

Identifying and understanding disease burden in patients with inflammatory bowel disease on biological therapy

Additional File 1

Identifying and understanding disease burden in patients with inflammatory bowel disease

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Table A1 Questionnaire for patients used in survey

NO#	Question	Response options
1	What type of disease, do you have?	<ul style="list-style-type: none"> - Crohn's disease - Crohn's disease with fistulas - Ulcerative colitis - Undecided
2	In what year did you get the diagnosis?	(Type in year)
3	What type of biologic therapy are you receiving?	<ul style="list-style-type: none"> - relevant trade name(s) for infliximab - relevant trade name(s) for adalimumab - relevant trade name vedolizumab - relevant trade name for ustekinumab - relevant trade name for certolizumab pegol - relevant trade name for golimumab
4	How long have you received biologic therapy?	(Type in estimated number of months)
5	Gender	<ul style="list-style-type: none"> - male - female
6	Age	(type in number)
7	Which of these symptoms and issues would you in general like to have taking care of or discuss in medical consultations with your doctor in the IBD Clinic? (choose up to 5)	<ul style="list-style-type: none"> - Stool frequency - Abdominal pain - Rectal bleeding - Urgency - Fatigue - Influence of disease on mood - Influence of disease on work - Influence of disease on daily activities - Influence of disease on sex life - Symptoms from fistulas (pain and secretion) - Pain (other than bowel pain) - Symptoms from skin, eye and/or joints - Side effects to current treatment

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		<ul style="list-style-type: none"> - Infectious disease - Discontinuation of treatment - Plan forward for the disease - Other treatment options - Test results - Research projects - Nutritional advice
8	Do you have other subjects, issues or symptoms you want to talk about with the doctor?	(type in text)
9	Which symptoms from your inflammatory bowel disease have most impact on your daily life? (choose up to 5)	<ul style="list-style-type: none"> - Stool frequency - Abdominal pain - Rectal bleeding - Urgency - Fatigue - Influence of disease on mood - Influence of disease on work - Influence of disease on daily activities - Influence of disease on sex life - Symptoms from fistulas (pain and secretion) - Pain (other than bowel pain) - Symptoms from skin, eye and/or joints
10	How do you evaluate your disease activity right now?	<ul style="list-style-type: none"> - There is activity - There is no activity
11	(branching: only if #10 = "there is activity" - To what extent do you experience activity (symptoms)?	<ul style="list-style-type: none"> - Mild symptoms - Moderate symptoms - Severe symptoms
11a	(branching: only if #11 = "there is activity" - Have you experienced remission (felt well) at any time after the	<ul style="list-style-type: none"> - Yes - No

