 (28.0)
	Pain in the mouth due to, for example, ulcers	37 (24,7)
	Difficult wound healing	36 (24.0)
	Vision problems or eye pain	35 (23.3)

		Elevated temperature or fever		26 (17.3)
	Pain/discomfort	***Before (%)***	***Today (%)***	**Delta (%)**
		No problems	61.3	15.3	-46.0
		Slight problems	16.7	33.3	16.7
		Moderate problems	11.3	41.3	30.0
		Severe problems	8.7	9.3	0.7
		Extreme problems	2.0	0.7	-1.3
Psychological				
	Frequency of psychological symptoms reported related to CD			n (%)
		Stress		71 (47.3)
		Fear or anxiety		65 (43.3)
		Feeling down, depressed, or sad		62 (41.3)
		Feelings of restlessness, nervousness or irritability		59 (39.3)
		Difficulty in concentration		46 (30.7)
		Mood swings		44 (29.3)
		Anger or aggressiveness		22 (14.7)
	Anxiety/depression	***Before (%)***	***Today (%)***	**Delta (%)**
		No problems	64.7	34.7	-30.0
		Slight problems	20.0	30.7	10.7
		Moderate problems	11.3	25.3	14.0
		Severe problems	4.0	8.0	4.0
		Extreme problems	0.0	1.3	1.3
Autonomy				
	Mobility	***Before (%)***	***Today (%)***	**Delta (%)**
		No problems	90.0	55.3	-34.7
		Slight problems	6.0	24.0	18.0
		Moderate problems	2.0	17.3	15.3
		Severe problems	1.3	3.3	2.0
		Extreme problems	0.7	0.0	-0.7
	Self-care	***Before (%)***	***Today (%)***	**Delta (%)**
		No problems	95.3	84.7	-10.6
		Slight problems	2.7	9.3	6.6
		Moderate problems	2.0	4.7	2.7
		Severe problems	0.0	1.3	1.3

	Extreme problems	0.0	0.0	0.0
Usual activities		***Before (%)***	***Today (%)***	**Delta (%)**
	No problems	82.0	26.7	-55.3
	Slight problems	9.3	38.0	28.7
	Moderate problems	5.3	23.3	18.0
	Severe problems	1.3	10.7	9.3
	Extreme problems	2.0	1.3	-0.7

*Fisher's exact test, NS=Not significantly different, * p-value <0.05, ** p-value <0.01, *** p-value <0.001*

Appendix 1.2. Summary table – Unmet healthcare needs

Burden of treatment				
Experienced burden of treatment				**n (%)**
	Very burdensome			7 (4.8)
	Rather burdensome			19 (13.1)
	Somewhat burdensome			58 (40.0)
	Not burdensome at all			58 (40.0)
Experienced burden of side-effects				
	Very burdensome	*Rather burdensome*	*Slightly burdensome*	*Not burdensome at all*
Fatigue or exhaustion	70 (72.2)	23 (23.7)	4 (4.1)	0
Weight gain	28 (59.6)	13 (27.7)	5 (10.6)	1 (2.1)
Skin irritation or eczema	18 (45.0)	16 (40.0)	5 (12.5)	1 (2.5)
Nausea and/or vomiting	12 (38.7)	13 (41.9)	6 (19.4)	0
Diarrhoea	18 (62.1)	10 (34.5)	1 (3.4)	0
Change of external characteristics	13 (56.5)	8 (34.8)	2 (8.7)	0
Infection	11 (57.9)	5 (26.3)	3 (15.8)	0
Constipation	5 (45.5)	5 (45.5)	0	1 (9.1)
Acne	3 (30.0)	5 (50.0)	2 (20.0)	0
Renal impairment	3 (30.0)	3 (30.0)	4 (40.0)	0
Infusion reactions	4 (57.1)	2 (28.6)	1 (14.3)	0
Surgical complications	6 (85.7)	1 (14.3)	0	0
Inflammation of the liver	0	2 (40.0)	2 (40.0)	1 (20.0)

Kidney stones		2 (50.0)	2 (50.0)	0	0
Inflammation of the pancreas		2 (50.0)	1 (25.0)	1 (25.0)	0
Other		14 (73.7)	2 (10.5)	2 (10.5)	1 (5.3)
Quality of care					
Experience with the organisation of care					
		Very satisfied	*Rather satisfied*	*Slightly satisfied*	*Very unsatisfied*
Specialist					
	Gastroenterologist	100 (69.9)	38 (26.6)	3 (2.1)	2 (1.4)
	Surgeon	35 (68.6)	11 (21.6)	5 (9.8)	0
	Rheumatologist	24 (48.0)	16 (32.0)	7 (14.0)	3 (6.0)
	Dermatologist	28 (57.1)	17 (34.7)	4 (8.2)	0
	Ophthalmologist	18 (66.7)	6 (22.2)	3 (11.1)	0
	Other	5 (45.5)	4 (36.4)	2 (18.2)	0
General practitioner		71 (61.2)	34 (29.3)	7 (6.0)	4 (3.4)
IBD nurse		42 (73.7)	14 (24.6)	1 (1.8)	0
Nurse on consultation in hospital		30 (69.8)	11 (25.6)	2 (4.7)	0
Emergency services		16 (45.7)	11 (31.4)	5 (14.3)	3 (8.6)
Psychologist		17 (51.5)	10 (30.3)	5 (15.2)	1 (3.0)
Physiotherapist		20 (69.0)	5 (17.2)	4 (13.8)	0
Dietitian		14 (50.0)	10 (35.7)	4 (14.3)	0
Home nurse		16 (76.2)	5 (23.8)	0	0
Social worker		2 (50.0)	2 (50.0)	0	0
Rehabilitation team		1 (100.0)	0	0	0
Other		3 (30.0)	6 (60.0)	1 (10.0)	0
Quantity and clarity of information received					**n (%)**
				Too much	1 (0.7)
				Sufficient	128 (85.3)
				Insufficient	21 (14.0)
				I didn't receive any information	0
				I don't know	0
Involvement in treatment choice					**n (%)**
				No	42 (28.0)

	Yes	52 (34.7)
	I don't know	26 (17.3)
	Not applicable	30 (20.0)
Accessibility of care		
Foregone care		**n (%)**
	Lack of competent staff to give care that was needed	10 (6.7)
	Very long waiting times	8 (5.3)
	Lack of information	6 (4.0)
	Transport problem	4 (2.7)
	Difficulties in paying for care	4 (2.7)
	Lack of time because of work, childcare, or other	4 (2.7)
	Fear of medical tests, hospital, or other examinations	1 (0.7)
	Other	4 (2.7)
Waiting time		**n (%)**
Time between first symptoms and decision to consult		
	Less than 1 week	4 (2.7)
	1 week to 1 month	32 (21.3)
	1 to 3 months	41 (27.3)
	More than 3 months	58 (38.7)
	I don't know	15 (10.0)
Time between decision to consult and first consult		
	Less than 1 week	33 (22.0)
	1 week to 1 month	42 (28.0)
	1 to 3 months	36 (24.0)
	More than 3 months	18 (12.0)
	I don't know	21 (14.0)
Time between first consult and diagnosis		
	Less than 2 weeks	36 (24.0)
	2 weeks to 2 months	49 (32.7)
	2 months to 1 year	29 (19.3)
	More than 1 year	29 (19.3)

	I don't know	7 (4.7)
Time between diagnosis and first treatment		
	Less than 1 week	58 (38.7)
	1 to 2 weeks	30 (20.0)
	2 weeks to 1 month	30 (20.0)
	More than 1 month	20 (13.3)
	I don't know	12 (8.0)

Appendix 1.3. Summary table – Unmet social needs

Impact on social functioning		
Social support needs not received		**n (%)**
	Talk to healthcare professionals	39 (26.4)
	Talk to other patients about your disease	35 (23.6)
	Administrative or social support	31 (20.1)
	More help with day-to-day activities that you are currently receiving	25 (16.9)
	Talk about things other than health problems	24 (16.2)
	Work resumption support	23 (15.3)
	Spiritual or religious support	7 (4.7)
	Other	6 (4.1)
Impact on work		
Experience with the organisation of care		**n (%)**
Unable to work because of health issue		
	Yes	64 (68.8)
	No	29 (31.2)
Return to work		
	Yes, as before	27 (42.2)
	Yes, less than before	18 (28.1)
	No, due to current state of health	11 (17.2)
	No, due to other reasons	8 (12.5)
Financial impact because of health issue		

Medical expenses	84 (85.7)
Loss or lack of income	45 (45.9)
Loss of employment or unemployment	19 (19.4)
Other	8 (8.2)

APPENDIX 2. ORIGINAL TESTIMONIALS

[1] « Bijvoorbeeld seksueel ook. Dus als je nu ergens anders gaat slapen, dus doordat je dus, in mijn geval, anaal geen controle meer hebt. En je gaat ergens gaan slapen, of bij iemand of op hotel of om het even wat. Dus, in uw hoofd weten dat je niet thuis bent, als je dat thuis tegenkomt is dat geen probleem, je kuist dat op en het is… Dat je dat probeert in te dekken. Dat is niet evident hé. Seksueel is dat juist hetzelfde. Het is niet… zo logisch van iemand die ineens zijn stoelgang verliest, dat is niet… Je kan dat niet, dat knopje moet je kunnen verzetten en dat is niet evident. En als je dan inderdaad nieuwe relaties aangaat, hoe ga je het uitleggen? » (5N1)

[2] « On ne parle pas non plus de la sexualité, alors ça parait vraiment très bête, mais euh… c c'est quelque chose de très gênant à partir du moment où on a des fistules, à partir du moment où on se contrôle pas et qu'on a des… pertes de selles ou des choses comme ça, ben je veux dire au niveau intimité, et ça c'est des choses en tout cas que moi je n'ai jamais abordées. » (3F2)

[3] « Parce que bon quand on a une poche, quand on a une stomie, on a peur des relations sexuelles aussi, et il faut penser à tout ça. » (4F2)

[4] « De beslissing van geen kinderen te nemen, terwijl dat wel mijn wens was, dat is een gevolg daarvan. Op latere leeftijd, toen ik al halverwege de 40 was ingezien dat ik, een laag zelfbeeld hoort daarbij. Ik vond ook van, wie zou ooit iemand willen in een beginnende relatie die al zo'n ziektebeeld meebrengt? » (4N2)

[5] « Ik zeg niet alleen omdat ik ook met een heel deel reumatologische problemen zit. En uiteindelijk is er nu ook nog eens spondylitis uitgekomen. Dus leg ik dat uit zo dat ik ook heel diverse klachten heb. Niet enkel darmgerelateerd.» (2N1)

[6] « Eh bien, je ne sais pas si c'est dû à la maladie de Crohn, au traitement par [TNF inhibitor], et il y a aussi évidemment l'antibiotique que je reçois par injection qui peut aussi donner ces fatigues et ces douleurs musculaires donc euh… tout ça l'un dans l'autre, je ne sais pas dire si c'est Crohn ou pas, mais je sais bien que Crohn était quand même très fatigant. » (5F2)

[7] « Tot nu eigenlijk dat ik andere symptomen begin te krijgen, het is eigenlijk neuropathie, beschadiging ergens aan de zenuwen dat ze nu nog aan het onderzoeken zijn, dus tot nu toe was ik eigenlijk heel goed, mijn darmen waren ook heel goed, maar helaas zijn er dan andere dingen die de kop opsteken. » (3N1)

[8] « Alors après la difficulté chez moi c'est que j'ai et la maladie de Crohn et le syndrôme du colon irritable et donc il y a des choses, parfois c'est un peu… Est-ce que c'est la poule ou l'œuf, c'est compliqué. Mais je pense que j'ai plus de symptômes dus au colon irritable qui peuvent être un peu désagréables. Mais le Crohn, franchement moi je pense que le médicament fait bien son boulot et donc euh… j'ai pas de période de diarrhées, ou voilà, non. » (4F1)

[9] « Avec les douleurs que c'est… c'est ingérable en fait. Les gens ne se rendent pas compte ce que c'est que de rester sur les toilettes pendant deux heures. On se relève « ah mais non il faut que je revienne » avec des crampes terribles, ou quand ça avait atteint mon œsophage, pendant trois semaines je ne savais même pas boire une goutte d'eau. Une goutte d'eau ne passait pas. » (2F1)

[10] «Tijdens een opstoot dan kan je natuurlijk niet veel doen, dan, tien minuten rechtstaan is eigenlijk al lang, ik vond het al een tijdje geleden, maar ik kan me dat wel nog goed herinneren, dan is dat eigenlijk constant van en naar het toilet lopen. » (3N1)

[11] « J'ai commencé à avoir des douleurs dans la fosse iliaque, de la diarrhée, des vomissements, de la température enfin une poussée classique. » (2F3)

[12] « J'avais un peu mal au duodénum du coup, et donc il m'a donné du [name antispasmodic] et il m'a dit « ça va passer, 'tracasse ! » et puis ça a continué comme ça pendant des mois et puis à un moment donné j'ai eu une énorme crise d'hémorroïdes à ne plus savoir marcher et des aphtes dans la bouche. Là je ne savais plus manger. Ma joue avait gonflé, je ressemble à hamster. » (1F1)

[13] « C'était des grosses, grosses crampes au niveau de l'abdomen. Des vomissements à longueur de journée. » […] « Donc j'avais les symptômes de douleur, j'avais les symptômes de ballonnements, j'avais les symptômes de vomissements, j'avais les symptômes d'aller à la toilette très régulièrement, j'ai eu cette fistule là aussi. » (3F1)

[14] « Ik moet zeggen, het is vastgesteld in 2011 bij mij, maar eigenlijk sinds dat ik 16 jaar ben heb ik wel zo op en af al last van de darmen, dus ik wist ook wel, er moest iets aan de hand zijn. » (3N1)

[15] « Donc j'allais très très très régulièrement à la toilette, et j'avais des saignements. Alors au début on a pensé à une gastro-entérite, qui se manifestait régulièrement. Mais j'avais des douleurs… enfin incroyables. J'avais une grande fatigue. Je ne dormais plus. Et ça durait comme ça des mois. » (3F3)

[16] « Je faisais une énorme sieste, je restais beaucoup dans le divan, et je disais tout le temps à ma maman « je couve quelque chose, je ne sais pas quoi», et je n'avais pas de fièvre, mais je sentais mon cerveau chauffer, vraiment. Je sentais qu'il y avait de l'inflammation mais je n'avais pas de fièvre. » (2F5)

[17] « Terug een week thuis geweest, en de vermoeidheid vond ik heel zwaar, je zal altijd maar slapen en slapen en op een gegeven moment heb ik gezegd, ik moet er mij over zetten. » (2N1)

[18] « Dat was de eerste keer dat ik eigenlijk niet wist dat ik het had, en toen was ik tien kilo vermagerd, ik was totaal niet goed en dan ben ik echt wel opgenomen. Ik was toen tien kilo vermagerd ook, uitgedroogd. Dan heb ik eigenlijk tien dagen in het ziekenhuis gelegen.» (2N1)

[19] « Het psychologische, leven met continu, ja ziek zijn en pijn hebben, dat vind ik niet altijd even evident. En dan, soms dacht ik, zeg je zo van als je kanker hebt dan krijg je begeleiding. Dat is heel erg hé, en psychologische begeleiding, maar dat stukje voor andere chronische aandoeningen dat is er niet altijd, terwijl dat ook wel een hele grote impact heeft op uw leven. » (2N1)

[20] « En fait le cercle vicieux entre le fait d'avoir cette maladie, et que ça déprime, et qu'en fait on est déprimé parce qu'on n'est pas bien, mais on est aussi pas bien parce qu'on est déprimé … donc ce cercle vicieux avec la santé mentale, très compliqué à vivre. » (2F5)

[21] « Je dis « j'ai pas besoin qu'on s'apitoie sur mon sort. Je n'ai pas besoin de psy ». Et en fin de compte, si ! Il faut un soutien psychologique. Je ne voulais pas, mais maintenant ça me fait vraiment vraiment du bien, et j'aurais dû le faire depuis le départ. Mais bon c'était aussi tout le contexte, l'annonce de la maladie, le fait que j'étais pas bien, il y avait tous ces traitements qui sont quand lourds et fatigants, ça n'allait pas au travail. Franchement je vous avoue je n'avais pas envie quoi… J'étais déprimée oui, ça oui. » (2F1)

[22] « Ja, ik heb dat er soms wel wat moeilijk mee, omdat mensen het niet zien, dus je kunt heel veel last hebben met een uiterlijk, iemand kan tegen je zeggen, je ziet er goed uit, terwijl je

eigenlijk weet dat je je echt niet goed voelt, dat je met krampen zit, of je constant naar het toilet moet lopen, of inderdaad enorm vermoeid bent, slecht slaapt, mensen zien het niet, het is een onzichtbare ziekte. » (3N1)

[23] « Physiquement ça ne se voit pas en fait quand on n'est pas bien, et donc c'est pas comme si on avait un bras cassé ou un pied dans le plâtre, les gens ne le voient pas et donc c'est « arrête un peu de te plaindre » quoi. On a mal, on devient toute blanche tellement on a mal, mais les gens ne se rendent pas compte quoi. Et donc non, l'entourage ne le comprend pas. » (3F2)

[24] « Je ne le cache pas non plus forcément. D'ailleurs parfois je le fais exprès en famille. Je m'injecte [name TNF inhibitor] devant tout le monde. Ce qui dégoute mes enfants évidemment, mais parfois j'ai l'impression que c'est nécessaire pour qu'ils comprennent. C'est bête hein. Mais je le fais dans la cuisse quand c'est comme ça, mais bon voilà, je change mon site d'injection tous les 15 jours, mais de temps en temps je ne me cache pas pour le faire. Pour montrer que, et bien, oui j'ai quelque chose quoi. Donc oui il y a un petit problème de légitimité avec la maladie, oui. » (2F4)

[25] « Beh en fait, c'est quand même quelque chose, j'ai toujours l'impression… oui, l'image d'avoir une épée de Damoclès au-dessus de la tête. » (2F3)

[26] « Enfin si des périodes que j'estime trop courtes malheureusement, où j'ai pu me reposer physiquement et psychologiquement parce que ça allait mieux, mais finalement on n'est jamais tranquille quoi. » (3F2)

[27] « Ik ben ooit een keer naar een psycholoog geweest. Toen zag ik het helemaal niet meer zitten. Ik kon mijn handen bijna niet wassen, dat pijn, al wat ik aanraakte. En ik wist dat het onomkeerbaar was. En het verergerde misschien ook. » (4N1)

[28] « …in mijn geval, anaal geen controle meer hebt. En je gaat ergens gaan slapen, of bij iemand of op hotel of om het even wat. Dus, in uw hoofd weten dat je niet thuis bent, als je dat thuis tegenkomt is dat geen probleem, je kuist dat op en het is… Dat je dat probeert in te dekken. Dat is niet evident hé. » (5N1)

[29] « Je suis partie en promenade, je venais d'avoir mangé, et là, voilà heureusement que c'était dans les bois mais… voilà puis petit accident et là franchement psychologiquement bah, j'étais pas prête. Et c'est bête car on se dit ça peut arriver à tout le monde en fait mais, ouais là ça a quand même un impact psychologique. » (1F1)

[30] « Ik moet altijd een wc binnen bereik hebben. Dus telkens waar ik kom, een winkel, ah daar is een wc, een stad, in die winkel, daar mag ik gaan. Dus in mijn achterhoofd, want als ik moet gaan, moet ik gaan. Dus in die tijd was er zo'n dik maandverband, die broekjes, pamperbroekjes, dat bestond toen nog niet. Dus ja, ik was altijd onzeker. » (4N1)

[31] « Je ne regrette pas ma stomie. Parce je ne suis plus stressée de pouvoir sortir. A part certaines fois… Parce que parfois elle est capricieuse donc il faut quand même la vider. Mais j'ai retrouvé une qualité de vie, c'est-à-dire que je peux fonctionner normalement, sans m'inquiéter, sans stresser, sans interrompre une réunion, sans… » (3F3)

[32] « En dan heb ik medicatie beginnen nemen, ik ben ook geopereerd geweest in 2000 denk ik. 1999 denk ik, geopereerd geweest dan medicatie beginnen nemen en dan eigenlijk niets meer. Instant geen klachten meer, geen krampen, diarree wel. De nood om naar het toilet te gaan, dat wel, maar voor de rest nooit niets niet meer.» (5N2)

[33] « En ik ben mankend van de pijn, van de gewrichten, binnengekomen. En een uur na het infuus stond ik al te springen. Ik zei, hoe kan dit? Maar omdat men toen nog niet besefte...dat je

dat infuus regelmatig moest hebben, is me van het infuus daarna overgeschakeld op [name immunomodulator]. Ben ik een aantal jaren goed geweest.» (4N2)

[34] « Sur mon quotidien ça va je vais dire, grâce au [name TNF inhibitor], je remercie tous les jours le [name TNF inhibitor] qui me permet de tenir debout et savoir faire tout ce que je peux faire aussi. » (4F2)

[35] « Le [name interleukin inhibitor] fonctionne très bien, je fais une injection toutes les 8 semaines, et en tout cas pour le Crohn et le Verneuil pour le moment ça marche impeccable. Vraiment. Ça marche très bien. » (2F1)

[36] « Oui, généralement c'était entre un et deux ans que c'était efficace, donc j'ai eu aussi bien des médicaments sous perfusion en hôpital de jour, que des… Actuellement j'ai le [name interleukin inhibitor]; c'est des piqures dans le ventre. » (3F3)

[37] « Ja, want momenteel zit ik nu al 9 weken zonder medicatie, dus ik weet niet welke dat ik dan ga hebben. […] Dat is moeilijk, de behandelingen zijn beperkt en ik weet dat ze in gradaties gaan, dus als het lichtste vorm niet helpt, dan gaan ze naar de volgende stap en de volgende stap, maar ze zitten daar ook vrij beperkt in, ik weet dat ze daar onderzoeken naar gebeuren, maar ja, het is niet dat je uit 100 verschillende medicamenten kan kiezen en hetgeen dat de minste bijwerkingen geeft, dat je dat eigenlijk kan nemen. » (3N1)

[38] « Depuis que j'ai été opéré et que je suis sous traitement, on a enfin trouvé le bon traitement parce que je suis passé sur cinq traitements différents, j'en suis au cinquième je crois maintenant, je n'ai absolument plus rien. » (3F1)

[39] « Dat is een beetje de stepping-stone-theorie. Je probeert eerst iets en als het niet werkt dan gaat men naar het volgende. En je moet die hele trein doorlopen. Om dan eindelijk te belanden bij iets dat wel werkt. Maar het hangt ook veel af van je insteek. Of je mee redeneert en mee rationeel alles probeert te volgen. En op een gegeven moment moet zeggen van stop.[…] Doordat men zei dat ik uitbehandeld was, terwijl ik kreeg nog wel de behandelingen met baxters en zo, die lopen nu al 15 jaar, dat ik biologische behandeling krijg. » (4N2)

[40] « Il n'a aucun traitement… enfin… donc [name immunomodulator A] ça c'était vite fini, [name TNF inhibitor A] a quand même fonctionné longtemps et puis là ça fait… donc, je ne répondais plus à [name TNF inhibitor A] et donc quand on ne répond plus à un traitement ben forcément d'abord on accentue la prise, donc là, je ne me piquais plus tous les quinze jours mais toutes les semaines, et au bout de x temps on refait le point. Non ça ne fonctionnait vraiment pas donc on change. Puis j'ai pris une autre molécule je ne sais plus laquelle. Ça n'avait pas fonctionné non plus, après… je crois qu'après un an je ne répondais déjà plus et ici je suis sous [name TNF inihbitor B], avec du [name immunomodulator B], et ici beh on vient de refaire un dosage parce que ça fait un mois et demi que je ne suis vraiment pas bien […] donc je suis au stade où je me demande si ça vaut encore la peine de prendre un traitement quoi. » (3F2)

[41] « J'ai appris et voilà, juste à me connaitre moi-même. Surtout que… euh.. est ce qu'on a vu un nutritionniste une fois je ne sais plus… Mais y'a pas le… D'après les informations que j'ai vues ou que j'ai lues, il n'y avait pas vraiment de consignes en disant « vous avez la maladie de Crohn donc vous ne pouvez plus manger ça parce que ça va avoir un impact négatif ». Il fallait un petit peu voir soi-même. » (2F2)

[42] « Oui. Non, non, je l'ai fait d'initiative… Parce que pour le coup il [= the doctor] était un peu à la traine… euh ben parce qu'on n'avait pas forcément d'étude là-dessus mais moi je me suis tout de suite dit, tout de suite, ce n'est pas possible que ce n'est pas rapport avec ce que je mange. Je mange mal. » (2F5)

[43] « Dan heb ik zelf een uitweg gevonden, per toeval, omdat ik op een gegeven moment wou vermageren, had ik een proteïnedieet gevolgd. En het rare was, vanaf het moment dat ik enkel die potjes at, was mijn diarree weg. Niet 100%, maar af en toe had ik nog eens een doorbraakdag, maar leefbaar. » (4N2)

[44] « Ce qui m'aurait vraiment aidé déjà au départ, c'est me dire « bah voilà, prenez directement rendez-vous avec une nutritionniste ou avec quelqu'un spécialisé dans l'alimentation, parce que votre maladie est étroitement liée à ça », ça quelque part mon diagnostic de ce que je pouvais manger et pas manger, et encore d'un jour à l'autre ce n'est même pas la même chose. » (3F2)

[45] « Dat was echt sap hé, ik kreeg gewoon sap van wortels en sap van rijst, dat kreeg ik als voedsel hé, hoe raar dat ook klinkt. En dieet heb ik dat ook allemaal gevolgd en gedaan. Nu heb ik de regel, al hetgeen dat ik eet, eet ik met mate en al hetgeen dat ik zin heb eet ik. » (5N1)

[46] « Het rotatie dieet, moet ik zeggen, dat heeft eigenlijk ook wel een jaar en een half wel gevolgen, maar is op lange termijn moeilijk houdbaar. Ik mocht bijvoorbeeld een jaar geen gist eten, zes maand geen tomaten eten en dan moest ik dat zo weer beginnen opbouwen, maar blijven roteren, want dat is moeilijk in dagelijks leven, ook als je op restaurant gaat, kun je niet vragen van ja, ik moet vandaag mijn vlees bakken in zonnebloemolie. » (3N1)

[47] « Comment dire… se faire… être méché pendant presqu'un an, c'est quand même long, pénible, même pas seulement physiquement mais psychologiquement c'est, voilà… Tous les jours avoir ce soin là c'est difficile. […] C'est lourd, même en termes d'organisation, et puis voilà psychologiquement et tout ça. » (2F2)

[48] « Ja. Ik besef ook wel dat elk medicijn zijn bijwerkingen zal hebben en dat is niet altijd gemakkelijk en dat heeft soms wat angst in, maar veel kan je daar eigenlijk niet aan doen, behalve afwachten natuurlijk en zien wat dat het geeft, maar dat is niet zo fijn. » (3N1)

[49] « Il n'y a pas que le Crohn, il y a les opérations, il y a les effets des opérations, ça joue psychologiquement parce que on n'est pas préparé à faire des allers-retours à l'hôpital, on nous a promis que la poche serait la solution miracle, et c'est vrai que j'avais retrouvé une qualité de vie par rapport aux allers-retours aux selles et aux douleurs, mais j'ai eu en contrepartie d'autres choses. » (3F3)

[50] « Ik ben blij dat er medicatie bestaat. Maar aan de andere kant moet ik me soms in duizend bochten wringen om naar mijn onderzoeken te kunnen gaan en om alles te kunnen geregeld krijgen. » (3N1)

[51] « Moi je sais qu'aller toutes les 6 ou 8 semaines à l'hôpital de jour, me faire piquer dans le bras une perfusion, et que ça coule pendant trois heures, ça me rendait folle de perdre une matinée… une matinée précieuse dans la semaine. » (2F4)

[52] « Les deux premières perfs, ça dure quatre heures. Donc euh ouais on a c'est quoi, une demi-heure de corticoïdes et après ça, c'est le traitement, puis après on reste en observation une heure pour voir si on supporte bien le traitement et alors on peut rentrer chez nous. » (1F1)

[53] « Mais en fait les boites sont grosses, or j'habite dans un appartement, enfin c'est une question technique mais il faut conserver ca au frigo, et j'ai un petit frigo donc je ne prends qu'une boite à la fois. » (3F2)

[54] « Et alors il y a le fait que ça se conserve au frigo, alors vous avez à tout bout de champ des jeunes à la maison qui vous

sortent votre boite de [name TNF inhibitor] du frigo pour aller mettre leurs bières. Et évidemment c'est un traitement qui ne peut pas être à l'air libre, donc il faut tout le temps réexpliquer « la boite qui est dans le frigo, il ne faut pas l'enlever ! » (2F4)

[55] « Nu neem ik nog iets van 15 medicamenten. Dus dat zijn een zestal verschillende. En als je die [hypolipidemic ion exchange resin], die poeier die ze voorstellen van te nemen om mijn stoelgang vaster te krijgen. Dat was dus drie keer per dag, 's morgens, 's middags en 's avonds. Ze zouden dat nog opgedreven hebben naar vier keer per dag, maar als je dat er nog eens moet bijnemen en heb je zodanige druk om te kijken wanneer dat je al uw medicatie moet pakken dat dat dus in plaats van ontlasting een belasting is. » (5N1)

[56] « On en a parlé avec mon gastro mais je sais comment ça va aller, comme c'est une fois toutes les semaines ou une fois… je vais l'oublier. Je vais faire ça les deux premières semaines, et après comme je me sens bien je vais oublier, et après je refais des crises, donc je préfère aller à l'hôpital. » (4F2)

[57] « Ik heb natuurlijk het feit meegemaakt van je pakt de pillen, je bent goed en je stopt ermee en je ziet dan toch van je denkt dat komt allemaal terug in orde, maar na een paar jaar herval je dan uiteindelijk terug. » (2N1)

[58] « J'ai déjà fait des petites bêtises de patient chronique, vu que la grande spécificité de la chronicité c'est l'automédication […]. Donc dès que je vais mieux, je vais pas dire que je m'auto-médique, mais je mets un peu de distance avec le traitement […]. Maintenant je m'auto-injecte les médicaments, et je remarque qu'au plus mon état de santé va bien, au moins je suis vigilante aux délais. » (2F4)

[59] « C'est toujours, y'a toujours de l'attente, c'est long… en fait ce qui est, voilà, j'ai quand même un calendrier médical qui est plus important que mes amis par exemple. J'ai au moins un rendez-vous par mois. Une fois c'est la gastro, et après il faut aller faire une prise de sang, puis il faut aller faire ceci, il y a des tests, enfin voilà, il y a plein de choses à faire. » (4F1)

[60] « Ik heb ook een paar maanden op de 2 gestaan, dus zowel [name immunomodulator A] als [name TNF inhibitor A], maar dat bleek dan heel zwaar te zijn. Ik was enorm, enorm vermoeid. De vermoeidheid, zowel op [name immunomodulator A] als [name TNF inhibitor A], is eigenlijk hetzelfde» (3N1)

[61] « Ici avec le traitement, la première perf' ça s'est pas super bien passé donc là j'étais vraiment KO pendant 2-3 jours même voire plus. » (1F1)

[62] « Nee, de initiële behandeling was dus opgestart met (name immunomodulator A) en die konden ik eigenlijk niet verdragen. Dat heb ik toch een maand of anderhalf genomen met klachten, dus buikpijn, buikpijn, etc. » (2N2)

[63] « J'avais des nausées constamment, y'avait rien qui passait… j'avais une perte d'appétit. Je vais dire je me faisais à manger je me disais « oh, ça a l'air super bon » et puis arrivé devant le plat c'était impossible de manger. » (1F1)

[64] «(name immunomodulator A), van die dingen, maar een halve (name immunomodulator A en ik lig boven de WC te braken. En dan (name immunomodulator A), dat heb ik wel gehad. Maar dat werd dan elke keer gestopt, omdat ik het niet verdroeg. » (4N1)

[65] « J'ai pas de boutons, j'ai pas de psoriasis, j'ai pas tous ces problèmes de peau, sauf que j'ai la peau sèche, depuis le [name TNF inhibitor B]; ça oui, j'ai la peau sèche. » (4F2)

[66] « En dan de [name immunomodulator A], als je daar aan terugdenkt, is het wel al een aantal jaren geleden, had ik zo rap wel al een keer huid uitslag, zo jeuk, rode huid en rap jeuk, vooral als ik zo uit de douche kwam, heel droge huid ook. » (3N1)

[67] « […] Ja, dat heb ik ook nog als bijkomend gevolg van het nemen van die medicatie. Dus niet Crohn-gerelateerd, maar medicatie-gerelateerd dat ik huidkanker heb. Dat komt dus onder andere door [name immunomodulator A]. Volgens de dermatoloog is de grote oorzaak [name immunomodulator A]. Maar wordt dan natuurlijk een stukje in stand gehouden door de immuunverlagende infusen die ik krijg. Die [name TNF inhibitor B] en zo. » (4N2)

[68] « J'ai eu des problèmes d'articulation, surtout au niveau des doigts, eh bien je constate aujourd'hui, alors que je ne prends plus de traitement que ça va beaucoup mieux quoi. » (2F3)

[69] « Ik ben met mijn handen beginnen te sukkelen, ik heb hier zo ene vinger, dat is heel dof en pijnlijk, en al die andere vingertoppen ook, dan ben ik een jaar lang bij verschillende neurologen geweest, niks gevonden, en dan was er in een [region], die had een studie ontdekt in [region] in Amerika, dat dat eventueel een bijwerking kon zijn van de [name TNF inhibitor A], van de [name TNF inhibitor B], dat heeft die zenuw uiteinden aangetast. » (4N1

[70] « Les douleurs ne s'estompent pas vraiment, et donc elles sont quand même de manière régulièrement là, tout ce qui est douleurs articulatoires… articulaires pardon, reviennent régulièrement aussi. Donc à certains moments, je suis au volant, puis j'ai des crampes aux doigts. Enfin ce ne sont même pas vraiment pas des crampes, ce sont des douleurs articulaires… et aux pieds aussi. Voilà, c'est mains et pieds. » (3F2)

[71] « Pendant tout un temps je n'osais plus sortir de la maison, parce que faut aussi savoir les traitements qu'on nous donne, ben c'est des traitements aussi… A un certain moment j'ai quand même pris 30 kilos, donc le corps change, il faut intégrer cette maladie. » (2F1)

[72] « En naar bijwerkingen, de [name corticosteroid], dat is geen leuke om te nemen. Ik heb dat zeven maand 32 milligram moeten nemen op een bepaald moment. Mijn gezicht was een ballon, ik was 10 kilo bijgekomen, ik had geen verzadigingsgevoel meer, dus ik was constant aan het eten, ik voelde me echt niet goed. » (3N1)

[73] « Alors j'ai fait appel à un kiné parce qu'il y avait un médicament qui m'avait fait prendre du poids, 17 kilos en moins d'un an, mal au dos, alors il a bien fallu. » (5F2)

[74] « J'ai des pellicules beaucoup plus importantes dans les cheveux et ça, ça fait aussi partie du traitement » (1F1)

[75] Significant allergic reactions to drugs have been reported, sometimes requiring hospitalisation, such as a doubling of the abdomen, dermatological reactions and even anaphylactic shock« En dat weten wij van toen zij 18, en zij kreeg [name TNF inhibitor] infuus, zij heeft twee keer een [name TNF inhibitor]-infuus gehad, dus de eerste keer, en de tweede keer ging ze alleen, […] toen belde ik dus naar die afdeling in [region], ah ja, sorry, maar ze heeft een anafylactische shock gedaan, dus die was weg, die was dus allergisch voor het muizeneiwit dat in die [name TNF inhibitor] zat. » (4N1)

[76] « Ça par contre l'induction s'est très bien passé en intra-veineuse mais une fois que je suis passée sur seringue, là je ne le supportais pas. J'avais des réactions au site d'injection. Bon j'ai essayé quelques fois, mais en fait c'était hyper inconfortable quoi, j'avais mon abdomen qui doublait de volume. » (2F3)

[77] «Ja, omdat ik er allergisch op reageerde. Maar in heel hoge mate. In die zin, als je van een grootwarenhuis komt met een karretje. En je laadt de auto in en je plaatst je karretje terug. Had ik al de eerste vlekken op mijn handen van reactie. En tegen dat ik thuis was stond er zelfs al een kopje op. Ja, dat heb ik ook nog als bijkomend gevolg van het nemen van die medicatie. […] Dat

komt dus onder andere door [name immunomodulator]. Volgens de dermatoloog is de grote oorzaak [name immunomodulator]. » (4N2)

[78] « Et donc il m'a donné un premier traitement donc [name immunomodulator] (c'était des cachets) et de la cortisone…que je n'ai pas supporté donc je me suis retrouvée à l'hôpital. » (3F2)

[79] « name TNF inhibitor que j'ai pris pendant quelques années pour stabiliser mon Crohn et qui a fragilisé un petit peu mon rein aussi, toutes des petites conséquences pas à cause de Crohn directement mais c'est suite aux médicaments que j'ai pris pour ça quoi. » (4F2)

[80] « Les traitements que j'ai eus, m'ont développé en fait d'autres maladies auto-immunes […] Les médecins me l'ont confirmé par rapport aux précédents traitements que j'ai eus, c'est eux qui ont déclenché, eh bien la maladie de Verneuil et une spondylarthrite ankylosante. » (2F1)

[81] « Une inflammation carabinée de la cornée, enfin des cornés des deux yeux. Enfin voilà l'ophtalmo s'est toujours posé la question de savoir s'il pouvait y avoir un lien…à l'époque c'était [name TNF inhibitor]. » (2F3)

[82] « Donc j'allais travailler avec mes intestins à l'extérieur si vous voulez, je voyais que dans ma poche il y avait tous mes intestins. Puis rentrée à la maison, une fois que je m'allongeais ils rentraient dans mon ventre, et puis la journée ils ressortaient. » (3F3)

[83] « J'ai un ventre déformé, j'ai le nombril qui n'est pas symétrique, j'ai une hernie qui restera là parce qu'on m'a posé le filet mais maintenant l'hernie ne partira pas, donc on a l'impression parfois que je suis enceinte, mais juste d'un côté quand on me voit de profil dans le bus, on me dit « vous voulez vous assoir, mademoiselle ? » » (3F3)

[84] « Donc finalement vous dites merci au package sans trop vous poser de question, et c'est seulement après, quand vous lisez la liste des effets secondaires que vous vous dites « ah oui, quand même ! ». Est-ce que c'était une bonne chose finalement. Mais voilà, c'est trop tard. » (2F4)

[85] « Vraiment, ça ne m'intéresse pas d'avoir des traitements qui sont tellement vieux que finalement, oui, ils fonctionnent mais avec tellement d'effets secondaires. » (2F5)

[86] « Vooral heel veel zelfdiscipline. Kritisch staan tegenover medicatie, in de zin van je neemt het zoals het moet. Maar als je dan ziet dat na verloop van tijd het niet werkt, dat ook bespreekbaar stellen. En in [region] had ik daar bij professor (name) de juiste professor bij. Dat hij dan zei van 'ja, ik heb nog nooit geweten dat iemand met die medicatie verslechterde. Maar als ik naar jou luister is dat wel zo. Dus ga ik jou opvolgen, we stoppen hiermee en we gaan dat iets anders doen.' En dan binnen de maand was ik plots beter. Dat is bewijs. Je kan dus verkeerd reageren op die medicatie. Maar dat wisten we nog niet. Dat de ziekte meer doorbrak in plaats van tegen te houden. Dus ik blijf wel kritisch tegenover wat ik neem. » (4N2)

[87] « Je refuse, c'est terminé hein je ne veux plus prendre de corticoïdes et tant pis si… non, c'est terminé je ne veux plus ! […] Mais ça je lui ai dit « peu importe, je serais même sur mon lit de mort je ne veux plus de [name corticosteroid], c'est terminé » donc là, il m'a entendu, il m'a écouté donc voilà. » (3F2)

[88] « Begin medicatie heb ik [name immunomodulator] en immunosuppressiva, aspirine, dat was 10 pillen op een dag. Ik denk ik dat 10 jaar heb gedaan. Van de ene moment op de andere had ik er genoeg van en heel raar, ik kon niet meer therapietrouw zijn, ik was het echt beu. Heb ik dat ook besproken met de gastro-enteroloog en gezegd « ik wil er eigenlijk mee stoppen ».» (2N1)

[89] « Moi je le vois, je suis souvent tentée de tout arrêter, parce que je connais les effets secondaires des médicaments […]. Et parfois je me dis, « allez, je vais arrêter tous ces poisons » mais voilà… ici je n'ose plus le faire parce que je me suis vraiment fait gronder par mon nouveau gastro-entérologue donc je n'arrête plus mon traitement. » (2F4)

[90] « Moi je ne veux pas être dépendante de médicaments toute ma vie, et je veux… je veux essayer au moins. Et donc il a dit « ben ok, on peut arrêter, vous êtes stabilisée, tout va bien, on peut arrêter ». J'ai arrêté pendant un an, et donc j'ai… pareil j'ai été hyper rigoureuse sur mon hygiène de vie. » (2F5)

[91] « J'ai eu de nombreuses hospitalisations donnant de nombreuses interventions chirurgicales donnant de nombreuses complications, j'ai failli y passer à deux reprises… pour de la négligence médicale. » (3F3)

[92] « Enfin c'est rare de trouver un médecin compétent, j'ai quand même fait plusieurs médecins pour trouver vraiment la perle rare et qui a pu mettre un bon traitement en place. » (2F1)

[93] « Je ne sais plus les doses que j'avais, mais j'avais ramené tous mes papiers, et il a dit « mais vous avez été complétement sur-dosée, mais qu'est-ce qu'il a fait ce médecin? Qu'est-ce qu'il a fait? ». Bon voilà, moi je n'y connais rien hein, moi on me donne un traitement je le prends. Il sait ce qu'il fait le médecin, je lui fais confiance…bah… Je trouve que non de côté-là on n'est pas assez encadrés, et il y a des médecins qui ne sont pas pros du tout. » (2F1)

[94] r« Het gaat goed zolang je bij dezelfde arts kan blijven gaan, die jouw traject kent, die al ervaring heeft dat je speciaal op zaken reageert of niet reageert en die niet elke keer het warm water wilt uitvinden. In het UZ [hospital] zijn het assistenten. En elke keer andere assistenten, assistenten die mijn dossier niet kennen. […] En dan komt het weer. In de toekomst, mevrouw, moet u zelf zeggen dat ze [name artificial tears] in uw ogen moeten doen. En dan heb ik zoiets van, oké, de verantwoordelijkheid wordt weer bij mij gelegd. » (4N2)

[95] « Je suis suivie à [name of the hospital] par un très bon médecin qui m'a sauvé la vie, mais je dirais maintenant il travaille même trop, et on… je sens vraiment la différence, ça fait quand même maintenant 6 ans qu'il me suit, je sens la différence, il a trop de travail, c'est… je suis un numéro quoi. » (2F1)

[96] « Je sais qu'il y a quelques médecins qui sont très bons, ceux-là ils sont tous full, mais bon la maladie aussi n'est pas très reconnue par d'autres spécialistes. Il y en a qui ne sont pas du tout spécialisés là-dedans, et je vous avoue que je n'ai pas du tout envie d'aller les voir. Mais bon, non ils ne sont pas assez présents, même s'ils essaient de faire leur maximum, non ils ne sont pas assez présents. » (2F1)

[97] « Donc vous voyez, on sent que le système médical est sous pression, on sent que les visites avec le chirurgien c'est 5 minutes, vite vite, on échange mais y'a pas d'examen, il n'y a rien finalement. » (3F3)

[98] « Il est censé avoir une infirmière-relais, qui gère un peu tous les problèmes. Ce que je ne sais pas, si c'est par manque de moyens ou… bref, elle n'est pas très accessible parce que je pense qu'elle n'a pas énormément d'heures pour s'occuper de ça. Il y a énormément de malades de Crohn et donc elle est un peu débordée. Donc pas vraiment suivi de dossier, quand on envoie des questions on doit renvoyer des messages pour obtenir des réponses, donc c'est un peu fatigant. » (4F1)

[99] « Het is als je bij een consultatie bij de maagdarm-specialist zelf wilt doen, dat je geconfronteerd wordt met die wachttijden. Ik heb nog altijd wel in mijn achterhoofd, in het UZ [hospital] werkt men ook met een IBD-contactverpleegkundige. En daar denk ik, als er echt iets ernstigs is en ik speel het via die

persoon, dat ik misschien vlugger bij de betreffende professor kan geraken. Maar daar heb ik nog geen ervaring mee. » (4N2)

[100] « En een psycholoog. Dat moet er zeker zijn want dat is belangrijk. » (4N1)

[101] « D'avoir un accès ben justement à pouvoir consulter un psychologue. » (2F1)

[102] « Op jongere leeftijd was psychologische begeleiding daar wel aangenaam geweest. Plus ook iemand die meer weet over welke ondersteunende maatregelen er allemaal waren. Hoewel toen was er bijna niets. » (4N2)

[103] « Je pense oui, peut-être psychologue. Parce que oui, moi je suis passée par cette phase de déni. J'en reviens aux trois piliers donc diététiciens parce que, moi c'était pas mon cas mais je pense qu'il y a des gens où l'alimentation entre fort en ligne de compte. Psychologue, plus coach. Je dirais activité physique et ce qui me vient en tête aussi c'est kiné, massage, ce genre de choses. » (2F3)

[104] « Des massages thérapeutiques, même dans un spa. Faire un massage dans un spa, ça nous fait du bien aussi, même moralement, mais même pour nous physiquement ça nous fait du bien. Parce que j'ai une copine qui avait étudié ça donc j'étais un peu son cobaye. Ça fait vraiment du bien quoi. » (4F2)

[105] « Ik vind het jammer dat men bij gastro-enterologie niet inzet op gezond voedingsadvies in samenwerking met diëtisten. In het ziekenhuis waar ik in behandeling ben wordt hieraan althans geen aandacht besteed. » (Answer to online questionnaire)

[106] « Donc en gros ça se résume à : prendre un rendez-vous sur internet, se déplacer jusque [name of the city] qui est à une vingtaine de kilomètres de chez moi, aller taper la discussion quelques minutes alors que franchement ca nécessiterait pas de voir un médecin mais bon, voilà. Il m'allonge deux secondes sur son […] brancard. Il me palpe le gros intestin quelques minutes pour dire de faire quelque chose. Et après il me dit « bon eh bien on va prescrire le médicament ». Franchement parfois c'est risible. » (2F4)

[107] « Maar ik denk ook wel in [region], als je zo'n dingen een vraag stelt, dan krijg je wel een antwoord op. Maar je moest het wel zelf een vraag stellen. Want als je zegt, alles oké, oké. Maar je bent letterlijk binnen en buiten geweest. De dokters schrijven de bloednamen voor. En dat is het. En uiteindelijk ben je max vijf minuten binnen geweest. » (2N2)

[108] « Ik heb ook ondertussen ondervonden, vandaag de dag, ook als je iets van een arts wil gedaan krijgen, moet je wel een keer het woordje inspectie laten vallen of het gevoel laten geven, in [region] toch alleszins, een deel van hun centen zouden kunnen verliezen. En dan gaat opeens alles. En dan merk je toch wel, die mentaliteit verschilt heel sterk individueel. » (2N2)

[109] « Ik heb dan zes kleinkinderen. Die hebben allemaal stoelgangproblemen. Maar als die dan naar de kinderarts gaan, daar wordt niet veel gevolg aan gegeven dat hun oma of tante de ziekte van Crohn hebben. [Dan weet je wat het grote probleem is bij die dokters tegenwoordig. Ze kijken allemaal in vakjes, alleen wat van hun is interesseert hen en de rest…] Dat is gelijk de gastro-enteroloog. Die kijkt alleen naar wat hij moet doen. […] Omdat de diverse afdelingen niet met elkaar spreken. Maagdarm stuurt u naar Reumato. En Reumato zegt, 'wat kom jij hier doen? Jij bent in behandeling bij maagdarm voor je reuma. Ja, ze sturen mij naar hier. Maar ja, wij kunnen niets doen. Want je neemt al de baxters die nodig zijn. '» (4N1)

[110] « Et dans les hôpitaux c'est une prise en compte qui n'est pas tellement…euh… En tout cas quand vous passez trois heures à l'hôpital de jour pour une perfusion de [name TNF inhibitor], on

vous prend votre tension avant de poser la perf, mais on ne vous demande jamais si vous avez d'autres symptômes. » (2F4)

[111] « Souvent mon cas était discuté en équipe pluridisciplinaire, donc je pense que c'était la différence par rapport au suivi d'un simple gastro-entérologue ou il n'y a pas cette approche pluridisciplinaire, et j'avais aussi pu intégrer une étude à laquelle j'ai très bien répondu. » (3F3)

[112] « C'est-à-dire que ce qui serait intéressant c'est de comprendre tout ce qui gravite, faire une prise en charge globale c'est-à-dire, quand vous entrez pour une opération où on vous pose la poche, euh c'est bien gentil qu'il faut aller voir un chirurgien un mois après ou une stomathérapeute, mais peut être voir qu'il faut… voilà aller voir un kiné, parce qu'il y a un relâchement de la paroi abdominale, et ça c'est ma rhumatologue qui m'a dit aujourd'hui, plusieurs années après, que j'ai mon abdomen qui est relâché et que je dois travailler dessus, on ne me l'avait pas dit. » (3F3)

[113] « En France en fait, une fois par an, ils sont invités à aller à l'hôpital donc qui les prend en charge, et ils ont un suivi global, c'est-à-dire qu'ils ont un suivi dermato, un suivi ophtalmo, un suivi pneumo,… enfin toutes les parties connexes liées à la maladie de Crohn. Moi je sais pas exemple qu'il y a quelques années, j'ai eu un érythème noueux. Eh, je ne savais même pas que c'était dû à ma maladie de Crohn. Personne ne m'en avait parlé. […] Et donc par rapport à l'hôpital, avoir cette vision un peu plus « 360 » sur les différents services qui peuvent être concernés. » (4F1)

[114] « En uiteindelijk moet je als patiënt inderdaad aan het roer staan, de zorg zelf in handen nemen, maar je moet ook als patiënt voldoende onderbouwd zijn, onderlegd zijn, om dat te beamen en te verwezenlijken. » (2N2)

[115] « Ik ga altijd terugkomen op hetzelfde, van de samenwerking die er nu al wel is, van arts en verpleegkundige of ook misschien maatschappelijk werker. Dat moet een samenwerking zijn. Dat is niet alleen uw arts, er komt zoveel meer bij kijken en ik denk als je van start gaat dat je al die mensen nodig hebt en dat moet aangeboden worden. Je moet, gestimuleerd en opgevolgd worden toch, dat het niet mag zijn van ik contacteer hen, maar zij contacteren mij nog meer. Ik moet zeggen dat dat over de laatste jaren verbeterd is, maar ik denk dat dat nog beter kan. En ja, het vergeten van het is niet alleen medisch en echo's en bloednames en colono's doen, maar het gewone gesprek psychologisch dat mis ik wel. » (2N1)

[116] « C'est très étonnant je trouve parce que, donc il y a énormément de progrès dans les rapports humains, et en même temps je trouve que l'hôpital, avec tous ses protocoles, c'est un petit peu… il a d'autres cotés moins humains. Je prends l'exemple bêtement des prises de sang, à l'époque il y avait une infirmière qui sortait de son petit box et qui appelait la personne par son nom, la personne venait se faire piquer, puis elle appelait la suivante. Maintenant c'est comme chez le boucher, avec des numéros […] Enfin, voilà… les routes maintenant. Avant, vous aviez des petites flèches pour indiquer, voilà, tel service est par là. Maintenant, c'est des routes, vous devez scanner votre ticket pour savoir que vous êtes bien arrivé. Avant vous alliez voir la secrétaire médicale pour signaler que vous étiez présent. Voilà, c'est des petites choses mais je me dis ça déshumanise quand même pas mal. » (4F1)

[117] « Je vous ai expliqué les fameuses 3 heures que je passais avec le [name TNF inhibitor] à une époque à l'hôpital de jour. Souvent on était à coté de quelqu'un d'autre qui avait la maladie de Crohn, et je trouvais que c'était assez intéressant comme démarche, parce qu'il y avait un gros partage d'expérience lorsque on était un peu coincés à l'hôpital. […] Et franchement j'en ai tiré beaucoup de bénéfices à l'époque. C'est peut-être le seul point positif de l'hôpital de jour à l'époque où j'avais mon [name TNF inhibitor]. » (2F4)

[118] « Et donc qui ne font rien de leur journée, et puis quand je les vois manger leurs trucs… leurs sodas et… Je suis un peu jugeante mais je me dis « allez ! ». Voilà… non, je n'ai jamais pu échanger avec ces personnes parce que… oui, sans doute que je suis un peu jugeante mais je me dis, si tu faisais déjà tout ça, ta maladie elle irait forcément un peu mieux. » (2F5)

[119] « Dus ik denk vooral, in het traject, en dat is vooral de manier waarop, en ook de volledigheid aan informatie. Ik persoonlijk zie daar gewoon een discrepantie in, tussen het universitair en universitair, om het eigenlijk objectief te kaderen, zonder instellingen te veroordelen. » (2N2)

[120] « Si tous les hôpitaux était comme le [name university hospital], ce serait merveilleux mais évidemment tous les hôpitaux ne sont pas universitaires, peut être que tous les gastro-entérologues ne sont peut-être pas aussi performants les uns que les autres. Donc tout ça mis l'un dans l'autre, on n'aura pas nécessairement les mêmes soins je pourrais dire. » (5F2)

[121] « Dus ik ben bij de specialist geweest, die heeft me uitgelegd dat ik die biologicals ga krijgen, dat dat met baxters is. En dan ben ik aansluitend bij de IBD verpleegkundige geweest en dan weet ik niet meer juist wie dat wat verteld heeft, maar uiteindelijk is mij alles wel goed meegedeeld, met een kaftje, met een boekje, met alles wat je hebben wil. » (5N2)

[122] « Maar nu ben ik voor het eerst bij IBD meegedaan, de professor die dus gans de groep die ondersteuning geeft aan Crohn en ook aan colitis, dus gans de groep eens voorgesteld op een middag van 5u tot 8 of 9u was dat in het UZ en dat is de eerste keer dat ik meegedaan heb in groepsverband. Dus gewoon van eens te luisteren, wat kan er allemaal, wat gebeurt er allemaal en wat doen we allemaal. […] Dus er zit daar een gans team achter en ze zetten dat in feite nu op die paar uur elk individueel uitgelegd wat hun taak en hun job is. En daardoor heb ik dus ook op Facebook, ik zit dus ook in de groep van IBD.» (5N1)

[123] « Of inderdaad veel meer informatie kunnen betekenen of overgeven aan de patiënt. En dan zie je dan wel bijvoorbeeld het contrast, tussen enerzijds, het [hospital] hier, en aan de andere kant dan het UZ [hospital]. Toch wel de informatie die je krijgt als patiënt, het is een wereld van verschil. Maar uiteindelijk bepaalde informatie vind ik wel mee de kwaliteit van de zorg. En ook de verdere opvolging daarvan. » (2N2)

[124] « Ah non non, mon médecin euh… Je vous dis hein, parfois c'est moi qui dois réclamer une vaccination : « est-ce que vous pensez que je doive me faire vacciner Docteur ? ». Alors « oui évidemment que vous devez vous faire vacciner, parce que vous avez une faible immunité ». « Ah ben merci de me le dire ! » « Est-ce que je dois aller voir le dermato Docteur ? », « Ah oui oui, bien sûr vous… ». Mais franchement non, c'est pas via mon médecin que j'ai trouvé l'info, non c'est moi. » (2F4)

[125] « Oui parce que déjà au niveau information, ce qui m'aurait vraiment aidé déjà au départ, c'est me dire « bah voilà, prenez directement rendez-vous avec une nutritionniste ou avec quelqu'un spécialisé dans l'alimentation, parce que votre maladie est étroitement liée à ça. » (3F2)

[126] « Quels sont les différents types ? Euh dans quel type je me trouvais. Les traitements, comment ça fonctionnait… Ce que je n'avais pas chez mon premier gastro-entérologue. Qui a posé des bons diagnostics, qui m'assure un suivi, mais qui en termes de dialogue avec le patient… Voilà, c'est un peu… on ne passe pas beaucoup de temps dans son cabinet quoi. Et donc en terme d'explications c'était un peu light. » (2F2)

[127] « « Est-ce que tu veux voir une infirmière qui va t'expliquer la maladie en long et en large tu peux prendre quelqu'un de ta famille avec » et moi ma maman avait dû mal à accepter – plus que moi finalement – la nouvelle et à se dire c'est la catastrophe donc j'ai pris ma maman avec moi à l'entretien et donc là c'était vraiment un rendez-vous d'une heure où j'ai pu poser toutes mes

questions où j'ai vraiment eu tous les renseignements et puis ils ont fait tous des fascicules sur la maladie j'avais tous les services auxquels j'avais droit. Voilà, c'était, je vais dire ça c'est chouette. » (1F1)

[128] « Moi qui suis dans la recherche etc., il y a une autre dimension où je pouvais poser toutes les questions que je voulais. Il connaissait toute la littérature, et donc moi ce côté-là c'était vraiment le côté qu'il me fallait. Il savait répondre à mes questions, en étant extrêmement rigoureux sur ce qu'il disait, nuancé, […] Donc oui c'est fortement influencé [l'annonce du diagnostic] par la manière dont on vous le dit et la personne qui vous le dit donc… Ça n'a pas fait l'effet de gros « splash ». » (2F5)

[129] « Dans mon boulot j'ai énormément de compassion et je trouve que parfois en fait les médecins ne se mettent pas à la place du patient. Un minimum de compassion je veux dire c'est pas… c'est pas une grippe qu'on a… c'est une maladie auto-immune qu'on va garder à vie et ça il faut quand même l'encaisser ; c'est pas évident. » (2F1)

[130] « Dat was eigenlijk raar, na de coloscopie, als ik dan wakker werd, kwam hij dan even vermelden en dan zei hij van ja, we gaan nog een vervolgafspraak maken en dan gaan we wel even een toelichting doen, maar dat was zo precies tussen de ene patiënt en de andere die dan moest binnen gaan voor een onderzoek, ja, dat dat zo een keer gezegd werd. » (3N1)

[131] « C'est lors de cette fameuse rentrée en chambre matinale avec l'infirmière en chef, vous avez le médecin titulaire avec toute sa horde d'assistants et puis… Ils ont des résultats à vous communiquer, et vous êtes là couché dans votre lit, et on vous dit « ah ben oui en effet, les examens complémentaires ont confirmé la maladie ». Je pense que ça s'est passé comme cela, ni plus ni moins. » (2F4)