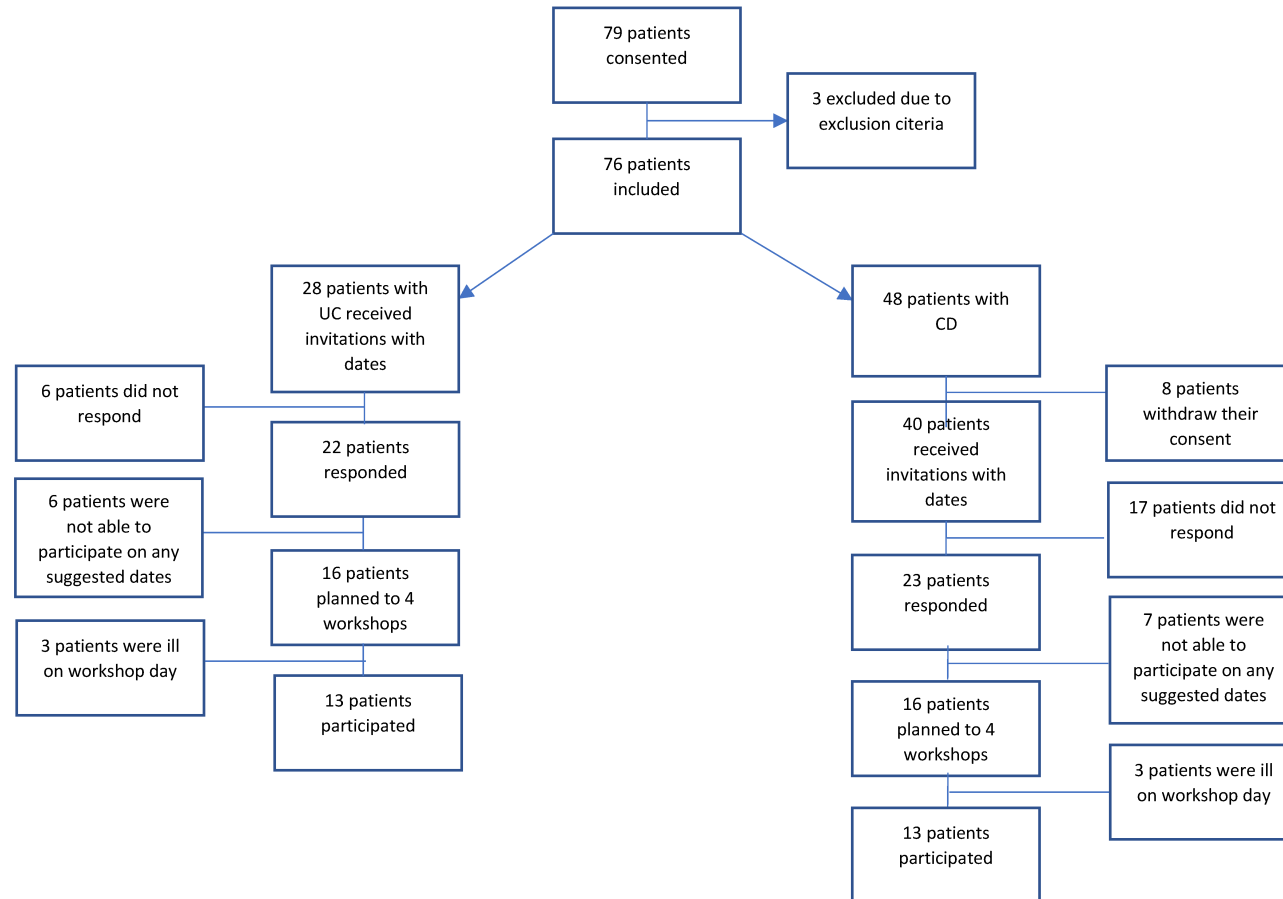
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	diagnosis of your inflammatory bowel disease?	
11b	(branching: only if #11 = "there is no activity" or 11b = "yes") - Which symptoms do you feel are absent or improve when you feel well?	<ul style="list-style-type: none"> - Stool frequency - Abdominal pain - Rectal bleeding - Urgency - Fatigue - Influence of disease on mood - Influence of disease on working life - Influence of disease on daily activities - Influence of disease on sex life - Symptoms from fistulas (pain and secretion) - Pain (other than bowel pain) Symptoms from skin, eye and/or joints

Note. The questionnaires are only validated in Danish. The English translation is not validated.

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Figure A1 Patient flow, concept mapping



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Table A2 Demographic data for non-participants (in the Group Concept mapping)

Variables	N=50^a	Comparison with participants (table I, main manuscript) (p-value)
Age , years, median (IQR)	43 (29-52)	0.432
Diagnosis		0.13
Crohn's disease	35 (70)	
Ulcerative colitis	15 (30)	
Gender , no (%)		0.47
Female	27 (54)	
Disease activity , (median, IQR)		
Harvey-Bradshaw Index, (n=31)	5 (2-8)	0.61
Simple Clinical Colitis Activity Index, (n=12)	0.5 (0-3.25)	0.05
Visual analogue scale for fatigue (0-10)	6 (3.5-8)	0.04
Patient reported disease activity , median score (IQR)		0.12
Remission	23 (46)	
Mild	7 (14)	
Moderate	13 (26)	
Severe	0	
Unknown	7 (14)	
Treatment , no (%)		0.47
Biologic	28 (56)	
Azathiopurine	7 (14)	
Combination	12 (24)	
Disease duration , years, median (IQR)	10 (4-40)	0.35

^aThree patients had complete missing data

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Table A3: All statements divided in clusters and concepts from Crohn's disease workshops