[132] « Niks, wel een boekske mee naar huis en dan hadden ze me gezegd, kom terug op de consultatie en dan bespreken we dat. Vond ik een beetje spijtig eigenlijk. Allez, misschien zeiden ze, natuurlijk omdat ik verpleegkundige ben dachten ze misschien dat ik een andere achtergrond heb en dat je dan misschien minder uitleg nodig hebt. Ik weet het niet. Maar op die moment is dat wel spijtig dat je heel weinig uitleg krijgt. Vind ik persoonlijk. » (2N1)

[133] « L'époque n'était pas aussi attentive au bien-être du patient qu'à l'heure actuelle. Ca je trouve que ça a quand même vachement changé. Il me l'a annoncé ni bien ni mal : il me l'a annoncé. Ce qui était très rigolo c'est qu'il avait ce jour-là justement un jeune médecin stagiaire […] qui m'a posé des questions qui n'étaient quand même pas très fute-fute, du style « Ah vous avez la maladie de Crohn, combien vous vous êtes déjà fait opérer de fois ? ». J'ai dit « mais jamais ! ». « Ah, mais ça va arriver bientôt ! » » (4F1)

[134] « […] het cliché doen in de zin van oké, dat het een soort van bandwerk is als het ware. Ik vond het oké, we hebben een colon, we hebben een diagnose en dat is het. En de verdere opvolging doen wij dan nog in een verdere samenspraak met al dan niet de huisarts. Maar ik denk wel inderdaad de manier waarop eigenlijk het wordt vastgesteld. Persoonlijk denk ik kon het beter zijn qua communicatie, ik denk inderdaad de manier waarop het werd verwoord. Ik kan me nog heel vaag herinneren, maar het is wel sowieso iets wat ook een impact heeft nagelaten. Dan denk je meteen van oei zo'n stempel dat je op je krijgt. » (2N2)

[135] « Donc non l'information n'a pas été… euh… non l'information n'a pas été clairement donnée et tous les aspects de la maladie, ce qui allait changer, la lourdeur quand même d'un traitement parce que finalement on nous donne des cachets, on ne se rend pas compte de ce que c'est, finalement c'est quand même un traitement que j'estime assez lourd, avec des effets secondaires très importants, et ça on en parle pas quoi. » (3F2)

[136] « Als ik het niet begrijp moeten ze maken, wacht ik tot dat ik het begrepen het, dus al is het moeilijk. Het is omdat ik er al zodanig veel zien passeren heb, van een assistent pik ik het niet als hij de moeite niet doet. Steek ik er ook geen energie niet meer in. Mijn vrouw vond dat ook raar, en als je dan de prof hebt en je legt dat uit, ze geven u gelijk hé. Je moet daarvan weten wat ze gaan doen en waarom ze het gaan doen. » (5N1)

[137] « Je dois vous avouer que voilà, j'ai fait confiance, après, quand j'en ai eu marre de prendre le premier traitement, avec [name immunomodulator], j'ai dit… C'est à ce moment-là qu'on en a discuté, qu'on est passé à [name TNF inhibitor]. Donc il y avait quand même un échange par rapport à tout ça. » (2F2)

[138] « Maar we hebben dat samen beslist. En nadien met de opstoot is er ook heel goed besproken met de gastro-enteroloog samen dat ze toch ook in, zoals ik al zei, in het hoofd hield met de reumatoloog van we moeten hier samenwerken en we gaan daar samen naar kijken. En wat ik ook altijd heel hard gehad heb is als je andere klachten aanhaalde bij de gastro-enteroloog, dan verwijzen die u onmiddellijk door. » (2N1)

[139] « Et ici par exemple, et bien comme ça va mieux, le traitement fonctionne, on m'a demandé si je voulais passer aux piqures ou pas. Et euh, moi je n'étais pas prête encore pour la piqure donc j'ai dit « non, on continue avec la perf ». » (1F1)

[140] « Het contrast zie je wel wederom tussen het [hospital] bijvoorbeeld, toen je zegt van oké, we gaan met dit beginnen, en het is zoiets van oké, dit is het. Terwijl in [region] werd letterlijk, hadden ze brochures, noem maar op, die en die opties, dat je kunt kiezen van dat, dat, dat of dat. Dus je had inderdaad veel meer inspraak, veel meer zeggenschap. Als het ware was, ja, is patiënten wel het laatste woord in [region]. Dan kon je echt wel zeggen. » (2N2)

[141] « Un moment donné il m'a dit « il faut absolument reprendre des corticoïdes », j'ai dit « non, je ne veux pas ». Donc en gros on a fait un deal (rires), … C'est risible mais c'est comme ça. » (3F2)

[142] « Et donc voilà, quand je lui ai dit « j'ai envie… je préfère si c'est possible de me piquer moi-même », peut être que lui dans son choix de traitement, peut être que lui à deux traitements identiques il va préférer un traitement ou je peux me piquer moi-même. Peut-être, j'en sais rien. En tout cas il écoute tout ça. » (3F2)

[143] « Là en fait le gastro-entérologue a commencé à augmenter les doses de [name TNF inhibitor]. Et les doses devenaient de plus en plus importantes. Et puis voilà, dans la prise en charge euh… je ne me sentais plus écoutée. » (2F3)

[144] « Ja, in [region] was dat inderdaad wat minder. De inspraak was ook wat minder. Dat was dan van ja, kijk, we gaan u dat geven. Er werd niet gezegd of geen uitleg gedaan. Van kijk, dat bestaat er allemaal. We beginnen daarmee en dan gaan we stapsgewijs kijken wat dat er werkt. In het UZ is dat dan wel anders. Daar krijg je echt zo'n schema mee van kijk, dit zijn alle mogelijke behandelingen. Je zit nu daar en er wordt … ja, de moment dat het nodig is, wordt dan wel besproken daar dan van wat de mogelijke opties zijn. » (3N1)

[145] « Non je pense que... en tout cas à l'époque où il y a eu des basculements de molécule… Quand vous allez voir un gastro-entérologue vous êtes souvent dans une situation… je vais dire de faiblesse, parce que vous allez le voir parce que vous allez un peu moins bien au niveau de vos symptômes, et donc tout ce qu'il vous dit, vous le prenez pour argent comptant. Souvent c'est accompagné d'un arrêt maladie pour pouvoir souffler. Donc finalement vous dites merci au package sans trop vous poser de question. » (2F4)

[146] « (…) je n'osais pas en fait vraiment contredire les médecins parce que je me suis dit « ils savent ce qu'ils font, c'est leur métier » et je me disais « bon ben d'accord, on change, on change, on change encore de traitement ». Je leur ai fait confiance. Et bon il y en a un que je n'aurais pas dû, en fin de compte. » (2F1)

[147] « J'ai demandé qu'on arrête la voiture, euh j'étais avec mon compagnon de l'époque, et j'ai dit il faut arrêter la voiture je dois aller aux toilettes, et que j'ai été aux toilettes sur le bord de la route. Là, je me suis dit « non, si je ne sais pas me retenir, si je ne sais pas attendre d'être dans un endroit où je peux aller aux toilettes c'est vraiment bizarre, et surtout en vacances. J'ai tendance à ne pas avoir trop de problèmes. Donc là je me suis dit que c'était bizarre. En rentrant, j'ai consulté mon médecin traitant. » (2F5)

[148] « Ik weet dat ik toen symptomen had waarvan ik niet wist van wat dat is. Maar ik moest vaak overgeven en ik had altijd last van krampen en ik ben niet iemand die meteen naar de dokter loopt, dus dat bleef maar aanslepen en aanslepen. Toch naar de huisdokter geweest, doorverwezen geweest, en plots had ik de ziekte van Crohn.» (5N2)

[149] « […] ça faisait une semaine je me souviens, donc j'ai fait venir mon médecin traitant. Mon médecin traitant m'a dit « beh [nom du patient], tu fais une petite gastro », euh une semaine au repos, et ça allait toujours pas, les douleurs étaient de pire en pire, je ne savais plus me lever, j'avais beaucoup de fièvre, j'ai perdu plus de 7 kilos en une semaine, et euh là j'ai fait revenir mon médecin et j'ai dit « Ecoute, y'a quand même quelque chose, ça ne va pas » et de là en fait il m'a envoyé aux urgences. » (2F2)

[150] « Ça c'est de ma faute, dans le sens où je suis… Ce n'est pas que je suis anti-médecin mais j'ai toujours considéré, encore une fois c'est un peu con de ma part en étant dans le milieu médical, que au plus je me tiens loin des médecins, au mieux je me porte. Voilà, donc c'est moi qui ai un petit peu fait trainer les choses aussi. » (3F1)

[151] « Donc là j'ai été voir mon médecin traitant qui m'a dit « Oh ce n'est pas grave ! ». […] Je vais dire c'était plutôt le médecin traitant qui… même lui finalement je me suis demandé s'il savait vraiment ce que c'était la maladie de Crohn parce que finalement je tapais mes symptômes sur internet et ça ressortait, c'était dans les premiers trucs qui sortaient quoi. » (1F1)

[152] « Et je pense même que mon médecin généraliste n'était pas tout à fait au courant de la maladie, parce que quand je suis arrivé avec mon abcès en fait, donc j'ai eu une fistule en fait… C'est comme ça que c'est arrivé, ça suintait et en fait mon médecin généraliste m'a dit « ah ben oui, tu as un petit abcès, je vais te donner un petit antibiotique, ça va passer. » (2F2)

[153] « Qui m'a dit « Non, c'est parce que tu manges trop épicé, t'as surement mal au ventre, il n'y a pas de soucis », il m'a donné un peu de vitamines. C'est passé. Sans savoir pourquoi. Moi je me suis fié à ce qu'il m'a dit de toutes façons. Maintenant voilà c'est revenu une ou deux semaines plus tard aussi, avec la même intensité. » (3F1)

[154] « Ja ja, dus, ik heb dus wreed diarree gehad en voor alles behandeld geweest. En rond 11-12 jaar krijg ik dus krampen in mijn buik, dus allez ja, wat niet onlogisch is met die diarree. En dan is een militaire dokter, want mijn pa was rijkswachter. Dus dat was een dokter die ook in de rijkswacht kwam, een gewone huisdokter. En die zei: « je moet met dat kind, hij zit heel zeker met een appendicitis, je moet daarmee verder gaan » . » (5N1)

[155] « Ik weet dat ik toen symptomen had waarvan ik niet wist van wat dat is. Maar ik moest vaak overgeven en ik had altijd last van krampen en ik ben niet iemand die meteen naar de dokter loopt, dus dat bleef maar aanslepen en aanslepen. Toch naar de

huisdokter geweest, doorverwezen geweest, en plots had ik de ziekte van Crohn.» (5N2)

[156] « J'ai été chez le médecin, j'ai été deux ou trois fois chez lui. J'ai été chez un théoriquement spécialiste. Je ne sais plus à quel hôpital c'était… Donc ça c'était, les premiers symptômes, au mois d'aout. J'ai été chez le médecin jusqu'en novembre. J'ai eu un rendez-vous chez un spécialiste au mois de décembre. Qui n'a… rien trouvé. Qui n'a pas exploré des masses non plus. » (3F1)

[157] « Il m'a fait une mini colonoscopie ; j'ai été juste endormie quelques minutes. Je suis sortie de là en m'entendant dire que je n'avais rien, que c'était juste un peu le côlon irritable, et qu'il fallait arrêter certains aliments. » (2F5)

[158] « En rentrant, j'ai consulté mon médecin traitant, qui a tout de suite… elle a travaillé en fait… elle a fait son stage d'interne dans le service de gastro-entérologie et c'est là où j'ai eu la chance, euh je crois dans mon parcours c'est ça qui a facilité les choses, c'est qu'elle a demandé un rendez-vous pour moi. » (2F5)

[159] « J'ai d'abord consulté dans des petites polycliniques euh… de quartier. J'étais étudiante donc je ne connaissais pas Bruxelles très très bien à l'époque […] enfin voilà ça a été un peu des sauts de puce, et puis j'ai eu la chance à un moment donné comme on m'envoyait de l'un à l'autre, d'avoir une amie dont le frère était tout jeune pédiatre et qui travaillait à [name of university hospital], et qui lui a dit « Ecoute il faut qu'elle aille absolument dans un hôpital universitaire, quel qu'il soit », voilà. [Name of university hospital] était le plus près, et je me suis retrouvée à [name of university hospital], et là ça a été très vite diagnostiqué. » (4F1)

[160] « On a chipoté un petit peu avec le diagnostic hein, je dois vous avouer que… je suis même allée jusqu'à [name of university hospital] en ambulance pour aller voir un spécialiste à l'époque, pour bien confirmer la maladie Je me souviens d'hospitalisation à rallonge, je pense que je suis resté un mois et demi à l'hôpital, à jeun, avec une voie centrale – qu'on a dû changer deux fois d'ailleurs – enfin bon… Je pense qu'actuellement par rapport à ça, c'est quand même un peu plus simple. Mais voilà, c'est le souvenir que j'en ai, un long diagnostic, une longue hospitalisation, et un parcours à l'hôpital universitaire pour confirmer le diagnostic. » (2F4)

[161] « Ja. Een universitair ziekenhuis in die tijd staat verder. Zeker qua onderzoeken. En de rest volgt. Ja, dat zijn kleinere ziekenhuizen. Ik denk nu, ja, gelijk een onderzoek zoals de dokter heeft, ik denk niet dat ze dat in kleine ziekenhuizen doen. » (4N1)

[162] « J'ai toujours gardé le même gastro-entérologue, on a juste été consulter un autre gastro-entérologue à [university hospital] […] Juste pour avoir un… parce que bon, c'est quand même des maladies chroniques et tout donc on voulait avoir un deuxième avis pour confirmer le premier diagnostic. » (2F2)

[163] « Et c'est vrai que pour moi, je n'ai pas toujours envie de me déplacer autant pour être prise en charge. Mais je dois accepter aussi de ne pas avoir les professionnels de la santé qui sont peut-être… Je sais que dans les hôpitaux universitaires par exemple ils ont une infirmière qui est dédiée à ça… En périphérie ça n'existe pas ça. […] Parce que l'hôpital de jour dans les hôpitaux universitaires il faut se garer, pour payer une place de parking parfois couteuse. Il faut aller jusque-là, moi c'est un environnement que je ne connais pas, les hôpitaux universitaires. » (2F4)

[164] « Ce que je remarque souvent avec les médecins c'est que voilà ils ont leur spécialité et donc lui, il regardait les aspects gynéco. Mon bébé allait bien, donc il m'a fait comprendre que le reste c'était dans ma tête. Or ce n'était pas dans ma tête, enfin j'étais vraiment pas bien. » […] Parce que ce n'était pas lié au

bébé, et finalement le premier gastro-entérologue que j'ai vu, ben après lui il ne voyait plus que mon intestin quoi. » (2F3)

[165] « Ik bedoel, ik ben één keer opgenomen geweest op de spoed. En dan ben ik gehospitaliseerd. Dan hebben assistenten gevonden dat ik aan lupus leed. Dat ik een tumor had in de baarmoeder. En dat mijn darm zo vernauwd was dat ik moest geopereerd worden. Reumatologie nadien, waar ik als ambulant patiënt dan naartoe verwezen was, die zeiden, 'wat kom jij hier doen, lupus, jij hebt gewoon rosacea en een beetje rode wangen, maar dat is geen lupus'. De gynaecoloog die lachte het uit van, wat, 'wat is dat hier? Tumor in je baarmoeder, je hebt een kleine gekantelde baarmoeder.' Dus dat was ook weg. En de vermoedelijke zware vernauwing waarvoor ik op geopereerd moest worden, die was ook verdwenen. Maar dat waren allemaal assistenten die hun uiterste best deden, maar die direct denken aan het ergste, omdat een UZ is ook een doorverwijsziekenhuis, als de anderen het niet meer weten, ga je naar het UZ. » (4N2)

[166] « Mais ça a duré longtemps et à l'époque on faisait… toute la série : la colono certainement, on faisait des colomba… on faisait toute une série d'examens mais extrêmement… enfin moi qui avais 18 ans et qui ne connaissait rien à tout ça, c'était extrêmement difficile à vivre. » (2F4)

[167] « Donc j'ai passé des examens pour finalement être diagnostiquée en 2013. […] J'ai attendu presque deux… je vais dire au moins un an et demi entre le moment où je me suis dit « tiens, il y a quelque chose qui ne va pas » et faire la démarche quoi. […] Oui, je crois que c'est vers la fin 2012 qu'il m'a envoyé vers un spécialiste et euh, bah le temps d'avoir les rendez-vous etc., j'ai eu le diagnostic final en… je crois que c'était début 2013. » (3F2)

[168] « Dat was dan in 1976. En de diagnose is gesteld in 1994, dus dat is 18 jaar later. Ja, 18 jaar later ja. » (4N1)

[169] « Men heeft ongeveer tien jaar over de diagnose gedaan. En na tien jaar toen men zei 'het is de ziekte van Crohn', had ik daar zelf al over gelezen. » (4N2)

[170] « Ben ça a été rapide… oui, je pense que ça a été rapide, ça a duré deux-trois mois… Et j'ai fait de, scanner, je pense qu'il n'y avait pas encore d'IRM, échographie, et puis, analyse des scelles et puis là, on a vu que c'était la maladie de Crohn. Ça oui. Ça a été très rapide. » (4F2)

[171] « Et là j'ai dû attendre […] 2 mois et demi avant d'avoir un premier rendez-vous avec la gastro-entérologue. » […] « Alors là par contre j'avais téléphoné le jour même de la colono pour donc là, la colono je l'ai fait le 15 février, et quand j'ai téléphoné pour avoir l'entéro-IRM, on m'a dit que j'avais pas rendez-vous avant le 17 juillet et donc là, ça c'est ça c'est très long comme temps d'attente. […] Et ça c'est quand même assez interpellant de se dire que il faut attendre des mois et des mois avant d'avoir tous les examens quoi. » (1F1)

[172] « Par contre il y a des délais hyper longs pour les IRM, pour les scanners, enfin ça c'est aberrant, il faut contacter… J'ai dû contacter plusieurs hôpitaux pour faire mon IRM à la demande de la rhumatologue. C'était trois mois hein, pour l'IRM hein. Finalement j'ai essayé à un autre Hôpital et il y avait une place qui s'était libérée et c'était un mois d'attente, mais pour le psychiatre c'était la même chose, il fallait attendre plus d'un mois avant de voir le psychiatre. Donc quand même c'est .. Oui il y a des longs… de plus en plus longs les délais d'attente. » (3F3)

[173] « Bon je pense que c'est peut-être aussi parce que je travaille là-bas, donc vu qu'entre guillemets je suis une collègue, il a peut-être pris les choses un peu plus rapidement » (2F1)

[174] « J'ai la chance d'avoir un papa qui est pneumologue et qui de son côté s'est renseigné aussi et donc très vite, on a pensé à la maladie de Crohn. Enfin, vu les symptômes il en a discuté

avec des collègues gastro-entérologues donc j'ai été vue euh… je ne sais plus exactement mais peut-être 2 ou 3 semaines après le début des symptômes par un gastro-entérologue à [nom de l'hôpital]. » (2F3)

[175] « Dat is het nadeel van mij. Ik zit er nu al zo lang in het UZ, ik heb in feite nog nooit moeten wachten. Dus ook, ik bedoel, allez ja. Ik probeer ook altijd, dus daarmee dat ik de telefoonnummer van de prof ook heb. » (5N1)

[176] « Et puis alors après, bah [nom du docteur] m'a contacté pour voir si je voulais rentrer dans l'étude [nom de l'étude clinique] j'ai accepté et là elle a réussi à me trouver un créneau. C'était quoi une semaine après qu'elle m'a téléphoné j'avais un rendez-vous pour l'entéro-IRM donc je l'ai passée. » (1F1)

[177] « Pareil, [name immunomodulator A], j'ai dû faire une induction en intra-veineuse, donc là j'avais quand même fréquemment… en plus j'habite dans [place of residence], bon ça c'est mon choix de me faire suivre à [place of care], mais donc il y avait la route donc c'était une journée où je ne travaillais pas. » (2F3)

[178] « Zeker als je naar gespecialiseerde zorg wilt, heb je in mijn geval een bepaalde afstand dient te overbruggen, [region-region]. Dat ligt inderdaad niet bij de deur. Dan zeggen ze bijvoorbeeld aan colonoscopie, waarbij je in slaap bent gedaan met hoe noemt het weer [name general anesthetic A] en [name general anesthetic B] waardoor je officieel niet met de auto kunt rijden. » (2N2)

[179] « D'un point de vue social etc., euh… parfois quand je sors et tout ça, les gens me disent « eh tu bois pas un verre, et tu fais pas ceci ? ». Ouais, mais je fais attention parce que je sais que quand je bois un verre, un verre de trop ben il me faut 2-3 jours pour m'en remettre, ou j'ai plus facilement…des problèmes gastro-entériques et donc voilà. Et donc là c'est pas toujours super… pas toujours super gai surtout que alors je dois dire « ah ben oui je suis malade » alors là, du coup, ça a plutôt tendance à plomber l'ambiance ! » (2F2)

[180] « Hetgeen waar dat ik wel zo psychologisch mee zit is altijd zo als je ergens heen gaat dat je altijd zo denk van 'ah, ik moet misschien naar het toilet gaan.' Dat speelt wel mee en dat is in het sociaal leven, bijvoorbeeld naar concerten gaan ofzo, dat is iets dat ik niet doe hé. Want in zo'n Dixie'ke, en dan is er misschien een lange wachtrij, dus dat sluit ik gewoon uit. Naar de stad gaan bij een evenement ofzo, doe ik ook meestal niet met het gedacht van « ga ik er wel naar het toilet kunnen? » » (5N2)

[181] « Parfois on a peur d'aller chez des gens, par exemple dormir chez des gens je n'ose pas trop. Parce que parfois des conséquences qui sont un peu gênantes, mais si après un certain temps, d'avoir dit je ne fais pas tout ça, on finit par s'habituer et on vit bien avec. » (5F2)

[182] « Pendant tout un temps je n'osais plus sortir de la maison, parce que faut aussi savoir les traitements qu'on nous donne, ben c'est des traitements aussi… à un certain moment j'ai quand même pris 30 kilos, donc le corps change, il faut intégrer cette maladie. Je n'osais plus du tout sortir de chez moi par peur que j'ai un accident, mes amies je n'avais plus envie de les voir parce que je n'étais pas bien. Je me suis en fait à un certain moment vraiment coupée du monde… Et beaucoup, oui beaucoup de jugement, beaucoup de jugement et puis aussi physiquement. » (2F1)

[183] « Er zijn dingen die ik wel mag eten, maar ja, je zit thuis, ik ben al thuis van 1983, 1984, dus dat is ook al 40 jaar. Daar word je ook weer gewoon in. Ik kan de hele week hier zijn zonder dat ik iemand anders gezien heb. » (4N1)

[184] « Ik ga nu alle weken, één keer de vrijdagavond gaan biljarten. Dus dat is normaal gezien gaan de meeste gaan van

zeven uur tot negen uur en een half. Ik ga vanaf acht uur tot tien uur/half elf. Ik speel dan twee matchkes en mijn licht is uit. […]. Maar uw energie dat je er in steekt om gewoon uw punten te kunnen spelen. Pakt veel energie voor mij. Je kan dat niet uitleggen tegen een ander. Ik kom thuis, mijn licht is uit. Je hebt in feit maar twee uur en een half weggeweest. » (5N1)

[185] « Niveau peut-être social, oui je en fait moi j'ai jamais arrêté le sport même en crise j'ai jamais arrêté de sortir, je suis juste – comment vous dire – adapté un peu à la situation quoi je veux dire, au sport, j'étais à côté de la porte pour si jamais je devais filer aux toilettes. […] Vis-à-vis du sport par exemple, là j'ai dû diminuer. Avant je faisais du sport 6 fois par semaine, j'ai dû diminuer à 3 quoi parce que physiquement c'était pas possible. […] Donc en fait je fais du sport en salle ; je fais du spinning, et de la zumba où voilà je faisais aussi des circuits trainings mais ça ce n'est plus possible de porter des poids etc., ça non. Je n'ai pas recommencé non plus. » (1F1)

[186] « Ik heb dat tegen mijn partner ook al gezegd, ik zou heel graag yoga gaan doen, maar ik durf soms niet omdat ik dan denk van, stel nu dat ik dan gas in de darm of lucht in de darmen heb en dat vliegt er dan ongewild uit, want dat gebeurt wel een keer, dan is dat niet zo fijn, dus ja, maar ja. » (3N1)

[187] « Et ici le club de sport où j'avais repris, enfin j'ai arrêté dernièrement parce que je n'étais vraiment pas bien mais c'est fait par une kiné, et en fait elle fait des groupes avec des personnes atteintes de diverses pathologies. Donc on sait bien en allant là qu'il n'y a pas de gêne, on n'est pas bien on n'est pas bien, on a mal mais on s'arrête. Elle adapte les exercices mais des clubs de sport comme ça il n'y en a pas partout. » (3F2)

[188] « Maar gelijk, die gaan nogal veel fietsen, fietsen, dat, ik kan niet lang op mijn poep zitten, dat doet pijn. Veel sociale contacten heb ik niet. Mijn familie en mijn kinderen, en daar houdt het mee op. En mijn man. » (4N1)

[189] « J'ai appris à être beaucoup plus à l'écoute de mon corps, euh… voilà, dans les trois piliers y'a le pilier sport, donc je me suis mise au sport et enfin limite je suis plus en forme aujourd'hui qu'avant d'être malade. » (2F3)

[190] « Disons que la maladie de Crohn, il faut se dire aussi qu'il faut faire abstraction de vouloir peut-être voyager loin, de partir dans un pays étranger et d'y vivre sachant que les soins ne sont peut-être pas les mêmes, peut-être pas aussi bons qu'en Belgique. Je ne critique aucun hein, mais je ne sais pas. » (5F2)

[191] « In 94 zijn we dan ook met het vliegtuig weg geweest, maar daar was dan ook een heel gedoe met mij. En dan hebben we gezegd in 95 hebben we toen een stacaravan gekocht in Malmedy, midden in de natuur. En dat is onze vakantie. Dus dat is niet ver van huis, ik moet niet zo lang in de auto zitten, ik ken daar alles. » (4N1)

[192] « C'est dire ok « quels sont les vaccins vivants ? », « qu'est-ce que je peux faire ? », ok ça va je ne pourrai plus aller dans tel pays car je ne peux plus me faire vacciner contre la fièvre jaune, voilà ce sont des décisions importantes à prendre évidemment, après voilà quand on est malade et qu'on est mal on attend qu'une chose, c'est d'avoir un traitement donc je vais dire ça passe à côté et puis quand on en parle avec sa famille on se dit « bah oui, finalement il vaut mieux que je sois bien » et on s'en fiche que je n'aille pas en Afrique noire. » (1F1)

[193] « Tout ce qui est contraignant c'est que c'est un produit qui doit rester au frigo, donc voilà quand on part en vacances je dois calculer, pour savoir quand est ce que revient… quand va arriver mon injection, est ce que je peux prendre mon injection avec ou pas, c'est aussi toute une logistique euh… qu'il faut mettre sur le côté. Je me souviens à l'époque où j'avais [name immunomodulator, je me souviens la seringue devait aussi rester au frigo, et on partait au ski, et le médecin m'avait dit « eh bien tu n'as qu'à acheter un espèce de frigobox justement pour tout ce

qui est insuline et tout ça, par contre il avait complètement oublié de me préciser que… moi aussi je n'y avais pas pensé mais que… beh quand on va au ski on est en altitude quoi. Donc ce qui fait que quand j'ai ouvert la seringue, la moitié du produit est sorti. » (2F1)

[194] « Ik ga met een vriendin op reis, die weet dat en soms moet ik, ik heb daar nachten liggen overgeven, voor hen is dat heel confronterend. » (2N1)

[195] « Ben j'ai toujours été extrêmement indépendante mais mon mari m'a quand même souvent accompagnée parce que c'est vrai que quand on est en crise on ne sait en fait rien faire. » (2F1)

[196] « Ja, bijvoorbeeld, maar ik zal maar zeggen, naar de apotheker als ik iets moet hebben, of ja… Ze gaat meestal ook mee naar het ziekenhuis. Gewoon in het algemeen, steun. » (2N1)

[197] « Eh bien les amis, c'est drôle la dernière fois je vais au restaurant, j'étais la dernière à arriver, et la première chose qu'ils m'ont dit après m'avoir dit bonjour c'est « les toilettes sont là si tu as besoin » quoi. Donc voilà, c'est rigolo mais c'est aussi une forme de soutien. Ou les personnes qui font du sport avec moi aussi, des fois ils me disent « oui non attends [name of the patient], ne force pas trop, tu n'es pas en super forme », ou alors « ah ben vas-y tu peux mieux faire » et voilà, c'est comme ça que ça se régule mais je pense que l'entourage effectivement a un grand rôle à jouer. » (1F1)

[198] « Gewoon het begrip dat hij ervoor heeft als ik mij niet goed voel, als ik weet van ik voel me niet goed dat er iemand naast mij staat die dat weet als ik ergens ben ik zeg het gaat niet, dat komt echt op en dan zou ik bijna flauwvallen en die weet dat en ik heb geen woorden meer nodig, zo iemand als je hebt naast u, ik heb nog mensen, vriendinnen ook die dat weten en dat geeft een steun en een gevoel van veiligheid als ik me niet goed voel, die mensen weten dat. » (2N1)

[199] « Et je crois que c'était plutôt une chance parce que effectivement, l'annonce du diagnostic, les opérations, etc., etc., ça vous met déjà un coup et si vous devez avoir le suivi administratif en plus, ça ne doit pas être évident. J'avais la chance d'avoir voilà, un entourage qui m'a soutenu et qui était disponible à ce moment-là. » (2F2)

[200] « Ik heb gelukkig wel een goede partner die mij daar enorm in ondersteunt en heel begripvol is op dat vlak. Dat scheelt ook wel. Die gaat bijvoorbeeld de kuis doen en koken. Hij gaat heel veel uit handen nemen. De momenten dat ik dat bijvoorbeeld moet afliggen in de zetel of langer slaap ofzo, gaat hij eigenlijk wel heel veel op zich nemen. » (3N1)

[201] « De keuze van mij, ik heb wel het geluk gehad dat ik enig kind was, achteraf gezien, mijn broer gehad, in die zin dat mijn ouders dan, die konden niet met de auto rijden, maar die kwamen van [region] naar [region] om mijn was te doen, om mijn strijk te doen, om te poetsen. » (4N2)

[202] « Même par rapport à la famille, ça a été très compliqué parce qu'en fait les personnes ne comprennent pas en fait ce que c'est. Oui on dit « maladie de Crohn », « maladie de Crohn » oui, mais ils ne savent pas en fait ce que c'est, et toutes les souffrances que c'est, et je vous avoue, et mon mari le sait, et mon fils le sait, s'ils n'étaient pas là, je serais déjà au ciel hein. » (2F1)

[203] « Et alors sur Facebook aussi j'ai trouvé… alors ça je ne sais plus comment je suis tombé là-dessus à l'époque, un groupe en fait qui a été mis en place par une dame je pense qui est suivie à Liège, en collaboration je pense avec les services de gastro-entérologie, et en fait toutes les personnes atteintes soit de l'aractélite soit de la maladie de Crohn peuvent échanger, poser des questions euh, balancer leur trop-plein d'émotions enfin, voilà

c'est vraiment un groupe où on peut tout poser, et alors si on pose une question eh bien voilà on a le retour d'expérience de certains. Enfin, faut trier aussi mais je veux dire ; voilà ça permet d'avoir le retour d'autres personnes et de se positionner un petit peu. (3F2)

[204] « A [name of the hospital], ils ont un groupe Facebook ça s'appelle [name of the group], et là c'est super chouette parce que, il y a toutes des activités […]. C'est chouette parce qu'on voit bien que c'est un groupe positif quoi. Et finalement […], y'a jamais personne qui se présente et qui dit « moi j'ai Crohn » ou « moi j'ai une recto-colite », on ne parle jamais de traitements ni rien, c'est plutôt « ah, est-ce que t'as été voir les nutritionnistes, est-ce que c'était chouette ? » ou alors se donner des petites astuces « ah tiens j'ai fait ça, c'était bien. » (1F1)

[205] «Ik zeg het, de mensen van het ziekenhuis zelf die heel veel steun geven, ook weten dat er een vereniging is waar je altijd vragen bij kan stellen of lotgenoten kan ontmoeten. Het feit ook dat je niet alleen bent. Ik word goed omringd. Ik heb heel veel mensen die mij wel begrijpen en mij gaan bijstaan. » (3N1)

[206] « Je le recommande, parce que quand on a des baisses de moral ou quoi que ce soit, on est tous… enfin tout le monde est vraiment adorable et sain avec les autres. Et ça c'est vraiment chouette, et si on a des questions et bien en général on trouve quand même une réponse. On a une baisse de moral, on se remonte le moral entre nous donc non, ça c'est quand même… C'est quand même important de faire partie d'un groupe comme ça moi je trouve. » (2F1)

[207] « Mon premier réflexe aussi ça été de voir par exemple sur Facebook s'il y avait des groupes de personnes qui étaient atteintes de la maladie parce qu'on vient d'être diagnostiquée mais on n'a pas forcément toutes les informations, on n'a pas encore eu rendez-vous avec le médecin, et donc je me suis mis dans un groupe où les gens étaient tous dépressifs et je me suis dit ça ne va pas aller, où je suis tombée, où ils mettent aussi tous que ça leur a coûté une fortune, que tel traitement ça ne va pas. » (1F1)

[208] « Je ne me retrouve pas en fait en tant que patient dans l'association de patients. Parce que j'ai l'impression que ce sont plutôt des associations de malades plutôt que des associations de patients. […] L'image que j'en ai c'est des associations de patients qui sont malades, et qui souffrent de cette maladie, qui déposent à travers cette association de patients une souffrance qui peut vivre à cause de la maladie. Si je peux faire le comparatif avec un forum. Enfin sur un forum, où les gens qui donnent leur avis sur internet ou dans un restaurant, on va avoir dix clients qui vont pas être satisfaits qui vont mettre leur avis dessus, mais les 100 clients qui sont à coté et qui ont passé un bon moment ne vont pas donner leur avis sur le restaurant. C'est un petit peu ce sentiment là que j'ai par rapport aux associations de patients. » (2F2)

[209] « Parfois il y a quand même des fausses informations. J'avais lu sur un forum qui parlait de transplantation fécale d'un porteur sain à un porteur pas sain. Et moi je m'étais dit « ah ben c'est cool ». Parce qu'ils disaient « oui c'est l'avenir », tout ça. Donc je m'étais dit en fin de compte, si on pouvait me donner la matière fécale d'une personne saine et que moi ça va mieux… Et j'en ai parlé à mon médecin et il m'a dit « bah oui écoute [name of the patient] si tu as envie de mourir je te le fais demain ! ». » (2F1)

[210] « Dus je kan wel, en heb je een probleem ergens mee, maar je wilt niet met het allernegatiefste geconfronteerd worden, dan lees je het niet. Dat is nog altijd je eigen keuze. » (4N2)

[211] « Chaque année en fait ils organisent des réunions enfin c'est un peu partout en Belgique, il y a Liège, Mons, cette année je ne sais pas où c'est mais là c'est plus des réunions d'information justement par rapport à la maladie de Crohn. Moi je vous avoue que je n'ai jamais voulu y participer parce que psychologiquement, je n'ai plus envie de me retrouver avec que des personnes qui

sont atteintes de cette maladie. Et j'ai besoin d'autre chose, parce que ça me rappelle trop que voilà, que je suis malade. » (2F1)

[212] « Wat ik lastig vind is dat je, je bent chronisch ziek en dan, ik heb dan een e-nummer voor de kinesist en die krijgt dan, dat is dan eerst voor een jaar, dan voor twee jaar, dan denk ik. Ik ga niet genezen hé, dus waarom moet je elke keer opnieuw gaan bewijzen dat je dat hebt. Dat zijn speciale attesten, die medicatie ok, dat gaat over veel geld, dat is elke keer opnieuw en elke keer opnieuw moet dat aangevraagd worden en dan moet je zien dat dat in orde is en allez, die tussenstappen daartussen, dan denk ik, als ik dat niet in het oog houd, dat attest vervangt, vervalt dan is dat niet meer in orde, dat kan dan allemaal niet rechtstreeks gaan, ik vind dat een beetje omslachtig. » (2N1)

[213] « La deuxième démarche administrative et là qui parfois pourrait poser problème, c'est qu'on doit demander au médecin conseil de la mutuelle l'autorisation de remboursement pour le traitement en cours. Puisqu'il est super couteux, c'est entre 1500 et 2000€ les boites de 6 injections donc selon la fréquence ça coute très cher. Nous on ne paie que 12€ par exemple pour vous donner un ordre d'idée [due to reimbursement from the sickness fund], 12,5€, et je suis encore remboursé de ces 12,5€ par l'extension maladie grave. Mais cette extension du médecin conseil, pour être sûr de l'avoir à temps, de recevoir le courrier etc., au moins 2 mois à l'avance. Donc on doit retourner vers le gastro, je crois que même la fois dernière c'est eux qui l'envoient directement à la mutuelle je pense. Le traitement est proposé, et donc il faut demander l'accord au médecin conseil. Et on reçoit un accord pour x injections par an. » (3F2)

[214] « Voor de medicatie moet dan nog altijd via een adviserend geneesheer van de mutualiteit gaan, dat is ook wel inderdaad wel wat papierwerk, dat erbij komt kijken en als je daar niet goed in bent, je moet dan zien dat op tijd opgestuurd is, dat je je goedkeuring krijgt, dat is altijd maar voor een jaar, dat moet elk jaar ook vernieuwd worden. […] Bijvoorbeeld bij [private insurance company], ik had me toen privé aangesloten en dat was buiten de werkgever om en ik was eigenlijk volledig uitgesloten voor alles van maagdarmstelsel. Ik vond dat verschrikkelijk erg. Dus ik wist, stel nu dat ik een appendicite bijvoorbeeld zou doen, iets dat iedereen kan krijgen los of dat je de ziekte van Crohn hebt of niet, ging ik alles zelf moeten betalen terwijl dat dat los van elkaar kan staan, iedereen kan dat krijgen. Dat vond ik heel erg. » (3N1)

[215] « Het is een puntensysteem, het is om de twee jaar dat ze komen. Dus ik heb iedere keer die mantelzorg gehad en nu is het, bij [private insurance company] is er iemand jong die gekomen is, die dat opgenomen heeft en die, inderdaad ik had een half puntje te kort, maar ja een half punt is een half punt, dus heb ik het van de jaar niet gekregen. Die jongen kan ook maar opnemen hetgeen hij constateert op het moment dat hij komt hé. Als ik uit het ziekenhuis kom, doe ik niets. Ik bedoel, het vuile van Crohn is, altijd geweest in al die jaren, je ziet er goed uit, ja vanbuiten zie je er goed uit, maar je hebt niets van energie. Dus van het minste dat je iets te veel doet heb je het zitten. » (5N1)

[216] « Donc ça veut dire que j'ai dans mes mémos la date à laquelle j'ai eu mon rapport du médecin-conseil, et donc en plus de gérer mon stock de seringues il faut que, avant la date fatidique, j'ai fait remplir un document par mon médecin spécialiste, que ce document arrive bien à la mutuelle pour que je puisse obtenir mon accord de médecin-conseil, pour pouvoir continuer à ce qu'on me délivre à un prix de 13€ parce que… je n'ai pas envie de mettre 500€ à chaque fois que je vais chercher mes seringues donc oui, il faut que j'ai l'accord du médecin-conseil et c'est un document que je dois remettre à mon pharmacien. » (2F4)

[217] « Et puis si mes frais dépassent les 400€ j'ai aussi droit à 50% de la prise en charge, ça demande des démarches administratives etc., qui sont un peu euh… ça dépend. Quand on

est travailleur ça demande quand même un peu de gestion. Quand on ne fait rien de ses journées c'est sûr, ce n'est pas trop compliqué de faire ces documents-là. » (2F5)

[218] « Et alors forcément ben les pharmacies, je comprends – au prix du médicament – n'avancent pas les injections donc là, il faut contacter des firmes qui donnent… mais voilà ce sont des démarches. Ça ne m'est arrivée qu'une fois depuis que j'ai des traitements en injection. Et alors le soutien administratif qui existe peut-être mais en tout cas que je ne connais pas. Peut-être une permanence ou une personne de contact justement pour toutes les démarches au niveau de l'AVIQ, au niveau des choses qui pourraient nous soulager au quotidien mais pour lesquelles il faut faire des démarches administratives. » (3F2)

[219] « Dus als je dan bijvoorbeeld extra in bekomende informatie wenst eromtrent, is dat veel, veel moeilijker om met die persoon in contact te komen. Terwijl iemand van je ziekenfonds geraakt je veel gemakkelijker binnen voor bijkomende informatie, maar eigenlijk weet je het meestal ook niet, en die verwijst je dan toch door naar de uitbetalingsinstelling, waarbij je toch aan moet bellen. En als je echt iets wilt weten, gaat ge toch even aan de lijn moeten hangen, want een mail duurt gemiddeld een maand of twee om te antwoorden. » (2N2)

[220] « Dat is een algemeen probleem denk ik, de ene keer staat die e-box de andere keer staat het in uw dingen van de mutualiteit. De andere keer sturen ze het op met de post. Ik kan dat niet volgen die papieren van de mutualiteit. Ik vind het ook altijd raar al die, ik heb een verzekering, waarom kan dat allemaal niet rechtstreeks gaan? Voor medicatie heb je al een 'app' en dat scannen dat is allemaal automatisch, maar al de rest dan moet je je kosten nog inbrengen en je moet dat wel kunnen en willen doen anders krijg je dat geld natuurlijk niet.» (2N1)

[221] « Je pense qu'il faudrait quand même à un endroit, et que ça je pense pour toutes les maladies, où on peut aiguiller les gens sur tout le pragmatique… encore une fois cette histoire de médicament avec le médecin de la mutuelle. Si la pharmacienne n'avait pas pris un peu de son temps pour m'expliquer le process, personne ne l'avait fait. Ce n'était pas son job de le faire. » (4F1)

[222] « Mon pharmacien s'est un petit peu démené, mais après ça… Je n'ai pas eu d'interruption de traitement, mais ça a été tout juste. Donc je dois vraiment faire très attention à avoir du stock. » (2F4)

[223] « Nee, de apotheek stuurt dat door, als er andere medicatie tussen zit voor het hart, dan zeggen ze gewoon, dit staat niet in verband met je ziekte, met je aandoening. Dat is een heel lijst doorgestuurd, maar daar staat toch één medicament tussen. Als ze de eerste keer een medicament moeten goedkeuren, dan moet je dan nog eens een verslag van de dokter hebben. Maar eens als dat in het dossier staat, is dat te doen. » (4N1)

[224] « En général ma pharmacienne habituelle savait bien que toutes les 6 semaines je revenais chercher une boite, donc je n'ai pas compris où il y avait eu le manquement, et j'étais chez elle depuis toujours donc toutes les 6 semaines j'achète une boite toute l'année donc là il y avait eu un « stuut » et donc là il a fallu agir en catastrophe. Je ne sais plus où la pharmacienne a eu la boite, si c'était d'une autre pharmacie où elle travaillait ou si c'était… enfin bref elle m'a dépannée quoi. » (3F2)

[225] « Maar mijn andere shiften ben ik wel blijven doen. Maar ik heb wel natuurlijk, ik werkte maar 75% en gelukkig, want ik denk niet, als ik 100% had gewerkt in dat regime, had ik niet gekund denk ik. » (2N1)

[226] «Ils m'ont hospitalisée pendant une semaine mais j'ai été à la maison pendant quand même plus d'un an avant de pouvoir aller retravailler. […] Et bien j'ai repris en fait juste avant la pandémie, et quand il y a eu la pandémie on m'a directement écartée, et puis là ben ça fait depuis plus de 2 ans que je suis en

grosse crise de spondylarthrite et euh… ben je ne peux plus travailler pour le moment, de toutes façons. […] Enfin j'ai repris on va dire, j'ai repris… puis euh je tenais le coup pendant un mois puis après je m'arrêtais de nouveau pendant un mois, puis je reprenais pendant un mois. Ça a été vraiment assez compliqué. Juste avant la pandémie avec la mutuelle j'ai pris la décision de demander un mi-temps médical. » (2F1)

[227] « C'est-à-dire que moi je vais devoir envisager un 4/5ème parce que j'accepte le fait que je ne pourrai plus jamais travailler à temps plein, que je dois préserver ma santé. Mais ça veut dire que de nouveau pour ma pension, pour etc., ben… j'aurai fait un temps partiel, alors que je ne demande pas mieux que de travailler à temps plein. » (3F3)

[228] « Ook op de dienst waar ik zat en hebben ze mij een voorstel gedaan om inderdaad op langdurig ziek te gaan. Dus doordat aangezien ik op langdurig ziek ga heb je dus in plaats van uw 100% loon maar 60% van uw loon, maar wel tot uw pensioenleeftijd hé. Ik heb dus, dat was de deal van [name of the company] dan naar mij toe. » (5N1)

[229] « (…) donc enfin professionnellement c'était un petit peu embêtant parce que c'était donc assez régulier et (…) il n'y a rien à faire, hôpital de jour le temps d'y aller, de faire le baxter et de revenir on perd une demi-journée de travail quoi. » (3F2)

[230] « Ja, de moeilijkheid is dan die overuren en zo proberen te plannen. Ik moet zeggen, bijvoorbeeld het systeem van progressieve tewerkstelling vind ik ook wel iets goed. Ik heb het ook een keer moeten doen na een opstoot, dat ik dan een tijdje iets minder gewerkt heb. Dat is ook wel iets dat wel helpt om terug eigenlijk te gaan werken. […] Ik ondervind het vooral als naar het werk toe, de consultaties zijn altijd overdag. Ik werkte normaal gezien ook voltijds tot mijn zoontje dan geboren is, dus het is niet gemakkelijk om dan zaken te plannen, moet altijd proberen om buiten uw uren te doen ofwel verlof daarvoor nemen, dat is soms een beetje zot, ik moet dan een paar keer in het jaar gaan om daar dan verlofdagen aan te hangen. » (3N1)

[231] « Ja, we hebben een flexrooster, dus we kunnen starten wanneer we willen en stoppen wanneer we willen, dus als je naar het ziekenhuis moet, ja is dat in mijn eigen tijd, dan stop ik met werken en ga ik naar het ziekenhuis en dan ga ik terug werken of ik kom een paar uren maar, of ik kom niet. Dat is eigenlijk heel flexibel, daar is nog nooit iets van gezegd geweest. » (5N2)

[232] « Ca a été très très compliqué en fait quand j'ai dû annoncer à mes patrons que…voilà que j'étais malade, et ils n'ont pas du tout, ils n'ont eu aucune compassion on m'a même dit… parce que bon je me suis un peu excusée j'ai dit « désolée d'être tout le temps absente euh… je n'y peux rien » et mon employeur m'a quand même dit « Ecoute, [nom du lieu de travail] c'est pas la charité ». Bon ben vous tombez un peu des nues comme ça, puis vous savez quand les collègues vous parlent enfin…ils parlent de vous derrière votre dos… ben, ça revient jusqu'aux oreilles, puis, oui beaucoup de réflexions, beaucoup de remarques euh… au début ça touche. » (2F1)

[233] « Dans la société dans laquelle je suis, les absences sont monitorées. Et que, de ce fait-là, ça c'est une de mes cheffes qui a eu la gentillesse de me le dire, c'est que en fait j'ai… le témoin clignotait pour moi parce que j'avais des absences répétées et donc elle s'est adressée aux ressources humaines en disant « voilà, cette personne on sait qu'elle a une maladie chronique, donc est ce que ça ne peut pas être notifié quelque part pour que…voilà il n'y ait pas une espèce ...elle ne soit pas flaggée finalement comme quelqu'un qui soit fréquemment absente » et la réponse a été non. Et honnêtement ça m'a… enfin voilà, je n'en ai pas fait tout un fromage mais voilà je trouve ça injuste. Parce que je ne triche pas ! » (2F3)

[234] « Et un impact sur mon travail aussi parce que ce n'est pas agréable d'être la fille qui se fait hospitaliser au moins deux

fois par an et… enfin voilà, on ne se sent pas légitime et c'est vrai que là, cette période que je traverse en ce moment a été particulièrement difficile pour moi. » […] « Il y a beaucoup de culpabilité. Euh voilà, parce qu'on ne se sent pas légitime hein, on se dit voilà, enfin moi je me dis, les collègues ne le disent pas, ils savent la maladie que j'ai, ils comprennent et… mais moi je me sens coupable, je me dis je ne suis pas légitime, on ne peut pas compter sur moi. » (3F3)

[235] « Je pense que effectivement pour tous ces malades, encore une fois quels qu'ils soient, c'est profondément injuste. Je vous dis, je pense que… alors peut-être qu'il y a des malades de la maladie de Crohn qui ont eu plus d'absences que moi mais moi, honnêtement, j'ai été nettement moins absente que plein de mes collègues. J'ai des collègues qui sont tombés en burnout, j'ai.. enfin…et c'est pas grave en soi, je ne dis pas que je fais mieux que tout le monde, et juste que je me dis « mais allez, c'est pas juste quoi ». » (4F1)

[236] « Il y en a qui ne sont pas compréhensifs en disant écoute… quand tu dois courir aux toilettes, les gens euh… Quelqu'un qui travaille à l'usine à la chaine il ne peut pas quitter son poste comme ça. On ne va pas dire « oui mais attends la pause pourra aller aux toilettes », non c'est impossible, c'est impossible. » (4F2)

[237] « En als je dat dan had, dan kan je niet anders dan tegen een collega te zeggen van ik voel me hier niet goed, zeker bij, na mijn eerste opstoot, het terugkomen dat is een moeilijk proces geweest, maar ja, dan zeiden ze 'ga zitten' of 'ik pak efkes over', allez ja, dat hebben ze wel allemaal gedaan, dus.(2N1)

[238] « Maar ik heb eigenlijk wel, geluk gehad dat ze het toen deed ik nog shiften dat ik een hele tijd geen nachtshiften heb moeten doen, dat ze gezegd hebben we gaan u dat niet laten doen. Anders had ik ook ander werk moeten zoeken denk ik. […] En nu mijn dagjob te doen en meer bureauwerk gaat dat wel eigenlijk. Ja, je zet je daar over altijd wel vind ik. » (2N1)

[239] « Op het werk weten ze wel van mijn aandoening en dan, ze houden daar wel erg rekening mee. Ik werk ook in een woonzorgcentrum, de zorg, het is een ideale plaats. […] dus ze gaan er ook niets van zeggen als ik meerdere keren op mijn dag naar het toilet moet gaan of zo. Ze zijn al blij dat ik kan komen werken. » (3N1)

[240] « Maintenant, à part les rendez-vous chez le gastro-entérologue qui malheureusement étaient pendant les heures de travail, je me suis toujours arrangée pour que ce ça n'impacte pas mon travail, je n'ai jamais été très souvent absente non plus mais comme je vous dis j'ai un seuil de tolérance assez élevé. Et bien je lui avais expliqué, maintenant voilà c'est quelqu'un qui a accepté, pourquoi parce que son papa avait eu des problèmes aussi et je crois qu'il se rendait compte de ce que… Je crois que son papa avait eu un cancer du côlon quelque chose comme ça, enfin bref donc il se rendait bien compte de ce qu'était la maladie quoi. Maintenant je ne suis pas certaine que ça se passe partout pareil, de la même façon. » (3F2)

[241] « Ik deed goed mijn job op het werk, heb ik tegen niet mijn directe baas, maar de hoogste daarvan, heb ik wel uitgelegd wat mijn situatie was, want ik ben dus meerdere keren opgenomen geweest, dat ik dus een maand of drie uit roulatie was. […] Er werden ook geen vragen bij gesteld. […] Op een bepaald moment stond ik dus aan mijn tekentafel en had ik dus inderdaad weer een opstoot, en ik inderdaad geen energie meer had. Dus die baas komt bij mij en zegt 5N zou beter naar huis gaan want ik zie dat het niet goed gaat. […] Ik heb dan open kaart gespeeld ten opzichte van hem en dan is de sociale dienst bij mij gekomen voor erover te spreken want ik had dan gezegd dat het Crohn was. » (5N1)

[242] « Officiellement non, mais officieusement oui avec mon chef, maintenant c'est un chef d'une écoute… euh « chef, ça va pas trop cette semaine euh, je peux faire un mi-temps je viens de 10h à 15h », même si je restais plus tard, mais ça me permettait de dormir un peu plus tard le matin, mais voilà quoi. Pendant 15 jours, mais sinon c'est 15 jours à la maison et je suis sous certificat, donc on s'est arrangé comme ça, et ça allait, et c'était mieux comme ça. Voilà des jours ou ça n'allait pas trop, et des fois ça n'allait pas trop je restais à la maison, et voilà quoi. C'était quoi… minimum 15 jours je suis à la maison pour mon Crohn. » (4F1)

[243] « Et même chose, enfin moi je travaille dans l'administration et y'a quand même assez bien de choses qui sont mises en place pour le personnel qui peut avoir des maladies chroniques ou… Enfin il y a assez bien de trucs, j'ai pas… je me sens à l'aise d'en parler aussi. Voilà. Il n'y a pas… j'imagine peut-être que dans une boite ou il y aurait beaucoup de pression, beaucoup de travail, où il faudrait suivre etc., peut-être dans le privé.» (2F2)

[244] « Nu, één van de gevolgen van jarenlang, doordat het voor een werkgever heel moeilijk is, zeker als ambtenaar, als iemand chronisch ziek is, om daar goede oplossingen voor te vinden. […] Omdat op een gegeven moment werkte ik bij de overheid en bij de overheid zijn er weinig mogelijkheden om minder te werken. » (4N2)

[245] « Par exemple moi j'ai dû demander à mon école, parce qu'on a 4 toilettes pour 300 élèves. Et je sais que lors des pauses de récréation, […] les toilettes sont véritablement prises d'assaut et donc… moi parfois il y a un gros souci avec ça. J'ai dû demander une clé, pour pouvoir utiliser des toilettes à un autre étage, et je trouve que c'est pas simple. » (2F4)

[246] « Een keer dat je dan thuis bent, ik heb dan ook in feite 6 maanden thuis getekend voor het werk. Ik mocht van het werk, dat was ook één van de voorstellen, mocht ik thuis werken. Dus mijn tekentafel werd naar huis gebracht, ik deed dus mijn job thuis. » (5N1)

[247] « Devoir quitter une réunion parce qu'on doit aller à la toilette, mais en fait il n'y a qu'une toilette dans le bâtiment pour 10 personnes et il y a des gens qui attendent devant la porte quoi. Donc ce que j'ai pris comme habitude, c'est quand j'avais des réunions ou des visites en entreprise, ou… voilà, je ne mangeais pas en fait. Je ne mangeais pas, je ne buvais pas avant, si je savais que je devais faire de la route, parce que au moins comme ça j'évitais tout, tout souci potentiel donc le premier impact c'est ça, on change sa façon de faire et on s'adapte parce qu'on sait que… en cas d'incident… ça m'est déjà arrivé d'avoir des incidents. » (3F2)

[248] « Alors la médecine du travail j'ai demandé une fois une adaptation du poste après ma colostomie je pense, pour un mi-temps médical qui était vivement conseillé par mon gastro-entérologue, parce que je devais apprendre à vivre avec. […] Et la médecine du travail pareil, ils ne comprennent pas vraiment, donc c'est pas évident parce que voilà ils vont dire le règlement prévoit un mi-temps médical, mais il faut venir tous les matins au travail. Donc tous les matins il faut faire les trajets, venir travailler, alors que vous n'avez pas dormi de la nuit. Et il va vous dire « ben vous n'avez qu'à vous reposer l'après-midi », alors que mon médecin préconisait « vous travaillez deux-trois jours la semaine, et après vous récupérez. » Mais ça a été rebelote, et il a fallu que je me batte pour qu'on comprenne mon besoin si vous voulez. Je pense que ce n'est pas très très bien compris non plus dans le milieu du travail. » (3F3)

[249] « Ce qui est très gênant c'est en société avoir une crampe, et ne pas pouvoir euh… flatuler comme je veux, aller aux toilettes quand je veux, où je veux, comme je veux. Et donc, oui, en société ce n'est pas évident, pas avec mes amis parce que tout le monde

sait, et je n'ai pas beaucoup de dignité donc je m'en fous. Je suis comme je suis et tant pis. Ce qui est plus gênant c'est sur le lieu de travail par exemple. Quand je vais aux toilettes c'est toujours très très bruyant, et donc ça c'est extrêmement gênant. » (2F5)

[250] « De diarrees zijn toch het grootste probleem geworden, ja. Het beperkt je beroepsleven, je keuze van waar je gaat werken, welk soort werk je kunt doen. Een job, voorheen, gaf ik voordrachten op verplaatsing. Ja, dat kon gewoonweg niet meer, dat was ook veel te zwaar. Ik heb ooit een aanbieding gehad om binnen de journalistiek gevraagd te worden, dat heb ik ook moeten afwijzen, omdat ik dacht, de combinatie met mijn ziekte, dat lukt gewoonweg niet. Je wilt dus een job waarbij je kort bij een toilet kunt zitten en waar je reisweg ook beperkt is. Dus dat maakt, dat geeft beperkingen. » (4N2)

[251] « Oui, parfois de refuser des voyages professionnels. Parce que justement ça n'allait pas trop. Des risques aussi de licenciement parce que trop souvent absent. On m'a fait changer souvent de service aussi à cause de ça, par exemple. Et, peut-être à cause de ça je suis peut-être un peu moins sociable. » (5F2)

[252] « Wat je mist als je iemand bent die altijd maar voortdoet en voortdoet, ik werk, doe mijn job heel graag, dus werken en voor mij is werken en voortdoen een ding van niet ziek zijn want ik wil ten allen kosten, ik loop nog liever ziek rond dan dat ik moet zeggen 'ik kom niet werken'. Omdat dat heel, dan wordt je geconfronteerd met ziek zijn en daar heb ik heel moeilijk mee en ik kan dan ook geen grenzen leggen, maar niemand gaat met u uw grenzen af hé. Want dat is altijd als je zegt 'gaat het?' 'ja, ja', niemand zal doorvragen. Dus je wordt eigenlijk niet altijd beschermd tegen jezelf. En ja, daar moet ik echt wel, mensen moeten tegen mij vaak zeggen 'het is goed geweest, je moet stoppen' en gelukkig heb ik mensen rondom mij die dat zeggen. Daar heb ik eigenlijk echt wel nodig. » (2N1)