	Ratings					mean	median
	1	2	3	4	5		
IMPACT ON WORKING LIFE						3.8	4.5
Worries							
I am without a job. I couldn't take care of my previous job because of my illness	1		1	1		2.7	3
I must start in "flexjob" (disability job). Agreed on in more detail with the public services	1				2	3.7	5
Do I need something completely different in terms of work / job?		1	1	1		3	3
I have worked very hard even though I should have stopped		1		1	1	3.7	4
If I get sick again, how do I tell my boss?	1			2		3	4
What are the consequences of absence from work due to illness?			1	2		3.7	4
Understanding							
I am amazingly happy to have a boss who has full understanding of my illness				1	1	4.5	4.5
Has always had understanding colleagues	1				2	3.7	5
The future							
Can I stay on the job market?				1	1	4.5	4.5
I was studying when I got sick that made me unsure if I could complete the education	1				3	4	5
I wonder if I will be able to stay in the field as a chef	1			1	2	4.8	5
I blamed myself for living a hard life that might be the cause of my illness	1		1	1	1	3.3	3.5
I do not get the job if I say I have Crohn's		1		2	1	3.8	4
Financial consequences							
My job situation has financial consequences (e.g. pension/retirement)				1	3	4.8	5
Impact on my personal economy (keep working)				1	1	4.5	4.5
TREATMENT AND EXAMINATIONS						3.815	4.5
Does the treatment work?							
It is frightening to think about that the treatment you have received not had the expected effect				1	2	4.7	5
Have I stuffed myself with pills that did not have any effect / been necessary			1		2	4.3	5
I do not know what consequences the medicine has later on			1		2	4.3	5

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Medicine has gotten better, but is still not good enough					3	5	5
After receiving infliximab, I experience that the symptoms have diminished	1			1	1	3.3	4
I have gotten much better from biological medicine					3	5	5
Side effects							
I have experienced that there has been a worsening after I switched to zessly				2	2	4.5	4.5
I never read leaflets	2	1			1	2.3	1.5
I have had various side effects associated with different medications - takes up a lot of space				3	1	4.3	4
The side effects have been worse than my illness at times			2	2		3.5	3.5
I have sleep problems and think it started when I started biological medicine (remicade)				1	3	4.8	5
Future perspectives							
Concern about my medication works today, but what about tomorrow?							
If my medication stops working, are there then other options?				2	2	4.5	4.5
Concern about the long-term effects of the medicine on my body	2	1			1	2.3	1.5
Was told that if the medicine did not work then it was surgery				1	3	4.8	5
I would prefer to do without medication because you do not know the effect / side effects in the long term		1	1		1	3.3	3
A good life with medicine							
Humira is droplets of gold	1				3	4	5
I think it is positive that medicine has improved and developed				1	3	4.8	5
Colonoscopies							
Visits to hospitals and colonoscopies. Can see it from a positive side. as I feel I am being closely monitored in relation to other diseases			3			3	3
I have always had my colonoscopies done under anesthesia	1	1		1		2.3	2
I do not get my colonoscopies done under anesthesia - it has gone really well	2	1				1.3	1
LIFE WITH CROHN'S DISEASE						3.8	4
Impact on quality of life							
It is a fragile period in my life where my life is changing	1			1	1	3.3	4
Was very tired				1	2	4.7	5
Can I continue to be physically active				1	2	4.7	5
Can I continue to watch the sunset without being affected by illness and pain	1			1	1	3.3	4

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It is important to find out what has value to me and focus on that				1	2	4.7	5
It has helped me a lot to have solid points of reference in my life		1	1		1	3.3	3
I was expecting a change in my eating habits, but found out which food I should avoid instead		1	1	1	1	3.5	3.5
I am very happy to have considered and talked about transmission of the disease before we had children		1		1	2	4	4.5
Quality of life. Can I maintain my quality of life					3	5	5
Social events/relationships							
Can I continue to attend social events				1	2	4.7	5
Can I continue to be a father in the role I am today	1		1	1		2.7	3
Meet others my age on social media - network			2		1	3.7	3
There must be assurance that I can get to the rest room - walk in the woods	1			1	1	3.3	4
It is a limiting factor if there is no toilet where I am			1	1	1	4	4
Sometimes I have to say no to attend events or leave early due to my illness				1	2	4.7	5
I do not want to be without medicine considering how I felt before					3	5	5
It is important for me to focus on taking responsibility in relation to medication (concentration) and treatments				3	1	4.3	4
Marriage can be difficult at times (cannot make dinner etc.)			1	2	1	4	4
Questions from family and friends regarding my stomach annoys me	2	1				1.3	1
I do not bother to talk about the chronic disease - it does not change	1	2				1.7	2
Do not use colitis Crohn's websites because they only tell stories from people who are feeling much worse	3					1	1
It could be nice to talk to like-minded people and share thoughts		1	1	1		3	3
My cousin's husband has told his colleague that I'm sick - I want to decide for myself who I tell			1		1	4	4
I had no energy to be a mother in the first year (small children)				4		4	4
Consequenses for everyday life							
The symptoms vary greatly. Should I be on guard. Should I respond to altered symptoms		1	1	1		3	3
It is difficult to assess whether symptoms are severe		1			2	4	5
I had a depression (not diagnosed)			1	3		3.8	4
Fatigue takes up a lot of space				1	3	4.8	5