[253] « Maar tegen mij werd dat niet gezegd en ik kreeg ook geen ziektebriefje of niets, dus ik bleef gewoon door doen, het werk op nummer 1. Want dat is toch het voornaamste als je alleenstaande bent, wat ik op dat moment was, dat je een inkomen hebt. Als je op het ziekenfonds belandt, dan zit je op de statistiek naar beneden. En daar is heel veel voor moeten wijken heel mijn leven dat werk te kunnen behouden en fulltime te kunnen blijven werken. » (4N2)

[254] « Parce que bon je pourrais arrêter de travailler mais j'ai pas envie d'arrêter de travailler donc je continue toujours à travailler. Euh jusqu'au moment où je ne pourrai plus ben je ne pourrai plus. » (5F1)

[255] « Pour quelqu'un qui travaille à temps plein, qui est hospitalisé deux fois par an, et bien on tombe très vite sur un salaire de 60% etc. et il y a d'autres frais… ça fait beaucoup. Beaucoup trop. » (3F3)

[256] « Het nadeel van een medisch pensioen, als je dat vergelijkt met de andere statuten, de statuut van zelfstandige en loontrekkende, is ook niet zo interessant. Een loontrekkende of zelfstandige die ziek wordt, die bouwt zijn pensioen op tot het moment van de wettelijke pensioenleeftijd. Een ambtenaar niet. Dus mijn pensioenrechten als werknemer, die kan ik maar op mijn 65e uitbetaald krijgen. En al die jaren ervoor heb ik dan enkel die beperkte loopbaan die ik dan had als ambtenaar. » (4N2)

[257] « […] mais je trouve quand même que de sortir quand même 60€ de sa poche c'est quand même beaucoup, je trouve. Je trouve que ça devrait être en fait, gratuit. Bon je sais que ça le sera jamais, mais… […] C'était pour le [name interleukin inhibitor], ma pharmacie en fait me faisait à chaque fois payer 60€, maintenant je ne paie plus que 10€ parce que je suis au statut « BIM ». […] Et ça, bon ok, c'est rien comparé aux 3.000€. Mais j'estime quand même que ça devrait être gratuit. Enfin je veux dire surtout maintenant, je pense que voilà le coût de la vie a augmenté

pour tout le monde, je me dis les gens qui n'ont pas les moyens, ben 60€ c'est 60€ quoi. » (2F1)

[258] « La calprotectine, la calprotectine j'ai du mal à me la faire rembourser. L'analyse de selles, on a droit à deux remboursements par an mais ils sont mis sur euh… il y a des dates à respecter, ça on ne me l'avait jamais dit. Et en fait chaque fois que je venais prendre ma calprotectine à 40€ j'étais là…enfin…ça c'est cher. » (2F5)

[259] « Magnésium, le Calcium quand je prenais de la Cortisone etc., enfin tout ça, ça coûte quand même assez cher, les probiotiques etc., enfin ce sont des choses qu'on doit prendre en complément finalement, mais euh… alors tout ça, ça n'est pas remboursé, mais par contre tout ce qui est rendez-vous médicaux liés à la maladie, donc tout ce qui est prise de sang, analyses complémentaires, le peu qui est encore à notre charge est quand même remboursé par la mutuelle. Mais voilà, tout ce qui est complément de traitement ne l'est pas. Et donc parfois j'en ai pour euh… les mois où je dois recharger, pas de chance tout tombe en même temps, j'en ai pour euh… oui 150€ par mois certains mois. » (3F2)

[260] « Oui là c'est… moi heureusement que j'ai mon assurance hospitalisation du travail qui prend en charge le tout, à 100%. Sinon c'est toutes les 6 semaines c'est 60€ hein. A ma charge. Parce que bon, c'est ça aussi le coût. Il y en a qui travaillent pas, c'est assez cher 60,5€, 60€ toutes les six semaines. […] C'est quand même un budget . » […] « (name proton pump inhibitor) qui n'est pas remboursé, avant je prenais (name immunomodulator) il était remboursé, et puis après qu'on devait payer 3€, vous allez dire 3€ c'est pas cher pour une boite de 100… mais à la longue voilà, si on en prend 3 par jour c'est 3€ par mois, mais bon, à la longue… Avant c'était gratuit, pourquoi c'est devenu payant, on ne sait pas. » […] « Le (name proton pump inhibitor) je prends du 20 mg mais je prends du 40 et je le coupe en deux parce que ça coute moins cher, et je prends les grandes boites […] Ca plus ça plus ça plus ça plus ça… Et puis on n'a pas que Crohn, il y en a qui ont la spondylarthrite tranquillisante, il y en a qui ont du psoriasis, il y en a qui ont ci, il y en a qui ont a, plus les médicaments des autres pathologies on arrive à…100€ facilement, hein. Même si le remboursement de la mutuelle, on arrive bien entre 50 et 100€ par mois hein. » (4F2)

[261] « En dan nam ik enkel die codeïne, want al de rest was toch overbodig. Dat komt zeer duur uit, omdat dat allemaal handmatig werk is. Dus dan ben ik toch afgestapt van die piste. […] Ik heb gemiddeld per maand 130€ aan medicatie. Ja, een keer dat je met pensioen bent, tikt dat aardig aan. » (4N2)

[262] « Quand on fait une analyse de selles… euh de sang, y'a certains éléments qui ne sont pas remboursés, je vais prendre par exemple la vitamine B12. Or justement dans la maladie de Crohn quand on a eu des résections, il y a toute une partie de l'intestin qui ne sait plus absorber les vitamines B ou le fer, etc. Et c'est quand même dû à la maladie, alors pourquoi est-ce que ces vitamines, par exemple l'analyse de la vitamine B12 n'est pas remboursée ? » (5F2)

[263] « Mais en plus de ça je dois payer mes soins, parce que je dois payer un kiné, parce que je dois payer un psychologue, parce que je dois payer mes consultations gastro, mon examen de colonoscopie, alors la mutuelle intervient, certes, mais il y a beaucoup de part personnelle quand même qui doit intervenir. » (3F3)

[264] « Die heeft mij dan doorverwezen naar een diëtist die dat rotatiedieet deed, waar hij mee samenwerkte. Dus dat was onafhankelijk van de ziekenhuizen eigenlijk, dat was zo via een bloedproef dat ik dan moest doen. Dat werd opgestuurd naar Duitsland, want dat was vrij duur en kostte 500€ ofzo. » (3N1)

[265] « Ben à un moment donné le psychologue s'avère nécessaire, mais c'est à vos frais. Parce que ce n'est pas compris dans le package Crohn, si vous voulez. » « On croit que le Crohn c'est un gastro-entérologue quoi, que c'est tout, mais non un Crohn ça peut aller à la kiné, au rhumatologue puisque j'ai été faire des examens chez un rhumatologue, ça peut… C'est plusieurs prises de sang. […] Oui, ça chiffre.» (3F3)

[266] « De parking is altijd een dagvisite. Morgen zal dat weer een euro of 6 zijn. Maar ja, dan moeten we er bij nemen. Op jaarbasis loopt dat wel op. Er zijn mensen die erger dingen aan de hand hebben. » (4N1)

[267] « J'ai été chez le CHU vendredi, donc j'ai été voir un médecin, suivre mon traitement etc., c'est une bêtise mais je vais au parking c'est 5€. Quand t'additionnes tout sur le mois etc., bon c'est vrai que je travaille mais c'est quand même un moins que j'ai dû à mes maladies quoi. » (5F1)

[268] « We hebben ook een poetsvrouw thuis, dus dat is ook wel een groot deel als ik dan wat moe ben. » (3N1)

[269] « Maar ik ben juist 65 van februari, dus ik was twee maanden te laat. Dan kreeg ik meer subsidie voor die traplift te zetten. Dus daar had de huisdokter mij meer moeten voor informeren. Ik wist het niet. Je bent te laat. Als we die nu laten plaatsen, loop ik daar een 6.000€ mis in. Dus dat is toch een heel bedrag. Maar voorlopig komt het er niet. » (4N1)

[270] « En het probleem is de verzekeringen worden zo mate duur. Ze krijgen geen ongevalverzekering. Ze heeft een dure hospitalisatieverzekering. Ze heeft een duurdere hypotheek op haar huis. En die verzekering... Ze heeft dat altijd allemaal eerlijk ingevuld. Omdat wij soms aangekomen zijn. Dat is allemaal een meerprijs. » (4N1)

[271] « Le fait d'avoir la maladie par exemple, au niveau de mon assurance vie j'ai eu une augmentation. Après l'opération, j'ai été opéré en 2012 je crois, j'ai demandé au [nom du médecin spécialiste] de m'écrire un rapport comme quoi il y avait une rémission à ce niveau-là, pour voir s'il n'y avait pas moyen de diminuer cette assurance-là. C'est ce qu'il m'a fait, et sur le papier, il y avait écrit « rémission clinique totale ». Depuis l'opération je n'ai vraiment plus rien. Et même avec ça l'assurance ne veut pas diminuer. » (3F1)

[272] « On me demandait de remplir un dossier médical, et qu'en tant que malade chronique, beh tout augmentait très très fort, je me suis dit, ben non je ne vais utiliser que mes fonds propres. Et encore une fois moi j'ai la chance d'être un peu plus âgée et donc d'avoir ma maison – je touche du bois – et donc je ne suis plus trop trop concernée, mais je me dis des jeunes malades, beh effectivement c'est compliqué. » (4F1)

[273] « Bijvoorbeeld bij [insurance company], ik had me toen privé aangesloten en dat was buiten de werkgever om en ik was eigenlijk volledig uitgesloten voor alles van maagdarmstelsel. Ik vond dat verschrikkelijk erg. Dus ik wist, stel nu dat ik een appendicite bijvoorbeeld zou doen, iets dat iedereen kan krijgen los of dat je de ziekte van Crohn hebt of niet, ging ik alles zelf moeten betalen terwijl dat dat los van elkaar kan staan, iedereen kan dat krijgen. Dat vond ik heel erg. » (3N1)

[274] « Parce que les gens ne se rendent pas compte en fait le coût que ça a. Ça a un impact en fait, vraiment. Oui en fait, moi je dirais le statut d'handicapé en fait, pour toutes les personnes atteintes de la maladie de Crohn. » (2F1)

[275] « A partir du moment où la personne a un dossier, où elle se fait hospitaliser très régulièrement, et très régulièrement elle tombe en indisponibilité, je pense qu'une aide, pour moi est normale. Enfin je veux dire… participer à la vie de la société, de cotiser, de payer les impôts, de payer les soins comme tout le

monde… alors que, on ne reçoit pas comme tout le monde. Notre quotidien est impacté. » (3F3)

[276] « On n'a pas demandé d'être malade non plus quoi. Surtout que c'est pas une maladie qu'on ne sait pas comment on l'a attrapé non plus quoi. Ça devrait être comme en France je trouve, gratuit pour les malades chroniques. Je sais que c'est assez, voilà quoi. Mais il y a beaucoup de pays où les malades chroniques comme les MICI et autre, c'est gratuit. » (4F2)

[277] « Que les patients aussi en cas de crise, quand ils sont vraiment confrontés ou quand ils se sont fait opérer, qu'ils ne savent pas faire le ménage chez eux, que le gouvernement puisse faire une aide, point de vue des aides ménagères. Pas payer le tarif plein mais quand même un tarif réduit. » (2F1)

[278] « Pourquoi je vais aller demander une infirmière qui va venir ici, alors ma femme va rester dans le fauteuil à regarder la tv etcetera, ou ma fille ou n'importe quoi alors qu'eux peuvent m'aider ? Mais alors le problème, c'est qu'il faut une reconnaissance. Si on paie une infirmière je vais dire je sais pas… 400 euros la semaine pour venir m'aider, ben qu'ils en donnent déjà 200 et tout le monde serait content je vais dire. L'Etat est gagnant, les gens sont gagnants…. Enfin, c'est un « win-win » quoi. Moi je vais dire, je trouve que c'est l'aide aux tâches ménagères, qu'il y ait une reconnaissance qui n'est pas un abus. » (5F1)

[279] « Qu'on puisse aller aux toilettes gratuitement. Instaurer… je sais qu'il y a – c'est en cours ou que c'est fait, ou que ça va se faire – des nouvelles cartes, mais c'est pas dit que les magasins connaissent la carte pour nous laisser aller aux toilettes. Faire une campagne pour les magasins, envoyer je ne sais pas moi, une mailing-list en disant voilà cette carte autorise tous les malades à aller aux toilettes, « laissez-les passer ». […] J'essayerais que les malades aient moins de soucis financiers pour se faire soigner quoi. » (4F2)

[280] « Vraiment oui, de pouvoir faire avancer cette recherche quoi. Parce que je me dis les gens qui l'apprennent comme aujourd'hui, eh bien ils doivent être dans le même état que moi. C'est vraiment un coup de massue quand on vous l'annonce quoi. […] J'ai vraiment envie en fait que les recherches avancent sur toutes les maladies auto immunes, pas spécialement Crohn, parce que déjà, il n'y a pas beaucoup […] Ce serait vraiment pour les générations futures. Franchement s'ils pouvaient vraiment trouver quelque chose et que cette maladie soit un peu plus reconnue. » (2F1)

[281] « Je ne trouve pas ça hyper compliqué de mener des études. Là on est pour le moment, on est vraiment dans des études beaucoup plus fondamentales… un peu trop fondamentales et pas assez cliniques. On ne considère pas vraiment le rôle clinique et la façon dont le patient se sent, qui est finalement le principal hein. […] Je pense que le monde médical doit vraiment faire plus de liens. Ou il devrait y avoir plus d'études. Ça je trouve qu'il n'y a pas assez d'études avec la santé mentale. » (2F5)

[282] « Ik denk vooral, goh tegenwoordig, we hebben toch allemaal apps, noem maar op, hè. En ik denk toch zeker, dat we daar in België toch wel een beetje achterlopen op de rest van de wereld. En zeker naar de medische technologie, aanvullende hulpmiddelen die bestaan. En zeker ook naar zorgtrajecten. En ik denk, gelijk, bestaat het, oké, je hebt [name application], je hebt [name application], je hebt verschillende applicaties op de markt, die toch wel je als patiënt kunnen een duwtje in de rug geven, in dat traject van zorg. En ik denk ook wel dat je dat gewoon vanuit het beleid, vanuit het RIZIV, maar veel harder op moet worden gepusht, om die innovatie te versnellen. » (2N2)

APPENDIX 3. SURVEYS

ENQUÊTE SUR LES BESOINS DES PATIENTS ATTEINTS DE LA MALADIE DE CROHN

Introduction

Merci d'avoir accepté de participer à notre enquête.
Notre étude vise à identifier les besoins des patients **atteints de la maladie de Crohn** afin d'améliorer leur prise en charge.
Ce questionnaire vous concerne si: Vous êtes atteint(e) de la maladie de Crohn Votre diagnostic de maladie de Crohn date de plus de 2 mois Vous avez 18 ans ou plus Vous habitez en Belgique (résidence principale)
Ou
Vous vous exprimez au nom d'une personne adulte atteint(e) de la maladie de Crohn diagnostiquée depuis plus de 2 mois, qui habite en Belgique, et qui n'est pas en mesure de répondre elle-même.
Avant d'accepter de participer à cette enquête, nous vous demandons de lire les informations suivantes sur la confidentialité de vos données, et de donner votre consentement à l'utilisation de vos données.

Confidentialité de vos données et consentement éclairé

1. Confidentialité des données

Vos données seront traitées conformément à la loi belge du 30 juillet 2018 sur la protection des personnes physiques relative au traitement des données à caractère personnel et conformément au règlement (UE) 2016/679 du 27 avril 2016, qui est entré en vigueur le 25 mai 2018, sur la protection des personnes physiques relative au traitement des données à caractère personnel et à la libre circulation de ces données.
Vous avez le droit de demander au Centre Fédéral d'Expertise des Soins de Santé (KCE) l'accès à vos données personnelles, de les rectifier, de les supprimer, de les transférer, d'en limiter le traitement et de vous opposer à leur traitement. Pour cela, il vous suffit de contacter le **KCE**, responsable de leur traitement, par mail (charline.maertens@kce.fgov.be) ou **par voie postale** à l'adresse Doorbuilding (10e étage), Boulevard du Jardin Botanique 55, 1000 Bruxelles. Si vous avez des questions ou des commentaires sur le traitement de vos données, vous pouvez contacter le responsable de la protection des données du **KCE via l'adresse** stephan.devriese@kce.fgov.be. Il pourra, si nécessaire, vous fournir davantage d'informations sur la protection de vos données personnelles.
Si cela ne vous semble pas suffisant, vous pouvez adresser une réclamation concernant le traitement de vos données à l'autorité belge de surveillance chargée de l'application de la législation en matière de protection des données (APD), Rue de la Presse 35, 1000 Bruxelles, ou contact@apd-gba.be. Pour l'implémentation et l'analyse des résultats de cette enquête du KCE, il a été fait appel à un sous-traitant (Deloitte) travaillant dans le cadre du mandat qui lui a été attribué par le KCE. Le traitement des données se fait sous la responsabilité du KCE.

2. Période de conservation

Les données sont sauvegardées pendant une période de deux ans après la publication du rapport.

3. Finalité du traitement

Cette étude a pour objectif d'identifier les besoins des patients qui ont la

maladie de Crohn afin d'améliorer leur prise en charge.

4. Déclaration de consentement

Je déclare par la présente avoir été informé(e) par écrit de la nature, de la méthode et du but de cette étude, de manière compréhensible pour moi. J'accepte de participer à cette étude. Je comprends que je peux me retirer à tout moment de cette étude jusqu'au moment où les données seront stockées dans la base de données, et ce sans avoir à faire de déclaration et sans que cela ait de conséquences pour moi.

Je comprends que mes données sont collectées et enregistrées de manière confidentielle et que l'enquêteur principal garantit leur confidentialité.

○ NL - Gelieve akkoord te gaan met het privacybeleid inzake gegevens om verder te gaan. (1)

○ FR - Pour continuer, veuillez d'abord accepter la politique de confidentialité des données. (3)

Informations générales

Vous remplissez ce questionnaire :

○ Pour vous-même (1)

○ Pour un autre adulte (veuillez répondre à toutes les questions comme si vous étiez la personne. Vous pouvez indiquer "je ne sais pas" si vous ne savez pas comment la personne répondrait). ⓘ La personne que vous représentez n'est pas en mesure de prendre une décision éclairée de participation pour le moment. En cochant cette case, vous participez à cette étude en fonction de sa volonté probable de participer. (2)

À quel genre vous identifiez-vous ?

○ Homme (1)

○ Femme (2)

○ Autre (3)

Quelle est votre année de naissance ?

▼ 2023 (4) ... 1920 (212)

Dans quelle province habitez-vous ?

- ○ Anvers (1)
- ○ Brabant wallon (13)
- ○ Bruxelles (14)
- ○ Hainaut (15)
- ○ Liège (16)
- ○ Limbourg (17)
- ○ Luxembourg (18)
- ○ Namur (19)
- ○ Flandre orientale (20)
- ○ Brabant flamand (21)
- ○ Flandre occidentale (22)
- ○ Je n'habite pas en Belgique (23)

Quel est le diplôme ou le degré le plus élevé que vous ayez obtenu jusqu'à présent ?

- ○ Pas de diplôme ou enseignement primaire (1)
- ○ Enseignement secondaire inférieur (2)
- ○ Enseignement secondaire supérieur (3)
- ○ Enseignement supérieur de type court (p.ex. Bachelier) (4)
- ○ Enseignement supérieur de type long (p.ex. Master) (5)
- ○ Doctorat (6)
- ○ Autre diplôme: (7) _____
- ○ Je ne sais pas (8)

Vous vivez …

- ○ Seul(e) (1)
- ○ Seul(e) avec enfant(s) (8)
- ○ En couple sans enfants (9)
- ○ En couple avec enfants (10)
- ○ En maison de repos (11)
- ○ Autre (12) _____

Quel est votre pays de naissance ?

- ○ Belgique (1)
- ○ Autre pays (2)

Sélectionnez le pays concerné

▼ Afghanistan (1) ... Suisse (199)

Quel était votre principal statut professionnel **juste avant** votre diagnostic de la maladie de Crohn ?

- ○ Ouvrier (1)
- ○ Employé (3)
- ○ Indépendant (4)
- ○ Sans emploi (5)
- ○ Etudiant (6)
- ○ Retraité (7)
- ○ Invalidité (8)
- ○ Autre (9) _____

Quel est votre principal statut professionnel **maintenant** ?

- ○ Ouvrier (1)
- ○ Employé (4)
- ○ Indépendant (5)
- ○ Sans emploi (6)
- ○ Etudiant (7)
- ○ Retraité (8)
- ○ Invalidité (9)
- ○ Autre (10)

_____

Avez-vous eu un emploi rémunéré depuis que vous avez la maladie de Crohn ?

- ○ Oui (1)
- ○ Non (2)

Avez-vous été en incapacité de travail (absence du travail pendant plus d'un mois consécutif) en raison de votre maladie de Crohn ?

- ○ Oui (1)
- ○ Non (2)

Êtes-vous de retour au travail?

- ○ Oui, je travaille à nouveau comme avant, le même nombre d'heures par semaine ou plus (1)
- ○ Oui, mais moins qu'avant (2)
- ○ Non, parce que mon état de santé ne le permet pas (encore) (3)
- ○ Non, pour une autre raison : (4)

_____

Concernant votre problème de santé

Depuis combien de temps approximativement avez-vous reçu le diagnostic de maladie de Crohn ?

- ○ Moins de 2 mois (1)
- ○ 2 à 6 mois (6)
- ○ 6 mois à 2 ans (7)
- ○ 2 à 5 ans (8)
- ○ 5 à 10 ans (9)
- ○ Plus de 10 ans (10)
- ○ Je n'ai pas reçu de diagnostic posé par un médecin (11)

Combien de temps est passé entre vos premiers symptômes et votre décision de consulter un médecin ?

- ○ Moins d'une semaine (1)
- ○ Entre 1 semaine et 1 mois (6)
- ○ Entre 1 et 3 mois (7)
- ○ Plus de 3 mois (8)
- ○ Je ne sais pas (9)

Combien de temps est passé entre votre décision de consulter un médecin et le premier rendez-vous ?

- ○ Moins d'une semaine (1)
- ○ Entre 1 semaine et 1 mois (6)
- ○ Entre 1 et 3 mois (7)
- ○ Plus de 3 mois (8)
- ○ Je ne sais pas (9)

Combien de temps est passé entre votre premier rendez-vous médical et le diagnostic ?

- ○ Moins de 2 semaines (1)
- ○ Entre 2 semaines et 2 mois (6)
- ○ Entre 2 mois et 1 an (7)
- ○ Plus de 1 an (8)
- ○ Je ne sais pas (9)

Combien de temps est passé entre le diagnostic et le premier traitement médicamenteux ou chirurgical ?

- ○ Moins d'une semaine (1)
- ○ Entre 1 et 2 semaine(s) (6)
- ○ Entre 2 semaines et 1 mois (7)
- ○ Plus d'1 mois (8)
- ○ Je ne sais pas (9)

Combien de poussées ⓘ de votre maladie de Crohn avez-vous eu au cours de la dernière année?
Par poussée on entend la réapparition ou aggravation de symptômes après une période où les symptômes étaient sous contrôle

- ○ Aucune (1)
- ○ 1 ou 2 (5)
- ○ 3 ou plus (6)
- ○ J'ai eu une poussée qui a duré toute l'année (7)
- ○ Je ne sais pas (8)

Etes-vous actuellement dans une phase de poussée ⓘ ?
Par poussée on entend la réapparition ou aggravation de symptômes de la maladie de Crohn après une période où les symptômes étaient sous contrôle

- ○ Oui (1)
- ○ Non (2)
- ○ Je ne sais pas (3)

vez-vous déjà été hospitalisé(e) à cause de la maladie de Crohn ? Considérez uniquement les hospitalisations avec nuitée(s)

- ○ Oui (1)
- ○ Non (2)
- ○ Je ne sais pas (3)

Quelle était la durée (en jours) de votre dernière hospitalisation pour votre maladie de Crohn?

_____

Pour votre maladie de Crohn, combien de fois avez-vous été hospitalisé(e) durant la dernière année écoulée (0 étant possible)? Considérez uniquement les hospitalisations avec nuitée.

_____

Votre état de santé général

Nous aimerions connaître votre état de santé tel que vous le percevez. Veuillez cocher la case à côté de l'affirmation qui décrit le mieux votre santé **juste AVANT l'apparition des premiers symptômes de la maladie de Crohn.**

Votre mobilité **avant** vos premiers symptômes de la maladie de Crohn

- ○ Je n'avais aucun problème pour me déplacer à pied. (1)
- ○ J'avais des problèmes légers pour me déplacer à pied. (2)
- ○ J'avais des problèmes modérés pour me déplacer à pied. (3)
- ○ J'avais des problèmes sévères pour me déplacer à pied. (4)
- ○ J'étais incapable de me déplacer à pied. (5)

Votre autonomie **avant** vos premiers symptômes de la maladie de Crohn

- ○ Je n'avais aucun problème pour me laver ou m'habiller tout(e) seul(e). (1)
- ○ J'avais des problèmes légers pour me laver ou m'habiller tout(e) seul(e). (2)
- ○ J'avais des problèmes modérés pour me laver ou m'habiller tout(e) seul(e). (3)
- ○ J'avais des problèmes sévères pour me laver ou m'habiller tout(e) seul(e). (4)
- ○ J'étais incapable de me laver ou de m'habiller tout(e) seul(e). (5)

Vos activités courantes **avant** vos premiers symptômes de la maladie de Crohn (Par exemples : travail, études, travaux ménagers, activités familiales ou loisirs)

- ○ Je n'avais aucun problème pour accomplir mes activités courantes. (1)
- ○ J'avais des problèmes légers pour accomplir mes activités courantes. (2)
- ○ J'avais des problèmes modérés pour accomplir mes activités courantes. (3)
- ○ J'avais des problèmes sévères pour accomplir mes activités courantes. (4)
- ○ J'étais incapable d'accomplir mes activités courantes. (5)

Votre douleur ou gêne **avant** vos premiers symptômes de la maladie de Crohn

- ○ Je n'avais ni douleur ni gêne. (1)
- ○ J'avais des douleurs ou une gêne légère(s). (2)
- ○ J'avais des douleurs ou une gêne modérée(s). (3)
- ○ J'avais des douleurs ou une gêne sévère(s). (4)
- ○ J'avais des douleurs ou une gêne extrême(s). (5)

Votre anxiété ou dépression **avant** vos premiers symptômes de la maladie de Crohn

- ○ Je n'étais ni anxieux(se), ni déprimé(e). (1)
- ○ J'étais légèrement anxieux(se) ou déprimé(e). (2)
- ○ J'étais modérément anxieux(se) ou déprimé(e). (3)
- ○ J'étais sévèrement anxieux(se) ou déprimé(e). (4)
- ○ J'étais extrêmement anxieux(se) ou déprimé(e). (5)

Nous aimerions savoir dans quelle mesure votre santé était bonne ou mauvaise **AVANT vos premiers symptômes de la maladie de Crohn** sur une échelle de 0 à 100.
L'échelle de mesure ci-dessous va de 0 à 100.
100 correspond à **la meilleure santé** que vous puissiez imaginer.
0 correspond à **la pire santé** que vous puissiez imaginer.

Nous aimerions savoir votre état de santé actuel, tel que vous le vivez aujourd'hui.
Maintenant, veuillez cocher la case à côté de l'affirmation qui décrit le mieux votre santé **AUJOURD'HUI.**

Votre mobilité aujourd'hui

- ○ Je n'ai aucun problème pour me déplacer à pied. (1)
- ○ J'ai des problèmes légers pour me déplacer à pied. (2)
- ○ J'ai des problèmes modérés pour me déplacer à pied. (3)
- ○ J'ai des problèmes sévères pour me déplacer à pied. (4)
- ○ Je suis incapable de me déplacer à pied. (5)

Votre autonomie aujourd'hui

- ○ Je n'ai aucun problème pour me laver ou m'habiller tout(e) seul(e). (1)
- ○ J'ai des problèmes légers pour me laver ou m'habiller tout(e) seul(e). (2)
- ○ J'ai des problèmes modérés pour me laver ou m'habiller tout(e) seul(e). (3)
- ○ J'ai des problèmes sévères pour me laver ou m'habiller tout(e) seul(e). (4)
- ○ Je suis incapable de me laver ou de m'habiller tout(e) seul(e). (5)

Vos activités courantes (exemples : travail, études, travaux ménagers, activités familiales ou loisirs) aujourd'hui

- ○ Je n'ai aucun problème pour accomplir mes activités courantes. (1)
- ○ J'ai des problèmes légers pour accomplir mes activités courantes. (2)
- ○ J'ai des problèmes modérés pour accomplir mes activités courantes. (3)
- ○ J'ai des problèmes sévères pour accomplir mes activités courantes. (4)
- ○ Je suis incapable d'accomplir mes activités courantes. (5)

Votre douleur ou gêne aujourd'hui

- ○ Je n'ai ni douleur ni gêne. (1)
- ○ J'ai des douleurs ou une gêne légère(s). (2)
- ○ J'ai des douleurs ou une gêne modérée(s). (3)
- ○ J'ai des douleurs ou une gêne sévère(s). (4)
- ○ J'ai des douleurs ou une gêne extrême(s). (5)

Votre anxiété ou dépression aujourd'hui

- ○ Je ne suis ni anxieux(se), ni déprimé(e). (1)
- ○ Je suis légèrement anxieux(se) ou déprimé(e). (2)
- ○ Je suis modérément anxieux(se) ou déprimé(e). (3)
- ○ Je suis sévèrement anxieux(se) ou déprimé(e). (4)
- ○ Je suis extrêmement anxieux(se) ou déprimé(e). (5)

Nous aimerions savoir dans quelle mesure votre santé était bonne ou mauvaise **AUJOURD'HUI** sur une échelle de 0 à 100.
L'échelle de mesure ci-dessous va de 0 à 100.
100 correspond à **la meilleure santé** que vous puissiez imaginer
0 correspond à **la pire santé** que vous puissiez imaginer

Autres problèmes de santé

Souffrez-vous également d'un ou de plusieurs autre(s) problème(s) de santé ?

- ○ Oui (1)
- ○ Non (2)
- ○ Je ne sais pas (3)

Veuillez cocher toutes les maladies qui s'appliquent. **Vous pouvez cocher plusieurs cases.**

Veuillez également indiquer le nom précis de votre/vos problème(s) de santé si vous le(s) connaissez.
Si vous ne connaissez pas (encore) votre diagnostic, cochez la case "pas de diagnostic connu".

- ☐ Maladie du cœur ou des vaisseaux sanguins (1)
- ☐ Maladie du système respiratoire (2)
- ☐ Maladie de l'appareil digestif (3)
- ☐ Maladie de la peau (4)
- ☐ Maladie des os, articulations, ou muscles (5)

- ☐ Trouble de santé mentale ou psychologique (6)
- ☐ Maladie du sang (hématologique) (7)
- ☐ Maladie immunitaire (15)
- ☐ Maladie endocrinienne, nutritionnelle, ou métabolique (8)
- ☐ Maladie du système nerveux (neurologique) (9)
- ☐ Maladie de l'œil (10)
- ☐ Maladie de l'oreille ou du système vestibulaire (11)
- ☐ Maladie des organes reproducteurs ou du système urinaire (par exemple vessie, reins) (12)
- ☐ Maladie qui touche plusieurs systèmes (13)
- ☐ Pas de diagnostic connu (14)

Symptôme(s) (physiques ou psychologiques) lié(s) à votre maladie de Crohn

Ressentez-vous ou avez-vous ressenti un ou plusieurs symptômes liés à la maladie de Crohn (**en excluant les effets secondaires du traitement**)? Précisez lesquels. (plusieurs réponses possibles)

- ☐ Diarrhée (1)
- ☐ Constipation (89)
- ☐ Besoin urgent ou impérieux d'aller à selle (57)
- ☐ Perte de sang lors de la défécation (58)
- ☐ Douleur anale (59)
- ☐ Crampes (60)
- ☐ Douleur abdominale continue (61)
- ☐ Nausées ou vomissements (62)
- ☐ Douleur dans la bouche due par exemple à la présence d'aphtes (63)
- ☐ Perte d'appétit (64)
- ☐ Perte de poids (65)

☐ Prise de poids (66)

☐ Douleurs ou gonflements articulaires (67)

☐ Fièvre ou augmentation de la température (68)

☐ Difficultés de cicatrisation des plaies (69)

☐ Peau sèche, douloureuse, démangeaisons ou éruption cutanée (70)

☐ Problèmes de vision ou douleur aux yeux (71)

☐ Maux de tête (72)

☐ Problèmes de concentration (73)

☐ Manque d'énergie (74)

☐ Fatigue ou épuisement (75)

☐ Sentiments d'agitation, de nervosité, ou d'irritabilité (76)

☐ Colère ou agressivité (77)

☐ Problèmes de libido (78)

☐ Changements d'humeur (82)

☐ Peur ou anxiété (83)

☐ Sentiment d'abattement, de déprime, ou de tristesse (84)

☐ Stress (85)

☐ Autre (88)

_____

☐ Aucun symptôme (90)

A quel point ces symptômes étaient/sont dérangeants?

	Très dérangeant (1)	Assez dérangeant (2)	Pas très dérangeant (3)	Pas dérangeant du tout (4)
Diarrhée (x1)	○	○	○	○
Constipation (x89)	○	○	○	○
Besoin urgent ou impérieux d'aller à selle (x57)	○	○	○	○

Perte de sang lors de la défécation (x58)	○	○	○	○	Fièvre ou augmentation de la température (x68)	○	○	○	○
Douleur anale (x59)	○	○	○	○	Difficultés de cicatrisation des plaies (x69)	○	○	○	○
Crampes (x60)	○	○	○	○	Peau sèche, douloureuse, démangeaisons ou éruption cutanée (x70)	○	○	○	○
Douleur abdominale continue (x61)	○	○	○	○					
Nausées ou vomissements (x62)	○	○	○	○	Problèmes de vision ou douleur aux yeux (x71)	○	○	○	○
Douleur dans la bouche due par exemple à la présence d'aphtes (x63)	○	○	○	○	Maux de tête (x72)	○	○	○	○
Perte d'appétit (x64)	○	○	○	○	Problèmes de concentration (x73)	○	○	○	○
Perte de poids (x65)	○	○	○	○	Manque d'énergie (x74)	○	○	○	○
Prise de poids (x66)	○	○	○	○	Fatigue ou épuisement (x75)	○	○	○	○
Douleurs ou gonflements articulaires (x67)	○	○	○	○	Sentiments d'agitation, de nervosité, ou d'irritabilité (x76)	○	○	○	○

Colère ou agressivité (x77)	○	○	○	○
Problèmes de libido (x78)	○	○	○	○
Changements d'humeur (x82)	○	○	○	○
Peur ou anxiété (x83)	○	○	○	○
Sentiment d'abattement, de déprime, ou de tristesse (x84)	○	○	○	○
Stress (x85)	○	○	○	○
Autre (x88)	○	○	○	○
Aucun symptôme (x90)	○	○	○	○

Souffrez-vous d'une des affections, pouvant-être associées à la maladie de Crohn ?
(plusieurs réponses possibles)

- ☐ Arthrites ou inflammation(s) articulaire(s) (par exemple du dos, des épaules, genoux, coudes, poignets, mains, ou chevilles,...) (1)
- ☐ Ostéoporose (8)
- ☐ Lésions cutanées (par example erythème noueux) (9)
- ☐ Maladies du foie et/ou des voies biliaires (10)
- ☐ Yeux (p.ex. uvéite, épisclérite) (11)
- ☐ Fatigue chronique (12)
- ☐ Fistule(s) ⓘ Une fistule est un canal non naturel entre deux cavités corporelles ou entre une cavité corporelle et la peau. (13)
- ☐ Je ne sais pas (14)
- ☐ Aucune (15)

Recours et accessibilité aux soins de santé

Au cours des 12 derniers mois, y a-t-il des soins pour la maladie de Crohn que vous n'avez pas obtenus alors que vous en auriez eu besoin ? Il peut s'agir d'un traitement, d'une consultation, d'analyses médicales, de rééducation, ou autre.

- ○ Oui (1)
- ○ Non (2)
- ○ Je ne sais pas (3)

Pour quelle(s) raison(s) principale(s) n'avez-vous pas reçu les soins dont vous aviez besoin?
(plusieurs réponses possibles)

- ☐ Distance entre le domicile et le lieu de soins (1)
- ☐ Problème de transport (par example pas de transport en commun à proximité, pas de véhicule personnel, impossibilité de conduire votre propre véhicule, personne pour vous emmener sur le lieu de vos soins) (2)
- ☐ Manque de personnel compétent pour vous administrer les soins dont vous avez besoin (3)
- ☐ Délais d'attente très longs (4)
- ☐ Difficultés pour payer les soins (5)
- ☐ Peur des examens médicaux, de l'hôpital, ou d'autre chose (6)
- ☐ Manque de temps à cause du travail, des enfants, ou autre (7)
- ☐ Manque d'information (8)
- ☐ Difficultés liées à la langue (9)
- ☐ Autre (10) _____

Avec quel(s) prestataire(s) de soins avez-vous été en contact dans le cadre de votre maladie de Crohn ?
(plusieurs réponses possibles)

- ☐ Médecin généraliste (1)
- ☐ Médecin spécialiste (40)

☐ Équipe du service des urgences (26)

☐ Équipe d'un centre de revalidation (27)

☐ Kinésithérapeute (28)

☐ Infirmier à domicile (29)

☐ Infirmier spécialisée dans les maladies inflammatoires de l'intestin (30)

☐ Infirmier (en consultation à l'hôpital) (31)

☐ Psychologue (32)

☐ Assistant social (33)

☐ Diététicien (34)

☐ Autre (41)

_____

Avec quel(s) médecin(s) spécialiste(s) avez-vous été en contact dans le cadre de votre maladie de Crohn ?
(plusieurs réponses possibles)

☐ Gastro-entérologue (1)

☐ Chirurgien (4)

☐ Ophtalmologue (5)

☐ Dermatologue (6)

☐ Rhumatolgue (7)

☐ Autre (8)

_____

Indiquez dans quelle mesure vous êtes ou vous avez été satisfait(e) de leurs services

	Très satisfait(e) (1)	Plutôt satisfait(e) (2)	Plutôt insatisfait(e) (3)	Très insatisfait(e) (4)
Médecin généraliste (x1)	○	○	○	○

Médecin spécialiste (x40)	○	○	○	○
Équipe du service des urgences (x26)	○	○	○	○
Équipe d'un centre de revalidation (x27)	○	○	○	○
Kinésithérapeute (x28)	○	○	○	○
Infirmier à domicile (x29)	○	○	○	○
Infirmier spécialisée dans les maladies inflammatoires de l'intestin (x30)	○	○	○	○
Infirmier (en consultation à l'hôpital) (x31)	○	○	○	○
Psychologue (x32)	○	○	○	○
Assistant social (x33)	○	○	○	○
Diététicien (x34)	○	○	○	○
Autre (x41)	○	○	○	○

	Très satisfait(e) (1)	Plutôt satisfait(e) (2)	Plutôt insatisfait(e) (3)	Très insatisfait(e) (4)
Gastro-entérologue (x1)	○	○	○	○
Chirurgien (x4)	○	○	○	○
Ophtalmologue (x5)	○	○	○	○
Dermatologue (x6)	○	○	○	○
Rhumatolgue (x7)	○	○	○	○
Autre (x8)	○	○	○	○

Traitements liés à votre maladie de Crohn

Recevez-vous (ou avez-vous reçu) un traitement lié à votre maladie de Crohn ?

- ○ Oui (1)
- ○ Non (2)
- ○ Je ne sais pas (3)

Quels traitements recevez-vous (ou avez-vous reçus) pour votre maladie de Crohn?
(plusieurs réponses possibles)

- ☐ Médicament sur ordonnance (1)
- ☐ Médicament sans ordonnance (7)
- ☐ Kinésithérapie (8)
- ☐ Adaptation de l'alimentation (9)
- ☐ Intervention chirurgicale (10)
- ☐ Autre (11)

À quel degré êtes-vous satisfait(e) de ce traitement ?

	Très satisfait(e) (1)	Plutôt satisfait(e) (2)	Plutôt insatisfait(e) (3)	Très insatisfait(e) (4)
Médicament sur ordonnance (x1)	○	○	○	○
Médicament sans ordonnance (x7)	○	○	○	○
Kinésithérapie (x8)	○	○	○	○
Adaptation de l'alimentation (x9)	○	○	○	○
Intervention chirurgicale (x10)	○	○	○	○
Autre (x11)	○	○	○	○

Si vous prenez ou avez pris des médicaments sur ordonnance pour la maladie de Crohn dans les 2 dernières années, lesquels ? (plusieurs réponses possibles)

- ☐ Corticoïdes Exemples Entocort® (Budosenide), Medrol® of Solu-Medrol® (Methylprednisone), Deltasone® (Prednisone) (1)
- ☐ Thérapie biologique Exemples Remicade® (Infliximab), Humira® (Adalimumab), Stelara® (Utsekinamab), Entyvio® (Vedolizumab), Cimzia® (certolizumab), (2)
- ☐ Immunomodulateurs Exemples Trexall® ou Ledertrexate® (Methotrexate), Imuran® (Azathiopirine) (6)
- ☐ Aminosalicylates Exemples Asacol®, Canasa®, Rowasa®, Pentasa® (Mesalamine), Colazal® (Balsalazide), Azulfidine® (Sulfasalazine), Dipentum® (Olsalazine) (3)
- ☐ Inhibiteurs de Janus-Kinase (anti-JAK) Exemples Cibinqo® (abrocitinib), Jyseleca® (filgotinib), Olumiant® (baricitinib), Rinvoq® (upadacitinib), Xeljanz® (tofacitinib) (4)
- ☐ Autre (5)

_____

Quelle intervention chirurgicale avez-vous reçue pour la maladie de Crohn ?
(plusieurs réponses possibles)

- ☐ Traitement chirurgical d'une fistule ⓘ Une fistule est la formation anormale d'une connexion entre deux organes internes. (1)
- ☐ Traitement chirurgical d'un abcès ⓘ Un abcès est une collection de pus due à une infection bactérienne. (2)
- ☐ Résection chirurgicale (enlèvement d'une partie de l'intestin) (3)
- ☐ Stricturoplastie ⓘ Une stricturoplastie est une réparation d'un rétrécissement, sans retirer une partie de l'intestin. (4)
- ☐ Stomie ⓘ Une stomie est une ouverture créée dans l'intestin à travers l'abdomen, permettant l'évacuation des selles, qui se fait dans une poche de recueil (5)
- ☐ Autre (6)

_____

Dans quelle mesure le ou les traitement(s) que vous recevez (ou avez reçu(s)) pour traiter la maladie de Crohn est (sont)/étai(en)t pénible(s) pour vous?

- ○ Extrêmement pénible(s) (1)
- ○ Très pénible(s) (2)
- ○ Assez pénible(s) (3)
- ○ Pas du tout pénible(s) (4)
- ○ Je ne sais pas (5)

Pour quelle(s) raison(s) le traitement est-il ou a-t-il été pénible?
(plusieurs réponses possibles)

- ☐ A cause des effets indésirables (1)
- ☐ Parce que cela m'oblige/m'obligeait à m'occuper constamment de ma maladie/de mon traitement (2)
- ☐ Parce que cela exige/exigeait une discipline de vie très stricte (prise de médicaments à des horaires stricts, hygiène…) (3)
- ☐ Parce que je suis ce(s) traitement(s) depuis longtemps (4)
- ☐ Autre (5) _____

Quel(s) effet(s) indésirable(s) avez-vous resenti(s) ou ressentez-vous lors du traitement de la maladie de Crohn?
(plusieurs réponses possibles)

- ☐ Nausées ou vomissements (1)
- ☐ Constipation (2)
- ☐ Diarrhée (17)

☐ Irritation cutanée, eczéma (3)

☐ Acné (4)

☐ Insuffisance/problèmes rénaux (5)

☐ Inflammation du foie (6)

☐ Calculs rénaux (7)

☐ Gain de poids (8)

☐ Infection (9)

☐ Réactions à la perfusion (10)

☐ Inflammation du pancréas (11)

☐ Changement d'apparence (12)

☐ Fatigue ou épuisement (13)

☐ Complications de la chirurgie (15)

☐ Autre (14)

_____

☐ Aucun effet indésirable (16)

Indiquez dans quelle mesure chacun d'entre eux sont/étaient dérangeant(s).

	Très dérangeant (1)	Assez dérangeant (2)	Pas très dérangeant (3)	Pas dérangeant du tout (4)
Nausées ou vomissements (x1)	○	○	○	○
Constipation (x2)	○	○	○	○
Diarrhée (x17)	○	○	○	○
Irritation cutanée, eczéma (x3)	○	○	○	○
Acné (x4)	○	○	○	○
Insuffisance/problèmes rénaux (x5)	○	○	○	○

Inflammation du foie (x6)	○	○	○	○
Calculs rénaux (x7)	○	○	○	○
Gain de poids (x8)	○	○	○	○
Infection (x9)	○	○	○	○
Réactions à la perfusion (x10)	○	○	○	○
Inflammation du pancréas (x11)	○	○	○	○
Changement d'apparence (x12)	○	○	○	○
Fatigue ou épuisement (x13)	○	○	○	○
Complications de la chirurgie (x15)	○	○	○	○
Autre (x14)	○	○	○	○
Aucun effet indésirable (x16)	○	○	○	○

Est-ce que le(s) traitement(s) que vous recevez/avez reçu est/a été efficace contre la maladie de Crohn, selon vous ?

- ○ Oui (1)
- ○ Oui, mais seulement pendant une période (4)
- ○ Non (5)
- ○ Je ne sais pas (6)

Informations sur la maladie de Crohn

La **quantité d'explications** que vous avez reçue de la part de vos soignants au sujet de votre maladie de Crohn et du traitement était selon vous:

- ○ Excessive (1)
- ○ Adéquate (8)
- ○ Insuffisante (9)
- ○ Je n'ai pas reçu d'information (10)
- ○ Je ne sais pas (11)

Les explications que vous avez reçues de la part de vos soignants au sujet de votre maladie de Crohn et du traitement étaient :

- ○ Très claires (1)
- ○ Raisonnablement claires (8)
- ○ Pas très claires (9)
- ○ Pas claires du tout (10)
- ○ Je ne sais pas (11)

Avez-vous cherché ou demandé des informations supplémentaires sur la maladie de Crohn?

- ○ Oui (1)
- ○ Non (2)
- ○ Je ne sais pas (3)

Quelle(s) information(s) avez-vous cherché ou demandé sur la maladie de Crohn?
(plusieurs réponses possibles)

- ☐ Votre maladie (1)
- ☐ La manière dont votre diagnostic a été posé (2)
- ☐ L'évolution de votre état de santé (3)
- ☐ Les possibilités de traitement (4)
- ☐ Les essais cliniques liés à votre traitement (5)
- ☐ Le coût du traitement et les frais à votre charge (ce qui n'est pas remboursé par votre mutuelle) (6)
- ☐ Les lieux où le traitement est possible (7)

☐ Les droits des patients (8)

☐ L'accès à vos propres données (9)

☐ Les associations de patients (10)

☐ Les aides disponibles (11)

☐ Le retour à domicile et les aménagements possibles (ou logement alternatif) (12)

☐ L'éducation thérapeutique (éducation pour apprendre à faire face à son problème de santé et à son traitement ; cela inclut la sensibilisation, l'information, le soutien psychosocial, etc.) (13)

☐ Les droits des aidants proches (14)

☐ L'accompagnement, le soutien psychologique, le coaching (15)

☐ Autre (16)
_____

Indiquez également votre degré de satisfaction par rapport aux informations cherchées/trouvées.

	Très satisfait(e) (1)	Plutôt satisfait(e) (2)	Plutôt insatisfait(e) (3)	Très insatisfait(e) (4)
Votre maladie (x1)	○	○	○	○
La manière dont votre diagnostic a été posé (x2)	○	○	○	○
L'évolution de votre état de santé (x3)	○	○	○	○
Les possibilités de traitement (x4)	○	○	○	○
Les essais cliniques liés à votre traitement (x5)	○	○	○	○
Le coût du traitement et les frais à votre charge (ce qui n'est pas remboursé par votre mutuelle) (x6)	○	○	○	○

Les lieux où le traitement est possible (x7)	○	○	○	○
Les droits des patients (x8)	○	○	○	○
L'accès à vos propres données (x9)	○	○	○	○
Les associations de patients (x10)	○	○	○	○
Les aides disponibles (x11)	○	○	○	○
Le retour à domicile et les aménagements possibles (ou logement alternatif) (x12)	○	○	○	○
L'éducation thérapeutique (éducation pour apprendre à faire face à son problème de santé et à son traitement ; cela inclut la sensibilisation, l'information, le soutien psychosocial, etc.) (x13)	○	○	○	○
Les droits des aidants proches (x14)	○	○	○	○
L'accompagnement, le soutien psychologique, le coaching (x15)	○	○	○	○
Autre (x16)	○	○	○	○

Souhaiteriez-vous ou auriez-vous souhaité être davantage impliqué(e) dans les choix relatifs à votre/vos traitement(s) pour la maladie de Crohn?

- ○ Oui (1)
- ○ Non (2)
- ○ Non applicable (3)
- ○ Je ne sais pas (4)

Conséquences financières

Votre maladie de Crohn a-t-elle (eu) des répercussions financières?

- ○ Oui (1)
- ○ Non (2)
- ○ Je ne sais pas (3)

Quel genre de répercussions a (ont) eu votre maladie de Crohn ? (plusieurs réponses possibles)

- ☐ Perte ou absence de revenus (1)
- ☐ Perte ou absence d'emploi (2)
- ☐ Frais médicaux (3)
- ☐ Autre (4) _____

Réseau d'aide autour de vous

Avez-vous (eu) parfois besoin d'aide pour les activités de la vie quotidienne suite à votre maladie de Crohn ?

- ○ Oui (1)
- ○ Non (2)
- ○ Je ne sais pas (3)

Indiquez de quel(s) type(s) d'aide logistique vous avez (eu) besoin. (plusieurs réponses possibles)

- ☐ Hygiène corporelle (1)
- ☐ Habillage (2)
- ☐ Déplacements (3)
- ☐ Ménage (4)
- ☐ Préparation des repas (5)
- ☐ Garde d'enfants (6)
- ☐ Autre (7)

_____

Qui vous fournit/vous a fourni cette aide ?

- ☐ Un aidant proche (1)
- ☐ Un aidant professionnel (2)
- ☐ Autre (3)

_____

À cause de la maladie de Crohn, avez-vous (eu) besoin, **sans y parvenir:** (plusieurs réponses possibles)

- ☐ D'une aide logistique plus importante que celle que vous recevez actuellement/avez reçu (1)
- ☐ De parler à d'autres patients atteints de la maladie de Crohn (2)
- ☐ De parler à des professionnels de santé (y compris un psychologue) (3)

☐ De parler d'autres choses que de vos problèmes de santé (4)

☐ D'une aide administrative ou sociale (6)

☐ D'un soutien pour le retour au travail (7)

☐ D'un accompagnement spirituel ou religieu (8)

☐ Autre (9)
_____

☐ Non (10)

Avez-vous (eu) des difficultés à trouver quelqu'un de confiance à qui parler de votre maladie de Crohn ?

○ Oui (1)

○ Non (2)

○ Je n'ai pas (eu) besoin d'une personne de confiance à qui parler de la maladie de Crohn (3)

○ Je ne sais pas (4)

Souhaitez-vous nous faire part d'un ou plusieurs autres besoins importants que vous n'avez pas pu exprimer dans le questionnaire ?

○ Oui (1)

○ Non (2)

Quel(s) besoin(s) n'a(ont) pas été abordé(s) dans le questionnaire ?

_____
_____

_____
_____

Poursuite de l'étude

Nous aimerions poursuivre la conversation sur les besoins et les difficultés que vous éprouvez ou que vous avez éprouvés dans le contexte de votre maladie de Crohn. **Si vous le souhaitez**, vous pouvez participer à **un entretien individuel (en ligne ou en face à face avec un chercheur)** pour aborder plus en détail votre expérience et vos besoins. Cet entretien sera mené de manière confidentielle et indépendante aux soins que vous recevez de la part des professionnels de la santé. Il est prévu que **24 patients (12 francophones et 12 néerlandophones)** soient interrogés. Cet entretien individuel durera environ **une heure et demie**.

Si vous êtes intéressé(e) par l'entretien individuel, merci de nous indiquer vos coordonnées (numéro de téléphone et adresse mail) afin que nous puissions vous contacter.

○ Email (1)

○ Confirmer l'email (2)

○ GSM (3)

○ GSM supplémentaire (optionnel) (3)

Êtes-vous impliqué(e) dans une association ou un groupe (par exemple un groupe Facebook) de patients?

- ○ Oui (1)
- ○ Non (4)
- ○ Je ne souhaite pas répondre (5)

Souhaitez-vous nous communiquer le nom de cette association ou de ce groupe de discussion?

_____

_____

ENQUÊTE OVER DE BEHOEFTEN VAN PATIËNTEN MET DE ZIEKTE VAN CROHN

Inleiding

Hartelijk dank voor uw deelname aan onze enquête.
Onze studie heeft als doel de behoeften van patiënten met de **ziekte van Crohn** te identificeren om de zorg te verbeteren.
Gelieve **deze vragenlijst enkel in te vullen** als u : De ziekte van Crohn heeft Minstens 2 maanden geleden de diagnose van de ziekte van Crohn kreeg 18 jaar of ouder bent In België woont (hoofdverblijfplaats)
Of
Deelneemt in naam van een volwassene met de ziekte van Crohn, die ten minste 2 maanden geleden is gediagnosticeerd en woonachtig is te België, maar zelf niet in staat om de vragen te beantwoorden
Voordat u akkoord gaat met deelname aan deze enquête, vragen wij u om onderstaande informatie over de vertrouwelijkheid van uw gegevens te lezen en uw toestemming te geven voor het gebruik van uw gegevens.

Vertrouwelijkheid van uw gegevens en geïnformeerde toestemming

1. Vertrouwelijkheid van de gegevens

Uw gegevens worden verwerkt in overeenstemming met de Belgische wet van 30 juli 2018 betreffende de bescherming van natuurlijke personen met betrekking tot de verwerking van persoonsgegevens en de Verordening (EU) 2016/679 van 27 april 2016, die op 25 mei 2018 in werking trad, betreffende de bescherming van natuurlijke personen in verband met de verwerking van persoonsgegevens en betreffende het vrije verkeer van die gegevens. U hebt het recht het Federaal Kenniscentrum voor de Gezondheidszorg (KCE) te verzoeken om toegang tot uw persoonsgegevens, te corrigeren, te verwijderen, over te dragen, de verwerking te beperken en bezwaar aan te tekenen tegen de verwerking ervan. Hiervoor kan u contact opnemen met het KCE, die verantwoordelijk is voor de verwerking ervan (charline.maertens@kce.fgov.be) of via brief naar het KCE (Postbus 10e verdiep, Kruidtuinlaan 55, 1000 Brussel). Indien u vragen of opmerkingen heeft over de verwerking van uw gegevens, kunt contact opnemen met de verantwoordelijke voor gegevensbescherming bij het KCE via stephan.devriese@kce.fgov.be. Hij zal u indien nodig meer informatie kunnen verstrekken over de bescherming van uw persoonsgegevens. Indien dit niet voldoende zou blijken, kan u een klacht indienen over de verwerking van uw gegevens bij de Belgische toezichthoudende instantie die verantwoordelijk is voor de toepassing van de wetgeving inzake gegevensbescherming: Gegevensbeschermingsautoriteit (GBA), Drukpersstraat 35, 1000 Brussel, of via contact@apd-gba.be. Voor de implementatie en analyse van de gegevens van deze KCE-enquête, doet het KCE beroep op een externe equipe (Deloitte) die werkt binnen het mandaat dat haar door het KCE werd toegewezen. De verwerking van de gegevens gebeurt onder de verantwoordelijkheid van het KCE.

2. Bewaartermijn

De gegevens worden bewaard tot twee jaar na publicatie van het rapport.

3. Verwerkingsdoel

Het doel van deze studie is om de behoeften van patiënten met de ziekte van Crohn in kaart te brengen om hun zorg te verbeteren.

4. Toestemmingsverklaring

Hierbij verklaar ik dat ik schriftelijk en op een voor mij begrijpelijke wijze ben ingelicht over de aard, de methode en het doel van deze studie.

Ik ga akkoord met deelname aan deze studie. Ik begrijp dat ik mij op elk moment kan terugtrekken uit dit onderzoek tot op het ogenblik dat de gegevens in de database worden bewaard zonder dat ik hiervoor een verklaring hoef af te leggen en zonder dat dit op enigerlei wijze gevolg zal hebben voor mij.

Ik begrijp dat mijn gegevens vertrouwelijk zullen worden ingezameld en geregistreerd, en dat de hoofdonderzoeker de vertrouwelijkheid ervan garandeert.

○ NL - Gelieve akkoord te gaan met het privacybeleid inzake gegevens om verder te gaan. (1)

○ FR - Pour continuer, veuillez d'abord accepter la politique de confidentialité des données. (3)

Algemene informatie

U vult deze vragenlijst in:

- ○ Voor uzelf (1)
- ○ Voor een andere volwassene (gelieve alle vragen te beantwoorden alsof u de persoon zelf bent. U kan aangeven 'ik weet het niet' als u niet weet hoe de persoon zou antwoorden). ⓘ De persoon die u vertegenwoordigt is op dit moment niet in staat om een weloverwogen beslissing te nemen om deel te nemen aan dit onderzoek. Door dit vakje aan te kruisen, neemt u deel aan dit onderzoek op basis van zijn of haar waarschijnlijke bereidheid om deel te nemen. (2)

Met welk geslacht identificeert u zich?

- ○ Man (1)
- ○ Vrouw (2)
- ○ Andere (3)

In welk jaar bent u geboren?

▼ 2023 (4) ... 1920 (212)

In welke provincie woont u?

- ○ Antwerpen (1)
- ○ Waals-Brabant (13)
- ○ Brussel (14)
- ○ Henegouwen (15)
- ○ Luik (16)
- ○ Limburg (17)
- ○ Luxemburg (18)
- ○ Namen (19)
- ○ Oost-Vlaanderen (20)
- ○ Vlaams-Brabant (21)
- ○ West-Vlaanderen (22)
- ○ Ik woon niet in België (23)

Wat is het hoogste diploma of graad die u tot nu toe hebt behaald?

- ○ Geen diploma of basisonderwijs (1)
- ○ Lager secundair onderwijs (2)
- ○ Hoger secundair onderwijs (3)
- ○ Hoger onderwijs van het korte type (vb. bachelor) (4)
- ○ Hoger onderwijs van het lange type (vb. master) (5)
- ○ Doctoraat (6)
- ○ Ander diploma, specifieer: (7) _____
- ○ Ik weet het niet (8)

U woont ...