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Sleep deprivation and fatigue take up a lot of space				1	3	4.8	5
Some days I have a lot of pain that I can get rid of by walking (exercise so I think of something else)	1		1	2		3	3.5
I take pills to soothe the pain before I must exercise because I know that exercise is good for me	1		1	1	1	3.3	3.5
I know that exercise is good for me to get to the toilet due to intestinal constrictions			2	2		3.5	3.5
If I cannot get rid of stuck feces. I throw it up		1	2	1		3	3
Sometimes I have so much pain that I cannot move and have to lie curled up			1	1	2	4.3	4.5
I think I have a high pain threshold - that's just the way it is			1		3	4.5	5
When I have an outbreak. I have a stomachache				3	1	4.3	4
For everyday life. it is joint pain and fatigue that fills			1	1	2	4.3	4.5
I live much of my life on the toilet (it's not a burden for me)			1		3	4.5	5
When I'm on holiday. I go to bed early or had a nap. and cancel events			1	1	2	4.3	4.5
Even though I'm dead tired during the day I have to keep my body moving (otherwise awake all night)				3	1	4.3	4
The consequence of my illness has affected the lives of my children		1			3	4.3	5
I do not want to take sleeping pills. but I thought it was problematic when I have not slept and have to go to work			1		3	4.5	5
At times I cannot eat. but have to force myself to eat (angry and tired of it all)			2	1	1	3.8	3.5
No input. no output is the thought. but it is not reality		1	1	1	1	3.5	3.5
I feel like I lack personal challenges in the workplace		1		2	1	3.8	4
Has become more isolated. Do not do the same things anymore				2	1	4.3	4
I have decided not to think about getting rid of flatulence anymore. It's only 10 seconds the smell annoys others.			3			3	3
When I was not medicated, I felt healthy		2	1			2.3	2
There is a difference between working days and days off in relation to stress and stomach symptoms			1	2		3.7	4
Must always find out where there is a toilet			2	1		3.3	3
Thinks a lot about sound and smell when I go to the toilet. Can make me opt out toilets		1	1	1		3	3
Fatigue				1	1	4.5	4.5

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I feel it is unworthy, when I suddenly needs to look for a toilet					2	5	5
Feels unworthy of open toilets				1	1	4.5	4.5
I always have a little perfume in my bag to be able to spray on in toilets				1	1	4.5	4.5
I am limited in the choice of holidays and trips				2		4	4
Never use public toilets		1	1	1		3	3
lack of energy							
I do not have the same energy to be social after my illness		1		2	1	3.8	4
Lack of energy for social life is of great importance for keeping friendships	1			2	1	3.5	4
Low food map is comprehensive and completely unmanageable to get started with		2				2	2
Positive experiences							
Despite four bad days life goes on		1	2			2.7	3
Secondary gain from being ill. Care was nice!				1	1	4.5	4.5
I am well treated. which is why I do not think about having a chronic illness		1			2	4	5
I have experienced that I have been called up and I have felt acknowledge in the system					2	5	5
I have been more present with my children due to my illness (positive)				1	3	4.8	5
I use my experiences as a patient in my work (good management)			1	1		3.5	3.5
I use my empathy better after I get sick				1	1	4.5	4.5
I have become better at feeling others because I have become better at feeling myself				1	1	4.5	4.5
My illness gives me power because it takes a lot to knock me out in relation to others			1		1	4	4
ACCEPT AND RECOGNITION						4	4.5
Acceptance can be difficult							
It has been hard to accept that I am not like others		1		1	1	3.7	4
It's been hard to tell others I'm sick	1		1		1	3	3
Felxjob works well. but it's a defeat to admit to me			1	1	2	4.3	4.5
Although I have had my illness for many years. it is only now that I am accepting it		1			2	4	5
I cannot live up to educations and ambitions (it is difficult to change flex jobs)			1	2	1	4	4
On the good days flexjob is luxury and on bad days it is necessity					4	5	5
Have for a long time had a hard time accepting that I have a chronic illness			1	2		3.7	4