- ○ Alleen (1)
- ○ Alleen met kinderen (8)
- ○ Samen zonder kinderen (9)
- ○ Samen met kinderen (10)
- ○ In een woon- en zorgcentrum (11)
- ○ Andere (12) _____

In welk land bent u geboren

- ○ België (1)
- ○ Ander land (2)

Selecteer desbetreffend land

▼ Afghanistan (1) ... Zwitserland (199)

Wat was uw voornaamste beroepsstatuut **net voor de diagnose** van de ziekte van Crohn?

- ○ Bediende (1)
- ○ Arbeider (3)
- ○ Zelfstandige (4)
- ○ Werkloos (5)
- ○ Student (6)
- ○ Gepensioneerd (7)
- ○ Invaliditeit (8)
- ○ Andere (9)

_____

Wat is uw voornaamste beroepsstatuut **momenteel**?

- ○ Bediende (1)
- ○ Arbeider (4)
- ○ Zelfstandige (5)
- ○ Werkloos (6)
- ○ Student (7)
- ○ Gepensioneerd (8)
- ○ Invaliditeit (9)
- ○ Andere (10)

_____

Heeft u betaald werk gehad voor u de ziekte van Crohn kreeg?

- ○ Ja (1)
- ○ Nee (2)

Bent u door de ziekte van Crohn arbeidsongeschikt geweest (langer dan 1 maand onafgebroken afwezig van het werk)?

- ○ Ja (1)
- ○ Nee (2)

Bent u opnieuw aan het werk?

- ○ Ja, ik werk terug zoals voordien, hetzelfde aantal uren per week of meer (1)
- ○ Ja, maar minder dan voordien (2)
- ○ Nee, mijn gezondheidstoestand laat dit (nog) niet toe (3)
- ○ Nee, om een andere reden: (4) _____

Over uw aandoening

Hoe lang bent u al ongeveer gediagnosticeerd met de ziekte van Crohn?

- ○ Minder dan 2 maanden (1)
- ○ 2 maanden tot 6 maanden (6)
- ○ 6 maanden tot 2 jaar (7)
- ○ 2 tot 5 jaar (8)
- ○ 5 tot 10 jaar (9)
- ○ Meer dan 10 jaar (10)
- ○ Ik heb nog geen diagnose gekregen van een arts (11)

Hoeveel tijd is er verstreken tussen het optreden van uw eerste symptomen en uw beslissing om op consultatie te gaan bij een arts?

- ○ Minder dan 1 week (1)
- ○ 1 week tot 1 maand (6)
- ○ 1 maand tot 3 maanden (7)
- ○ Meer dan 3 maanden (8)
- ○ Ik weet het niet (9)

Hoeveel tijd is er verstreken tussen de eerste consultatie met een arts en de diagnose?

- ○ Minder dan 2 weken (1)
- ○ 2 weken tot 2 maanden (6)
- ○ 2 maanden tot 1 jaar (7)
- ○ Meer dan 1 jaar (8)
- ○ Ik weet het niet (9)

Hoeveel tijd is er verstreken tussen uw beslissing om op consultatie te gaan bij een arts en de eerste consultatie?

- ○ Minder dan 1 week (1)
- ○ 1 week tot 1 maand (6)
- ○ 1 maand tot 3 maanden (7)
- ○ Meer dan 3 maanden (8)
- ○ Ik weet het niet (9)

Hoeveel tijd is er verstreken tussen de diagnose en het krijgen van uw eerste behandeling (chirurgisch of medicamenteus)?

- ○ Minder dan 1 week (1)
- ○ 1 week tot 2 weken (6)
- ○ 2 weken tot 1 maand (7)
- ○ Meer dan 1 maand (8)
- ○ Ik weet het niet (9)

Hoeveel opstoten ⓘ van de ziekte van Crohn heeft u gehad in het laatste jaar?
Een opstoot is het heroptreden of verergeren van uw symptomen gerelateerd aan de ziekte van Crohn na een periode waarin deze symptomen onder controle waren

- ○ Geen (1)
- ○ 1 of 2 (5)
- ○ 3 of meer (6)
- ○ Ik heb een opstoot gehad die het hele jaar heeft geduurd (7)
- ○ Ik weet het niet (8)

Heeft u momenteel een opstoot ⓘ ?
Een opstoot is het heroptreden of verergeren van uw symptomen gerelateerd aan de ziekte van Crohn na een periode waarin deze symptomen onder controle waren

- ○ Ja (1)
- ○ Nee (2)
- ○ Ik weet het niet (3)

Werd u ooit gehospitaliseerd (enkel hospitalisaties met overnachting) omwille van de ziekte van Crohn?

- ○ Ja (1)
- ○ Nee (2)
- ○ Ik weet het niet (3)

Wat was de duur (in dagen) van uw laatste ziekenhuisopname voor de ziekte van Crohn?

_____

Hoe vaak bent u het afgelopen jaar in het ziekenhuis opgenomen wegens de ziekte van Crohn? (enkel hospitalisaties met overnachting) (0 is mogelijk)

_____

Uw algemene gezondheid

We willen graag uw gezondheidstoestand kennen zoals u die ervaart.
Gelieve het vakje aan te kruisen bij de uitspraak die het best uw gezondheid beschrijft **VOOR de eerste symptomen van de ziekte van Crohn optraden.**

Uw mobiliteit **vóór** de eerste symptomen van de ziekte van Crohn optraden

- ○ Ik had geen problemen met rondwandelen. (1)
- ○ Ik had een beetje problemen met rondwandelen. (2)
- ○ Ik had matige problemen met rondwandelen. (3)
- ○ Ik had ernstige problemen met rondwandelen. (4)
- ○ Ik was niet in staat om rond te wandelen. (5)

Uw zelfzorg **vóór** de eerste symptomen van de ziekte van Crohn optraden

- ○ Ik had geen problemen met mijzelf te wassen of aan te kleden. (1)
- ○ Ik had een beetje problemen met mijzelf te wassen of aan te kleden. (2)
- ○ Ik had matige problemen met mijzelf te wassen of aan te kleden. (3)
- ○ Ik had ernstige problemen met mijzelf te wassen of aan te kleden. (4)
- ○ Ik was niet in staat mijzelf te wassen of aan te kleden. (5)

Uw dagelijkse activiteiten **vóór** de eerste symptomen van de ziekte van Crohn optraden (bv. werk, studie, huishouden, gezins- en vrijetijdsactiviteiten)

- ○ Ik had geen problemen met mijn dagelijkse activiteiten. (1)
- ○ Ik had een beetje problemen met mijn dagelijkse activiteiten. (2)
- ○ Ik had matige problemen met mijn dagelijkse activiteiten. (3)
- ○ Ik had ernstige problemen met mijn dagelijkse activiteiten. (4)

○ Ik was niet in staat mijn dagelijkse activiteiten uit te voeren. (5)

Uw pijn of ongemak **vóór** de eerste symptomen van de ziekte van Crohn optraden

○ Ik had geen pijn of ongemak. (1)

○ Ik had een beetje pijn of ongemak. (2)

○ Ik had matige pijn of ongemak. (3)

○ Ik had ernstige pijn of ongemak. (4)

○ Ik had extreme pijn of ongemak. (5)

Uw angst of depressie **vóór** de eerste symptomen van de ziekte van Crohn optraden

○ Ik was niet angstig of depressief. (1)

○ Ik was een beetje angstig of depressief. (2)

○ Ik was matig angstig of depressief. (3)

○ Ik was erg angstig of depressief. (4)

○ Ik was extreem angstig of depressief. (5)

We willen weten hoe goed of slecht uw gezondheid was **VOOR de eerste symptomen van de ziekte van Crohn optraden**, op een schaal van 0 tot 100.
Hieronder ziet u een meetschaal genummerd van 0 tot 100.
100 staat voor de **beste gezondheid** die u zich kunt voorstellen.
0 staat voor de **slechtste gezondheid** die u zich kunt voorstellen.

We willen graag uw huidige gezondheidstoestand kennen zoals u die vandaag ervaart.
Gelieve het vakje aan te kruisen bij de uitspraak die het best uw gezondheid **VANDAAG** beschrijft.

Uw mobiliteit vandaag

- Ik heb geen problemen met rondwandelen. (1)
- Ik heb een beetje problemen met rondwandelen. (2)
- Ik heb matige problemen met rondwandelen. (3)
- Ik heb ernstige problemen met rondwandelen. (4)
- Ik ben niet in staat om rond te wandelen. (5)

Uw zelfzorg vandaag

- Ik heb geen problemen met mijzelf te wassen of aan te kleden. (1)
- Ik heb een beetje problemen met mijzelf te wassen of aan te kleden. (2)
- Ik heb matige problemen met mijzelf te wassen of aan te kleden. (3)
- Ik heb ernstige problemen met mijzelf te wassen of aan te kleden. (4)
- Ik ben niet in staat mijzelf te wassen of aan te kleden. (5)

Uw dagelijkse activiteiten vandaag (bv. werk, studie, huishouden, gezins- en vrijetijdsactiviteiten)

- Ik heb geen problemen met mijn dagelijkse activiteiten. (1)
- Ik heb een beetje problemen met mijn dagelijkse activiteiten. (2)
- Ik heb matige problemen met mijn dagelijkse activiteiten. (3)
- Ik heb ernstige problemen met mijn dagelijkse activiteiten. (4)
- Ik ben niet in staat mijn dagelijkse activiteiten uit te voeren. (5)

Uw pijn of ongemak vandaag

- Ik heb geen pijn of ongemak. (1)
- Ik heb een beetje pijn of ongemak. (2)
- Ik heb matige pijn of ongemak. (3)
- Ik heb ernstige pijn of ongemak. (4)
- Ik heb extreme pijn of ongemak. (5)

Uw angst of depressie vandaag

- ○ Ik ben niet angstig of depressief. (1)
- ○ Ik ben een beetje angstig of depressief. (2)
- ○ Ik ben matig angstig of depressief. (3)
- ○ Ik ben erg angstig of depressief. (4)
- ○ Ik ben extreem angstig of depressief. (5)

We willen weten hoe goed of slecht uw gezondheid **VANDAAG** is, op een schaal van 0 tot 100.
Hieronder ziet u een meetschaal genummerd van 0 tot 100.
100 staat voor de **beste gezondheid** die u zich kunt voorstellen.
0 staat voor de **slechtste gezondheid** die u zich kunt voorstellen.

Andere gezondheidsproblemen

Heeft u last van een of andere gezondheidsproblemen?

- ○ Ja (1)
- ○ Nee (2)
- ○ Ik weet het niet (3)

Duid in de lijst hieronder die andere aandoeningen aan. **U kan meer dan één vakje aankruisen**. Geef ook de specifieke naam van uw aandoening aan als u die kent. Als u uw diagnose (nog) niet kent, vink het vakje "geen bekende diagnose" aan.

- ☐ Hart- en vaataandoeningen (1)
- ☐ Aandoeningen van het ademhalingsstelsel (2)
- ☐ Aandoeningen van het spijsverteringsstelsel (3)
- ☐ Huidaandoeningen (4)
- ☐ Aandoeningen van het bewegingsstelsel (beenderen, gewrichten, spieren) (5)
- ☐ Mentale/psychische aandoeningen (6)

☐ Hematologische aandoeningen (bloed) en/of immuunziektes (7)

☐ Immuunziektes (15)

☐ Endocriene, voedings- of stofwisselingsaandoeningen (8)

☐ Aandoeningen van het zenuwstelsel (9)

☐ Oogaandoeningen (10)

☐ Ooraandoeningen of aandoeningen aan het evenwichtsorgaan (11)

☐ Aandoeningen aan het urine- (bv. blaas, nieren) en voortplantingsstelsel (12)

☐ Aandoeningen die meerdere systemen aantast (13)

☐ Geen bekende diagnose (14)

Symptomen (lichamelijk of psychologisch) die verband houden met de ziekte van Crohn

---

Ervaart u (of heeft u ervaren) één of meerdere van de volgende symptomen die verband houden met de ziekte van Crohn **(Bijwerkingen van uw behandeling hoeft u hier niet aan te duiden)?** Welke zijn of waren deze symptomen?
(meerdere antwoorden mogelijk)

☐ Diarree (1)

☐ Constipatie (89)

☐ Urgency of stoelgangsdrang (57)

☐ Bloedverlies bij stoelgang (58)

☐ Anale pijn (59)

☐ Krampen (60)

☐ Continue buikpijn (61)

☐ Misselijkheid of braken (62)

☐ Pijn in de mond door bijvoorbeeld aanwezigheid van aften (63)

☐ Verlies van eetlust (64)

☐ Gewichtsverlies (65)

- ☐ Gewichtstoename (66)
- ☐ Gewrichtspijn of ontstekingen (67)
- ☐ Verhoogde temperatuur of koorts (68)
- ☐ Moeilijke wondgenezing (69)
- ☐ Droge, pijnlijke of jeukende huid of huiduitslag (70)
- ☐ Problemen met het zicht of pijn aan de ogen (71)
- ☐ Hoofdpijn (72)
- ☐ Concentratieproblemen (73)
- ☐ Gebrek aan energie (74)
- ☐ Vermoeidheid of uitputting (75)
- ☐ Gevoelens van rusteloosheid of nervositeit, irriteerbaarheid (76)
- ☐ Woede of agressiviteit (77)
- ☐ Libidoproblemen (78)
- ☐ Stemmingswisselingen (82)
- ☐ Angst/ongerustheid (83)
- ☐ Zich down of depressief voelen, verdriet of triest (84)
- ☐ Stress (85)
- ☐ Andere (88) _____
- ☐ Geen symptomen (90)

Hoe storend zijn of waren deze symptomen?

	Zeer storend (1)	Redelijk storend (2)	Niet erg storend (3)	Helemaal niet storend (4)
Diarree (x1)	○	○	○	○
Constipatie (x89)	○	○	○	○
Urgency of stoelgangsdrang (x57)	○	○	○	○

Bloedverlies bij stoelgang (x58)	○	○	○	○
Anale pijn (x59)	○	○	○	○
Krampen (x60)	○	○	○	○
Continue buikpijn (x61)	○	○	○	○
Misselijkheid of braken (x62)	○	○	○	○
Pijn in de mond door bijvoorbeeld aanwezigheid van aften (x63)	○	○	○	○
Verlies van eetlust (x64)	○	○	○	○
Gewichtsverlies (x65)	○	○	○	○
Gewichtstoename (x66)	○	○	○	○
Gewrichtspijn of ontstekingen (x67)	○	○	○	○

Verhoogde temperatuur of koorts (x68)	○	○	○	○
Moeilijke wondgenezing (x69)	○	○	○	○
Droge, pijnlijke of jeukende huid of huiduitslag (x70)	○	○	○	○
Problemen met het zicht of pijn aan de ogen (x71)	○	○	○	○
Hoofdpijn (x72)	○	○	○	○
Concentratieproblemen (x73)	○	○	○	○
Gebrek aan energie (x74)	○	○	○	○
Vermoeidheid of uitputting (x75)	○	○	○	○
Gevoelens van rusteloosheid of nervositeit, irriteerbaarheid (x76)	○	○	○	○
Woede of agressiviteit (x77)	○	○	○	○

Libidoproblemen (x78)	○	○	○	○
Stemmingswisselingen (x82)	○	○	○	○
Angst/ongerustheid (x83)	○	○	○	○
Zich down of depressief voelen, verdriet of triest (x84)	○	○	○	○
Stress (x85)	○	○	○	○
Andere (x88)	○	○	○	○
Geen symptomen (x90)	○	○	○	○

Lijdt u aan één van de volgende aandoeningen die geassocieerd kunnen zijn met de ziekte van Crohn?
(meerdere antwoorden mogelijk)

- ☐ Arthritis of gewrichtsontsteking(en) (bijvoorbeeld rug, schouders, knieën, ellebogen, polsen, handen, enkels,…) (1)
- ☐ Osteoporose (8)
- ☐ Huidletsels (bijvoorbeeld erythema nodosum, …) (9)
- ☐ Aandoeningen van lever en/of galwegen (10)
- ☐ Ogen (bijvoorbeeld uveïtis, episcleritis,…) (11)
- ☐ Chronische vermoeidheid (12)
- ☐ Fistel(s) ⓘ Een fistel is een niet-natuurlijk kanaal tussen twee lichaamsholten of tussen een lichaamsholte en de huid. (13)
- ☐ Ik weet het niet (14)
- ☐ Geen (15)

Zorggebruik en toegankelijkheid van zorg

Hebt u in de afgelopen 12 maanden bepaalde zorg voor de ziekte van Crohn niet gekregen terwijl u die wel nodig had? Dit kan gaan om een behandeling, consultatie, medische tests, revalidatie of andere.

- ○ Ja (1)
- ○ Nee (2)
- ○ Ik weet het niet (3)

Om welke reden(en) heeft u zorg die u nodig had niet gekregen? (meerdere antwoorden mogelijk)

- ☐ Afstand tussen mijn woonst en de plaats van zorg (1)
- ☐ Vervoersproblemen (geen openbaar vervoer in de buurt, geen eigen voertuig, niet in staat om eigen voertuig te besturen, niemand om u naar de plaats van zorg te brengen) (2)
- ☐ Gebrek aan bekwaam personeel om u de zorg te bieden die u nodig had (3)
- ☐ Lange wachttijden (4)
- ☐ Moeilijkheden om de zorg te betalen (5)
- ☐ Angst voor medische-, ziekenhuis- of andere onderzoeken (6)
- ☐ Tijdsgebrek door werk, kinderen of andere (7)
- ☐ Gebrek aan informatie (8)
- ☐ Taalproblemen (9)
- ☐ Andere (10) _____

Met welke zorgverlener(s) heeft u contact gehad in verband met de ziekte van Crohn?
(meerdere antwoorden mogelijk)

- ☐ Huisarts (1)
- ☐ Arts-specialist (40)
- ☐ Team van de spoeddienst (26)
- ☐ Team van het revalidatiecentrum (27)
- ☐ Kinesitherapeut (28)
- ☐ Thuisverpleegkundige (29)

☐ Verpleegkundige gespecialiseerd in inflammatoire darmziekten (30)

☐ Verpleegkundige (op consultatie in het ziekenhuis) (31)

☐ Psycholoog (32)

☐ Maatschappelijk assistent (33)

☐ Diëtist (34)

☐ Andere (41)

_____

Met welke arts-specialist(en) heeft u contact gehad in verband met de ziekte van Crohn?
(meerdere antwoorden mogelijk)

☐ Gastro-enteroloog (1)

☐ Chirurg (4)

☐ Oogarts (5)

☐ Dermatoloog (6)

☐ Reumatoloog (7)

☐ Andere (8)

_____

Hoe tevreden bent u of was u met hun diensten?

	Zeer tevreden (1)	Eerder tevreden (2)	Eerder ontevreden (3)	Heel erg ontevreden (4)
Huisarts (x1)	○	○	○	○
Arts-specialist (x40)	○	○	○	○
Team van de spoeddienst (x26)	○	○	○	○
Team van het revalidatiecentrum (x27)	○	○	○	○
Kinesitherapeut (x28)	○	○	○	○

Thuisverpleegkundige (x29)	○	○	○	○
Verpleegkundige gespecialiseerd in inflammatoire darmziekten (x30)	○	○	○	○
Verpleegkundige (op consultatie in het ziekenhuis) (x31)	○	○	○	○
Psycholoog (x32)	○	○	○	○
Maatschappelijk assistent (x33)	○	○	○	○
Diëtist (x34)	○	○	○	○
Andere (x41)	○	○	○	○

	Zeer tevreden (1)	Eerder tevreden (2)	Eerder ontevreden (3)	Heel erg ontevreden (4)
Gastro-enteroloog (x1)	○	○	○	○
Chirurg (x4)	○	○	○	○
Oogarts (x5)	○	○	○	○
Dermatoloog (x6)	○	○	○	○
Reumatoloog (x7)	○	○	○	○
Andere (x8)	○	○	○	○

Behandeling voor de ziekte van Crohn

Wordt u momenteel behandeld (of werd u behandeld) voor de ziekte van Crohn?

- ○ Ja (1)
- ○ Nee (2)
- ○ Ik weet het niet (3)

Welke behandelingen krijgt u (of hebt u gekregen) voor de ziekte van Crohn?
(meerdere antwoorden mogelijk)

- ☐ Geneesmiddel op voorschrift (1)
- ☐ Geneesmiddel zonder voorschrift (7)
- ☐ Kinesitherapie (8)
- ☐ Aanpassen van de voeding (9)
- ☐ Chirurgische ingreep (10)
- ☐ Ander (11) _____

Hoe tevreden bent u over deze behandeling(en)

	Zeer tevreden (1)	Eerder tevreden (2)	Eerder ontevreden (3)	Heel erg ontevreden (4)
Geneesmiddel op voorschrift (x1)	○	○	○	○
Geneesmiddel zonder voorschrift (x7)	○	○	○	○
Kinesitherapie (x8)	○	○	○	○
Aanpassen van de voeding (x9)	○	○	○	○
Chirurgische ingreep (x10)	○	○	○	○
Ander (x11)	○	○	○	○

Welke geneesmiddelen op voorschrift gebruikt u of heeft u gebruikt in de afgelopen 2 jaar voor de ziekte van Crohn?
(meerdere antwoorden mogelijk)

☐ Corticosteroïden Voorbeelden Bijvoorbeeld: Entocort® (budosenide), Medrol® of Solu-Medrol® (methylprednisone), Deltasone® (prednisone) (1)

☐ Biologicals Voorbeelden Bijvoorbeeld: Remicade® (infliximab), Humira® (adalimumab), Stelara® (utsekinamab), Entyvio® (vedolizumab), Cimzia® (certolizumab), (2)

☐ Immunomodulatoren Voorbeelden Bijvoorbeeld: Trexall® of Ledertrexate® (methotrexate), Imuran® (azathiopirine) (6)

☐ Aminosalicylaten Voorbeelden Bijvoorbeeld: Asacol®, Canasa®, Rowasa®, Pentasa®(mesalamine), Colazal® (balsalazide), Azulfidine®(sulfasalazine), Dipentum® (olsalazine) (3)

☐ Janus kinase inhibitors (anti-JAK) Voorbeelden Bijvoorbeeld: Cibinqo® (abrocitinib), Jyseleca® (filgotinib), Olumiant® (baricitinib), Rinvoq® (upadacitinib), Xeljanz® (tofacitinib) (4)

☐ Andere (5)
_____

Welke chirurgische ingreep heeft u ondergaan voor de ziekte van Crohn?
(meerdere antwoorden mogelijk)

☐ Chirurgische behandeling van fistel ⓘ Een fistel is een niet-natuurlijk kanaal tussen twee lichaamsholten of tussen een lichaamsholte en de huid. (1)

☐ Chirurgische behandeling van abces ⓘ Een abces is een holte gevuld met etter of pus en is vaak het gevolg van een bacteriële infectie. (2)

☐ Chirurgische resectie (wegnemen van een deel van de darm) (3)

☐ Stricturoplastie ⓘ Een stricturoplastie is het chirurgisch verwijderen van een vernauwing, zonder het wegnemen van een deel van de darm. (4)

☐ Stoma ⓘ Een stoma wordt geplaatst via een chirurgische ingreep waarbij een kunstmatige uitgang in de buikwand voor urine of ontlasting wordt aangelegd. (5)

☐ Andere (6)
_____

In welke mate is of was de behandeling(en) die u krijgt (of heeft gekregen) voor de ziekte van Crohn pijnlijk of vervelend?

- ○ Zeer pijnlijk of vervelend (1)
- ○ Behoorlijk pijnlijk of vervelend (2)
- ○ Enigszins pijnlijk of vervelend (3)
- ○ Helemaal niet pijnlijk of vervelend (4)
- ○ Ik weet het niet (5)

Om welke reden(en) is of was de behandeling pijnlijk of vervelend?
(meerdere antwoorden mogelijk)

- ☐ Door de bijwerkingen (1)
- ☐ Het dwingt me om constant rekening te houden met mijn aandoening en/of behandeling (2)
- ☐ Het vereist een strikte levensdiscipline (innemen van medicatie op vaste tijdstippen, hygiëne...) (3)
- ☐ Omdat ik deze behandeling(en) al een lange tijd volg (4)
- ☐ Andere (5) _____

Hebt (of had) u last van bijwerkingen van de behandeling voor de ziekte van Crohn?
(meerdere antwoorden mogelijk)

- ☐ Misselijkheid of braken (1)
- ☐ Constipatie (2)
- ☐ Diarree (17)
- ☐ Huidirritatie, eczeem, (3)
- ☐ Acne (4)
- ☐ Nierinsufficiëntie/problemen (5)
- ☐ Ontsteking van de lever (6)
- ☐ Nierstenen (7)
- ☐ Gewichtstoename (8)

☐ Infectie (9)

☐ Reactie op een infuus (10)

☐ Ontsteking van de pancreas (11)

☐ Verandering van uiterlijke kenmerken (12)

☐ Vermoeidheid of uitputting (13)

☐ Complicatie(s) van chirurgie (15)

☐ Andere (14)

_____

☐ Geen bijwerkingen (16)

Geef aan hoe storend elke bijwerking is of was.

	Zeer storend (1)	Redelijk storend (2)	Niet erg storend (3)	Helemaal niet storend (4)
Misselijkheid of braken (x1)	○	○	○	○
Constipatie (x2)	○	○	○	○
Diarree (x17)	○	○	○	○
Huidirritatie, eczeem, (x3)	○	○	○	○
Acne (x4)	○	○	○	○
Nierinsufficiëntie/problemen (x5)	○	○	○	○
Ontsteking van de lever (x6)	○	○	○	○
Nierstenen (x7)	○	○	○	○
Gewichtstoename (x8)	○	○	○	○
Infectie (x9)	○	○	○	○
Reactie op een infuus (x10)	○	○	○	○
Ontsteking van de pancreas (x11)	○	○	○	○

Verandering van uiterlijke kenmerken (x12)	○	○	○	○
Vermoeidheid of uitputting (x13)	○	○	○	○
Complicatie(s) van chirurgie (x15)	○	○	○	○
Andere (x14)	○	○	○	○
Geen bijwerkingen (x16)	○	○	○	○

Werkt de behandeling die u gekregen heeft tegen de ziekte van Crohn volgens u?

- ○ Ja (1)
- ○ Ja, maar enkel gedurende een bepaalde periode (4)
- ○ Neen (5)
- ○ Ik weet het niet (6)

Informatie over de ziekte van Crohn

De **hoeveelheid uitleg** die u van uw zorgverleners gekregen heeft met betrekking tot de ziekte van Crohn was volgens u:

- ○ Te veel (1)
- ○ Voldoende (8)
- ○ Onvoldoende (9)
- ○ Ik heb geen informatie ontvangen (10)
- ○ Ik weet het niet (11)

De uitleg die u van uw zorgverleners krijgt of heeft gekregen over de ziekte van Crohn en de behandeling ervan is of was:

- ○ Zeer duidelijk (1)
- ○ Redelijk duidelijk (8)
- ○ Niet erg duidelijk (9)
- ○ Helemaal niet duidelijk (10)
- ○ Ik weet het niet (11)

Hebt u bijkomende informatie gezocht of gevraagd over de ziekte van Crohn?

- ○ Ja (1)
- ○ Nee (2)
- ○ Ik weet het niet (3)

Welke bijkomende informatie heeft u gezocht of gevraagd over de ziekte van Crohn?
(meerdere antwoorden mogelijk)

- ☐ Uw aandoening (1)
- ☐ De manier waarop de diagnose is vastgesteld (2)
- ☐ De evolutie van uw gezondheidstoestand (3)
- ☐ De behandelingsmogelijkheden (4)
- ☐ Klinische studies over uw behandeling (5)
- ☐ De kosten van de behandeling en de uitgaven voor eigen rekening (die niet worden terugbetaald door het ziekenfonds) (6)
- ☐ De plaatsen waar behandeling mogelijk is (7)
- ☐ Patiëntenrechten (8)
- ☐ De toegang tot uw eigen gegevens (9)
- ☐ Patiëntenverenigingen (10)
- ☐ Beschikbare ondersteuning (11)

☐ De terugkeer naar huis en eventuele regelingen (of alternatieve huisvesting) (12)

☐ Therapeutische educatie (informatie om te leren omgaan met de aandoening en behandeling; dit omvat o.a. bewustwording, voorlichting, psychosociale ondersteuning) (13)

☐ De rechten van mantelzorgers (14)

☐ Begeleiding, psychologische ondersteuning, coaching (15)

☐ Andere (16)

_____

Geef aan in welke mate u tevreden bent over opgezochte of opgevraagde informatie.

	Zeer tevreden (1)	Eerder tevreden (2)	Eerder ontevreden (3)	Heel erg ontevreden (4)
Uw aandoening (x1)	○	○	○	○
De manier waarop de diagnose is vastgesteld (x2)	○	○	○	○
De evolutie van uw gezondheidstoestand (x3)	○	○	○	○
De behandelingsmogelijkheden (x4)	○	○	○	○
Klinische studies over uw behandeling (x5)	○	○	○	○
De kosten van de behandeling en de uitgaven voor eigen rekening (die niet worden terugbetaald door het ziekenfonds) (x6)	○	○	○	○
De plaatsen waar behandeling mogelijk is (x7)	○	○	○	○
Patiëntenrechten (x8)	○	○	○	○
De toegang tot uw eigen gegevens (x9)	○	○	○	○
Patiëntenverenigingen (x10)	○	○	○	○
Beschikbare ondersteuning (x11)	○	○	○	○

De terugkeer naar huis en eventuele regelingen (of alternatieve huisvesting) (x12)	○	○	○	○
Therapeutische educatie (informatie om te leren omgaan met de aandoening en behandeling; dit omvat o.a. bewustwording, voorlichting, psychosociale ondersteuning) (x13)	○	○	○	○
De rechten van mantelzorgers (x14)	○	○	○	○
Begeleiding, psychologische ondersteuning, coaching (x15)	○	○	○	○
Andere (x16)	○	○	○	○

Zou u meer betrokken willen zijn (geweest) bij het maken van keuzes over uw behandeling(en) voor de ziekte van Crohn?

- ○ Ja (1)
- ○ Nee (2)
- ○ Niet van toepassing (3)
- ○ Ik weet het niet (4)

Financiële gevolgen

Heeft de ziekte van Crohn financiële gevolgen (gehad)?

- ○ Ja (1)
- ○ Nee (2)
- ○ Ik weet het niet (3)

Welke financiële gevolgen heeft de ziekte van Crohn (gehad)?
(meerdere antwoorden mogelijk)

- ☐ Verlies van of gebrek aan inkomen (1)
- ☐ Verlies van werk of werkloosheid (2)
- ☐ Medische kosten (3)
- ☐ Andere (4) _____

Ondersteuningsnetwerk

Hebt u ooit hulp nodig (gehad) bij uw dagelijkse activiteiten als gevolg van de ziekte van Crohn?

- ○ Ja (1)
- ○ Nee (2)
- ○ Ik weet het niet (3)

Geef aan waarvoor u logistieke hulp nodig heeft of heeft gehad.
(meerdere antwoorden mogelijk)

- ☐ Persoonlijke hygiëne (1)
- ☐ Aankleden (2)
- ☐ Verplaatsingen (3)
- ☐ Huishouden (4)
- ☐ Bereiden van maaltijden (5)
- ☐ Kinderopvang (6)
- ☐ Andere (7) _____

Wie verleent of heeft u deze ondersteuning verleend?

- ☐ Een mantelzorger (1)
- ☐ Een professionele zorgverlener (2)
- ☐ Andere (3) _____

Hebt (of had) u door de ziekte van Crohn behoefte aan ondersteuning die **u niet gekregen heeft:**
(meerdere antwoorden mogelijk)

- ☐ Meer logistieke hulp bij dagdagelijkse activiteiten dan u momenteel krijgt (1)
- ☐ Praten met lotgenoten over de ziekte van Crohn (2)
- ☐ Praten met professionele zorgverleners (bv. Psycholoog,…) (3)
- ☐ Praten over andere zaken dan uw gezondheidsprobleem (4)
- ☐ Administratieve of sociale ondersteuning (6)
- ☐ Ondersteuning bij werkhervatting (7)
- ☐ Spirituele of religieuze ondersteuning (8)
- ☐ Andere (9) _____
- ☐ Neen (10)

Hebt (of had) u problemen om iemand te vinden met wie u in vertrouwen kan (of kon) praten over de ziekte van Crohn?

- ○ Ja (1)
- ○ Nee (2)
- ○ Ik heb geen vertrouwenspersoon nodig (gehad) om te praten over mijn ziekte van Crohn (3)
- ○ Ik weet het niet (4)

Hebt u nog andere belangrijke behoeften die niet aan bod kwamen in de vragenlijst en die u met ons zou willen delen?

- ○ Ja (1)
- ○ Nee (2)

Wat is of zijn deze behoefte(n) die niet aan bod kwamen in de vragenlijst?

_____
_____

_____
_____

Vervolg van de studie

We wensen graag dit gesprek verder te zetten omtrent uw behoeften en de moeilijkheden die u ervaart of hebt ervaren met de ziekte van Crohn. **Indien u wenst**, kunt u deelnemen aan **een individueel interview (online of ter plaatse met een onderzoeker)** om uw ervaringen en behoeften meer in detail te bespreken. Dit gesprek zal vertrouwelijk worden gevoerd en staat los van de zorg die u van uw zorgverleners ontvangt. Er zullen **24 patiënten (12 Franstalige en 12 Nederlandstalige)** worden geïnterviewd. Het individuele interview zal ongeveer **anderhalf uur** duren.

Als u geïnteresseerd bent in het interview, geef ons dan uw contactgegevens (telefoonnummer en e-mailadres) zodat we u kunnen contacteren.

○ Email (1) _____

○ Bevestig email (2) _____

○ GSM (3) _____

○ Extra GSM (optioneel) (3) _____

Bent u betrokken bij een patiëntenvereniging of discussiegroep (bv. Facebook-groep) van Crohn patiënten?

- ○ Ja (1)
- ○ Nee (4)
- ○ Wens ik niet te beantwoorden (5)

Wenst u de naam van deze vereniging of discussiegroep met ons te delen?

_____

APPENDIX 4. INTERVIEW GUIDE

Appendix 4.1. Interview guide - Dutch

Hartelijk dank voor uw deelname aan dit interview in het kader van het project "Evaluatie van de behoeften van patiënten met de ziekte van Crohn" van het Federaal Kenniscentrum voor de Gezondheidszorg.

Mijn naam is .... en ik ben ....

Het doel van ons project is om uw ervaringen en behoeften na de ziekte van Crohn te begrijpen, zodat we indien nodig verbeteringen kunnen voorstellen.

We willen dit interview graag opnemen om het gesprek te vergemakkelijken, om te voorkomen dat wat er gezegd wordt vertekend wordt en om het interview te kunnen uitwerken voor analysedoeleinden. De opname wordt gewist zodra de notities zijn gemaakt. De inhoud van de interviews wordt geanonimiseerd en er wordt geen informatie gepubliceerd waarmee de persoon kan worden geïdentificeerd.

Er zijn geen goede of foute antwoorden. Het gaat om uw ervaring en mening.

Ik zal u kort voorlezen en uitleg geven over de informatie op het informed consent formulier. Daarna nodig ik u uit om het te ondertekenen en daarna zal ik het zelf ondertekenen.

	Questions	Follow-up	Objectif
	ICE BREAKER		
1	**Hoe voelt u zich over het algemeen vandaag?**		Mensen aanmoedigen om te spreken Het interview contextualiseren
2	**Wat motiveerde u om deel te nemen aan het online onderzoek en in te stemmen met het interview van vandaag?**		
3	**Als u de ziekte van Crohn aan iemand zou moeten uitleggen, hoe zou u dat dan doen?**	- Wist je al iets over de ziekte van Crohn?	
	We willen je nu graag door jouw "diagnostische traject" leiden.		

	Questions	Follow-up	Objectif
4	**Hoe ontdekte je dat je de ziekte van Crohn had?**	- Wanneer besloot u uw arts te raadplegen? - Wie stelde de eerste diagnose? - Was de manier waarop de diagnose werd aangekondigd gepast? - Wanneer werd de diagnose gesteld en hoe lang duurde dat? - Hoelang duurde het voordat de behandeling begon (indien van toepassing)? - Bent u bij verschillende zorgverleners geweest voordat de diagnose werd bevestigd?	
5	**Hoe beïnvloedt de ziekte van Crohn je dagelijks leven?**		Contextualiser
	We gaan nu bekijken welke moeilijkheden je ervaart of hebt ervaren als gevolg van de ziekte van Crohn. We proberen ze te begrijpen voordat we kijken in hoeverre je suggesties hebt om de situatie te verbeteren.		
6	**Ervaar je gezondheidsproblemen als gevolg van de ziekte van Crohn?**	In termen van : • Symptomen? • Psychologische gevolgen (stemming, emotioneel beheer, enz.) • Sociale gevolgen? • Professionele gevolgen? • Dagelijks functioneren? • Beschikbare informatie? • ...	Vaststellen van **therapeutische, informatieve en sociale behoeften** in de breedste zin van het woord

	Questions	Follow-up	Objectif
7	**Hoe behandel je jezelf?**	– Medicijnen op voorschrift – Medicijnen zonder voorschrift – Operatie (colostomiezakje) – Dieet aanpassingen – Benodigde apparatuur – Fysiotherapie – Niet-conventionele praktijken (acupunctuur, osteopathie, homeopathie, enz.) – Psychologische ondersteuning…	**Therapeutische behoeften** identificeren
7-	**[INDIEN GEEN BEHANDELING].** **Waarom neemt u geen behandeling?**	– Geen raadpleging? ➔ Belemmeringen voor raadpleging : ○ Gebrek aan informatie over wie te raadplegen? ○ Angst om niet serieus genomen te worden ○ Angst dat gezondheidswerkers niet genoeg weten over het probleem ○ ... – Niets aangeboden – ...	Eventuele **moeilijkheden** in het **therapeutische traject** identificeren
7+	**[INDIEN BEHANDELING].**		

	Questions	Follow-up	Objectif
	a) Hoe ben je ertoe gekomen om deze behandeling(en) te nemen?		Eventuele **moeilijkheden** in het **therapeutische traject** identificeren
	b) Hoe duidelijk was het voor u wat u moest doen?		**Netwerken en informatiebronnen** over de ziekte en onderliggende behoeften identificeren
	c) Wie heeft deze 'behandelingen' geadviseerd/voorgeschreven?	– Arts – Andere gezondheidsprofessional – Familieleden – Andere patiënten via groepen – Internet – Andere	
8	**Ervaar je moeilijkheden met de verschillende behandelingen die je worden aangeboden?**	In termen van : – Doeltreffendheid? – Bijwerkingen? – Belastend? – Type aanpak (bijv. gecompartimenteerd of te globaal)? – Beschikbaarheid? – Basisprijs? – Vergoeding? – Zorg beschikbaar? – Complicaties/gevolgen chirurgie – ...	Identifier les **besoins médicaux**, **d'information** et **financiers** relatifs aux traitements

	Questions	Follow-up	Objectif
9	**In welke mate hebt u moeilijkheden ondervonden (of ondervindt u nog moeilijkheden) bij de verzorging van uzelf?**	Bv. afstand/bereikbaarheid van de plaats van zorg; logistieke hulp nodig	Identificeren van **informatiebehoeften** en eventuele **moeilijkheden in het therapeutische traject**
10	**Hoe beoordeelt u de follow-up van uw aan de ziekte van Crohn gerelateerde gezondheidsproblemen?**	*Wat gaat er voor u niet goed op het gebied van opvolging?*	De **therapeutische en ondersteuningsbehoeften** vaststellen
11	**Welke oplossingen zou u voorstellen om het beheer van uw medische problemen te verbeteren?**	– Op het gebied van behandeling – Op het gebied van follow-up en zorgverlening – Op het gebied van informatie – Op administratief gebied – Op financieel gebied	De **therapeutische en ondersteuningsbehoeften** vaststellen
12	**Ervaart u moeilijkheden in uw relaties met verzorgers?**	In termen van : – Het meest geschikte type dienstverlener identificeren – Luisteren – Respect – Serieus genomen worden – Betrokkenheid bij beslissingen – Duidelijke informatie – Toegang (wachttijd) – Basisprijs – Vergoeding – ...	**Informatie, ondersteuning en financiële** behoeften vaststellen

	Questions	Follow-up	Objectif
12'	**[INDIEN MOEILIJKHEDEN] Hoe kunnen deze moeilijkheden overwonnen worden?**	*Wat kan er gedaan worden om de situatie te verbeteren?*	
13	**Ondervindt u moeilijkheden op administratief vlak of met de administratieve diensten (ziekenfonds, RIZIV, enz.)?**	Bijvoorbeeld : – Erkenning als ziek – Vergoedingen krijgen van je ziekenfonds – Erkenning als beroepsziekte – Verzekering – ...	Identificeren van **administratieve behoeften** met betrekking tot het gezondheidszorgsysteem in bredere zin
13'	**[indien problemen ondervonden] Hoe kunnen deze administratieve problemen opgelost worden?**	*Wat kan er gedaan worden om de situatie te verbeteren?*	
14	**In welke mate voel je je gesteund bij je huidige gezondheidstoestand?**	*Welke positieve maatregelen zie je?* *Wat mis je eventueel aan ondersteuning?* *Van wie verwacht je ondersteuning die je niet krijgt?* *Wie zou je nodig hebben om je ondersteund te voelen?* – Professionals in de gezondheidszorg – Professionals in de geestelijke gezondheidszorg – Maatschappelijk werkers – Patiëntengroepen – Vrienden en familie – ...	**Ondersteuningsbehoeften** identificeren

	Questions	Follow-up	Objectif
15	**Tot slot, van alle behoeften en problemen die je tegenkomt, welke moeten volgens jou prioritair worden aangepakt door wetenschappers en/of politici?**	*Als jij een politieke (of wetenschappelijke) beleidsmaker was, welke acties zou jij dan prioriteit geven om het dagelijks leven van patiënten met de ziekte van Crohn te verbeteren?*	
	SLOT		
16	**Zijn er nog andere kwesties die volgens jou moeten worden aangepakt in verband met de behoeften waarmee je wordt geconfronteerd als gevolg van de ziekte van Crohn?**	*Welke andere elementen zijn belangrijk en moeten we weten?*	Volledigheid?

Nous vous remercions pour votre participation. Comme annoncé, cet entretien sera retranscrit, anonymisé et analysé avec les entretiens des différentes personnes que nous aurons rencontrées.

L'ensemble des résultats sera présenté dans un rapport publié sur le site internet du KCE d'ici mars 2024 https://kce.fgov.be/ .

Appendix 4.2. Interview guide - French

Nous vous remercions d'avoir accepté de participer à cet entretien dans le cadre du projet « Evaluation des besoins de patients avec la maladie de Crohn», mené par le Centre Fédéral d'Expertise des Soins de Santé.

Je m'appelle …. et je suis ….

L'objectif de notre projet est de comprendre vos expériences et vos besoins suite à la maladie de Crohn, et ce, afin de proposer des pistes d'amélioration si nécessaire.

Nous souhaitons enregistrer cet entretien dans le but de faciliter la discussion, de ne pas dénaturer les propos tenus et de retranscrire l'entretien à des fins d'analyse. L'enregistrement sera effacé lorsque les transcriptions seront faites. Le contenu des entretiens sera anonymisé et aucune information permettant d'identifier la personne ne sera publiée.

Il n'y a pas de bonnes ou de mauvaises réponses. Votre expérience et vos opinions sont ce qui importe.

Je vais brièvement vous lire et expliquer l'information du formulaire de consentement éclairé. Après je vous inviterai à le signer et je le signerai moi-même ensuite.

	Questions	Relances	Objectif
	ICE BREAKER		
1	**De manière générale, comment vous sentez-vous aujourd'hui ?**		Favoriser la parole Contextualiser l'entretien
2	**Quelles ont été vos motivations pour participer à l'enquête en ligne et pour accepter l'entretien de ce jour ?**		
3	**Si vous deviez expliquer à quelqu'un la maladie de Crohn, comment le feriez-vous ?**	- Connaissiez-vous la maladie de Crohn auparavant ?	
	Nous souhaiterions maintenant passer au travers de votre « parcours diagnostic »		
4	**Comment avez-vous découvert que vous aviez la maladie de Crohn ?**	- Quand avez-vous pris la décision de consulter ? - Qui a posé le premier diagnostic ? - La manière dont a été annoncé le diagnostic était-elle adéquate ? - Quand a-t-il été posé et combien de temps a-t-il fallu pour obtenir le diagnostic? - Après combien de temps avez-vous commencé un traitement (le cas échéant) ? - Avez-vous rencontré plusieurs professionnels de soins avant que le diagnostic ne soit confirmé ?	

	Questions	Relances	Objectif
5	**Comment s'exprime votre maladie de Crohn au quotidien?**		Contextualiser
	Nous allons maintenant passer en revue toutes sortes de difficultés que vous pouvez ou avez pu éventuellement rencontrer suite à votre état de santé en raison de votre maladie de Crohn. Nous allons essayer de les comprendre avant de voir dans quelle mesure vous avez des propositions à faire pour améliorer la situation.		
6	**Rencontrez-vous des difficultés par rapport à votre état de santé dû à la maladie de Crohn ?**	En termes de : – Symptômes ? – Conséquences psychologiques? (Humeur, gestion des émotions?) – Conséquences sociales ? – Conséquences professionnelles ? – Fonctionnement au quotidien ? – Informations disponibles ? – …	Identifier les **besoins thérapeutiques**, **d'information** et **sociaux** au sens large
7	**Comment vous soignez-vous ?**	– Médicaments prescrits – Médicaments non-prescrits – Chirurgie (poche de colostomie) – Adaptations régime alimentaire – Matériel nécessaire – Kiné – Pratiques non conventionnelles (acupuncture, osteo, homeo…) – Soutien psy – …	Identification des **besoins thérapeutiques**

	Questions	Relances	Objectif
7-	**[SI AUCUN TRAITEMENT]** **Pourquoi ne prenez-vous aucun traitement ?**	– Pas de consultation ? → Obstacles à la consultation : – Manque d'info pour savoir qui consulter ? – Peur de ne pas être pris au sérieux – Peur que les professionnels de la santé n'aient pas assez de connaissances du problème – … – Rien n'a été proposé – …	Identifier **difficultés** éventuelles du **parcours thérapeutique**
7+	**[SI TRAITEMENT]** **a) Comment en êtes-vous arrivé(e) à prendre ce/ces traitements ?**	– Médecin – Autre professionnel de santé – Proches – Autres malades via groupes – Internet – Autre	Identifier **difficultés** éventuelles du **parcours thérapeutique**
	b) Dans quelle mesure avez-vous su clairement ce que vous deviez faire ?		Identifier les **réseaux** et **sources d'infos** autour de la maladie et les besoins sous-jacents
	c) Qui vous a conseillé/ prescrit ces 'traitements'?		

	Questions	Relances	Objectif
8	**Rencontrez-vous des difficultés par rapport aux différents traitements qui vous sont proposés ?**	En termes de : – Efficacité ? – Effets secondaires ? – Lourdeur ? – Type d'approche (compartimentée par ex ou trop globale…) – Disponibilité ? – Prix de base ? – Remboursement ? – Offre de soins disponible ? – Complications/conséquences chirurgie – …	Identifier les **besoins médicaux**, **d'information** et **financiers** relatifs aux traitements
9	**Dans quelle mesure avez-vous éprouvé (ou éprouvez-vous encore) des difficultés pour vous soigner ?**	Ex : distance/accessibilité du lieu de soins ; aide logistique nécessaire	Identifier les **besoins d'informations** et les **difficultés** éventuelles du **parcours thérapeutique**
10	**Comment évaluez-vous le suivi de vos problèmes de santé liés à la maladie de Crohn?**	*Qu'est ce qui ne se passe pas bien pour vous en termes de suivi ?*	Identifier les **besoins thérapeutiques** et de **soutien**
11	**Quelles pistes de solutions verriez-vous pour améliorer la prise en charge de vos problèmes médicaux?**	– En termes de traitement – En termes de suivi et offre de soins – En termes d'information – En termes administratifs – En termes financiers	Identifier les **besoins thérapeutiques** et de **soutien**

	Questions	Relances	Objectif
12	**Eprouvez-vous des difficultés dans vos relations avec les soignants ?**	En termes de : – Identifier le type de prestataire le plus approprié – Ecoute – Respect – Prise au sérieux – Inclusion dans décisions – Informations claires – Accès (temps d'attente) – Prix de base – Remboursement – …	Identifier les **besoins d'information**, de **soutien** et **financiers**
12'	**[SI DIFFICULTÉS ÉPROUVÉES] Comment ces difficultés pourraient être surmontées ?**	*Qu'est-ce qui pourrait être mis en place pour améliorer la situation ?*	
13	**Rencontrez-vous des difficultés d'un point de vue administratif ou avec les services administratifs (mutuelle, INAMI, etc.)?**	Par exemple : – Reconnaissance comme malade – Obtention de remboursements par la mutuelle – Reconnaissance comme maladie professionnelle – Assurances – …	Identifier les **besoins administratifs** liés au système de santé au sens large
13'	**[SI DIFFICULTÉS RENCONTRÉES] Comment ces difficultés administratives pourraient être surmontées ?**	*Qu'est-ce qui pourrait être mis en place pour améliorer la situation ?*	
14	**Dans quelle mesure vous sentez-vous soutenu(e) face à votre état de santé actuel ?**	*Quelles sont les mesures positives que vous percevez ?*	Identifier les **besoins de soutien**

	Questions	Relances	Objectif
		Qu'est-ce qui vous manque éventuellement en termes de soutien ? *De la part de qui attendez-vous un soutien que vous n'obtenez pas ?* *Quelles sont les personnes dont vous auriez besoin pour vous sentir soutenu ?* – Professionnels de santé – Professionnels de la santé mentale – Assistants sociaux – Groupes de patients – Entourage – …	
15	**Pour conclure, parmi tous les besoins et les difficultés que vous rencontrez, quels sont ceux que vous estimez devoir être prioritairement pris en charge par les scientifiques et/ou les politiques ?**	*Si vous étiez décideur politique (ou scientifique), quelles actions prendriez-vous en priorité pour améliorer le quotidien des patients atteints de la maladie de Crohn ?*	
	CLOTURE		
16	**Est-ce qu'il y a d'après vous d'autres problèmes à aborder par rapport aux besoins que vous rencontrez suite à la maladie de Crohn**	*Quels autres éléments sont importants et devrions-nous connaitre ?*	Complétude ?

Nous vous remercions pour votre participation. Comme annoncé, cet entretien sera retranscrit, anonymisé et analysé avec les entretiens des différentes personnes que nous aurons rencontrées.

L'ensemble des résultats sera présenté dans un rapport publié sur le site internet du KCE d'ici mars 2024 https://kce.fgov.be/ .

APPENDIX 5. QUALITATIVE ANALYSIS CODE

Name	Description
Administrative procedures	All aspects related to administrative procedures
Insurance	All aspects related to extra (private) insurances (ex: hospitalization insurances)
Sickness fund	All aspects related to procedures with sickness funds
Other administrative aspects	All other types of administrative aspects related to CD
Communication	Aspects related to general communication around CD
Promoting well-being	All aspects related to the promotion of well-being of the patients/population at large. Ex: healthy food, sport, etc.
Raising awareness	All aspects related to awareness-raising of CD
Consequences	Consequences of the CD
Affective	Affective consequences (ex: difficulties to find a partner, tension with the partner due to the CD, impact on sex life, etc.)
Financial	Financial consequences (ex: cost of the treatment, financial difficulties because of loss of income, etc.)
Lifestyle	Consequences on the lifestyle in general
Food	Changes in food habits (ex: specific diet, non-tolerated food, appetite, etc.)
Sport	Changes in sport habits (more/less sport, choice of an adapted sport, etc.)
Travel	Changes in terms of travels (ex: travel constraints, change of habits in terms of frequency of travelling/choice of destination, etc.)
Other - consequences	Other types of consequences
Professional	Professional consequences (ex: reduced working hours, need to decline business trips, impact on career progression, stress during physical meetings, comments from colleagues, work/life balance, etc.)
Psychological	Psychological consequences (ex: depression, sadness, feeling of abandonment, need to go to a psychologist, etc.)
Social	Social consequences (ex: declining cultural activities because of CD, isolation, embarrassment towards friends, etc.)
Diagnosis	All topics related to diagnosis
Announcing the diagnosis	How the diagnosis has been communicated to the patient (incl. human aspects)?
Negative - announcement	Negative aspects on the way the diagnosis has been announced
Positive - announcement	Positive aspects on the way the diagnosis has been announced
Decision to consult	How was taken the decision to consult? Why? When? Etc.

Other - diagnosis	Other elements related to the diagnosis
Patient journey	All the steps that have been taken and that led to the CD diagnosis
Exams	Types of tests/examinations performed
First contact	First contact with a healthcare professional about the CD
Stages & routes	Steps taken by the patient, that ultimately led to the CD diagnosis?
Type of doctors	All types of doctors met during the diagnosis phase
Quality of the diagnosis	All elements related to the quality of the diagnosis
Negative - quality diagnosis	Negative elements related to the quality of the diagnosis
Positive - quality diagnosis	Positive elements related to the quality of the diagnosis
Timing	Timing between the different steps, appointment and results delivery times, etc.
Negative - patient journey	Negative aspects in terms of timing during the patient journey
Positive - timing	Positive aspects in terms of timing during the patient journey
Disease description	Topics related the description of the CD
Chronic aspect	Elements of the description of CD related to its chronic characteristics
Embarrassing aspect	Elements of the description of CD related to its embarrassing characteristics
Incurable aspect	Elements of the description of CD related to its incurable characteristics
Invisible aspect	Elements of the description of CD related to its invisible dimension
Knowledge before diagnosis	Did the person know CD before the diagnosis?
Other - disease description	Elements of the description of CD related to other characteristics
Painful aspect	Elements of the description of CD related to its painful characteristics
Follow-up therapy	How the therapy is being followed/managed
Compartmentalisation	Potential compartmentalisation in the way the therapy is organised, coordination between the different doctors, complementarity of the monitoring, etc.
Other - follow-up therapy	Other aspects related to the follow-up of the therapy
Physio	All aspects of the follow-up related to physiology
Psychological support	Any kind of psychological support offered during the therapy
Quality of the follow-up	Is the patient satisfied of the follow-up?

Relations with medical staff	What kind of interpersonal interactions with healthcare professionals?
Compassion & humanity	Aspects related to compassion & humanity when interacting with healthcare professionals
Involvement in decision-making	Feeling of being involved (or not) on the decisions related to therapy
Taken seriously	Sense of having been taken seriously (or not)
Information received	Information received (without proactivity)
Healthcare professional - info received	Information received from healthcare professionals (general information about CD, information regarding administrative actions, information about scientific progresses, new medicines, clinical trials, etc.)
Other - info received	Information received from other actors (general information about CD, information regarding administrative actions, information about scientific progresses, new medicines, clinical trials, etc.)
Patients groups - info received	Information received from patients groups (general information about CD, information regarding administrative actions, information about scientific progresses, new medicines, clinical trials, etc.)
Personal network - info received	Information received from personal network/relatives (general information about CD, information regarding administrative actions, information about scientific progresses, new medicines, clinical trials, etc.)
Infrastructures	All aspects related to infrastructures relevant in the context of CD
Access	Access to infrastructures
Parking - access	Access to parking: paying or for free, specific rights for disabled people, etc.
Place of care (hospital) - access	Access to place of care (hospital): distance, accessibility, opening hours, etc.
WC - access	Access to WC: availability, right to use it in private domain, etc.
Other - infrastructures	Other aspects related to infrastructures
Quality of the infrastructures	Quality of the infrastructures
Parking - quality	Availability of adequate parking spaces (close enough of the destination)
Place of care (hospital) - quality	Quality of the hospital infrastructures
WC - quality	Quality of the WC: cleanliness, paper available, etc.
Motivations	Motivations to participate in the survey/interview
Advancing research	Motivations related to support research/science
Helping others to benefit	Motivations related to the wish to help others benefit from their experience/ideas
Other - motivations	Motivations related to other reasons
Share experiences	Motivations related to the need to share/confide a personal experience

Search for information	Behaviours when proactively searching for information
Healthcare professionals - search for info	When turning to healthcare professionals when looking for information
Internet	When searching on internet to find information related to CD
Other - search for information	When searching for information through other channels
Patients groups - search info	When searching information through patients groups
Personal network - search info	When searching information through personal network
Scientific literature	When searching for CD related information through scientific literature/academic papers
Suggestions	All recommendations formulated by interviewed patients
Financial - suggestions	Suggestions related to financial matters
Information & awareness	All recommendations related information & awareness
General public - information & awareness	All recommendations related to information & awareness of the general public/population at large
Healthcare professionals - information & awareness	All recommendations related to information & awareness of the healthcare professionals
Infrastructures - suggestions	All recommendations related to infrastructures
Regulations	All recommendations related to regulations
Status & recognition	All recommendations related to status/recognition of the disease and its consequences
Invalidity card	All recommendations related to an invalidity card
Treatment - suggestions	All recommendations related to treatment
Support	All types of support that Crohn patients can enjoy/benefit from
Family	Support received from the family
Friends and social networks	Support received from friends and social networks
Involvement patients groups	Experiences with patients groups/organisations
Negative - patients groups	Negative aspects of patients groups
Positive - patients groups	Positive aspects of patients groups
Online communities and forums	Support received from online communities and forums (excl. patients organisations)
Symptoms	All symptoms related to CD

Flares	Symptoms occurring when flares
Post-treatment	All symptoms post treatment
Pre-treatment	All symptoms prior to the treatment
Remission	Symptoms occurring while in remission
Requiring hospitalizations	All symptoms that led to a hospitalization
Treatment	Treatment of CD
Alternative medicines	Use of alternative medicines and impact (positive or negative)
Availability	Availability of the medicines
Barriers & obstacles	All kinds of barriers & obstacles to the treatment
Coping mechanisms	Next to prescribed treatment, how to manage symptoms, emotions, etc.
Efficiency	Efficiency of the treatment
Non-prescribed medicines	Taking of non-prescribed medicines
Other - treatment	Other topics related to treatment/therapy
Prescribed medicines	Taking prescribed medication
Refusing therapy	When a person refused the therapy/to take prescribed medicine
Reimbursement	Reimbursement of the treatment
Side effects	Side effects of treatment
Temporality of the treatment	Evolutions of the treatment over time / different steps of the treatment
Frequency treatment	What is the frequency of the treatment?
Start treatment	When the treatment did start