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Doctors thought my symptoms were worse than I myself would accept		2	1			2.3	2
Hard to accept that I have got something I do not get rid of			1	2		3.7	4
Who are you talking to - it can not be me who has got a chronic illness"		2	1			2.3	2
Acceptance of having a chronic illness				1	1	4.5	4.5
A condition of life							
I had an easier time accepting my illness because I was diagnosed as a child (living conditions)	1		1		2	3.5	4
I do not consider Crohn's as a disease, but as a life condition			1	2	1	4	4
I was asked what I could not because people were worried about me	1	1	1	1		2.5	2.5
My illness is my companion		1		1	2	4	4.5
I have gained a slightly more relaxed relationship with the functions of the body, which is why talk in plenary does not bother me		2	1			2.3	2
I do not feel that there is anything that can surprise me more				1	3	4.8	5
If I wake up in the morning and have pain then I know I'm alive		1		1	2	4	4.5
There is no guarantee in life				1	3	4.8	5
Learn to live with the disease							
You get to know your illness and yourself better over time				2	1	4.3	4
It was transgressive to have injected medicine into the blood. but the experience of feeling completely healthy 24 hours is good to tell on to new ones who must start up		1	1	1		3	3
Has had a long course before final diagnosis	1	1		1		2.3	2
It's nice to know that I'm not alone and that there are others who feel like me		1	1	1		3	3
A psychologist might be a good idea to have affiliated with the department					2	5	5
The better balance I have in my life. the better I feel about my illness					2	5	5
Losing control							
I have been ill for 21 years. I could use help to process / control thoughts					2	5	5
Need to be heard				1	1	4.5	4.5
My life was put on hold			1	1		3.5	3.5
I am controlled by something from the outside. My illness took power for a period of time				1	1	4.5	4.5
I do not have control over all the choices that have to be made				1	1	4.5	4.5
Deselecting would have been easier if I had made the decision myself					2	5	5

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I feel like I'm a number in the system					2	5	5
Doctors take control							
Feeling that the doctors are controlling my life when I get to the hospital			1		1	4	4
The doctors have my life in their hands				1	1	4.5	4.5
The doctors could do with me whatever they wanted - I was left to the doctors (while I was sick)					2	5	5
MEETING THE HOSPITAL						3.60	4
Time until diagnosis							
It took a very long time from symptom onset to diagnosis		1		1	1	3.7	4
Frustrating that I have been to a myriad of examinations on Zealand without a diagnosis. Got a blood sample taken in Jutland where they said intestinal disease		1		1	1	3.7	4
Good experiences							
The hospital takes good care of me			2	1		3.3	3
There is typically flexibility in moving agreements				2	1	4.3	4
When I get medicine there is small talk about things, I had not even thought of		1	2			2.7	3
At IBD school arranged by the hospital, I could meet like-minded people	1		2			2.3	3
The nurses are sweet				1	2	4.7	5
I have been offered a dietitian who helped me with a low food map (it did not help though)	1		2			2.3	3
If I have questions, they will be answered by the healthcare staff			1	2		3.7	4
Bad experiences							
I have several times gone from doctor appointments with an empty feeling afterwards			1	2		3.7	4
Many different doctors with changing good / bad experience		1	2			2.7	3
Constant discomfort			2	1		3.3	3
Follow-up after colonoscopy has been terrible several times. I've had a very bad time	1				2	3.7	5
My symptoms got worse. Why did it take so long before I had surgery again? Could have avoided some of the inconvenience		2			1	3	2
I'm tired of blood tests and examinations			1	1	2	4.3	4.5
Uncertainty when waking up after surgery (stoma or not) - 17 years		1		2	1	3.8	4
I feel like a guinea pig			1	1	2	4.3	4.5

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I do not always feel I get anything out of the doctor appointments. Why then should I go to all the appointments?		1		1	1	3.7	4
My illness does not stop because it is chronic (persistent contact with the hospital)				2		4	4
I miss the doctor who has followed me for 30 years and knows my medical history					4	5	5
Meeting with hospital every 3 months makes me feel sick			1	1	2	4.3	4.5
Identity theft in relation to confidentiality (give social security number in plenary)		1		1	2	4	4.5
When giving medication there are issues in plenary can be too personal		2	1			2.3	2
I often tell doctors that I have flatulence. I am always told that "there can be many reasons for this" (no explanation)		1	1	1		3	3
Asked for diet. The doctors say no	1	1	1			2	2
Have received a lot of medication that has not worked with many side effects before they found something that worked on me				2	1	4.3	4
I have been asked if my parents had rheumatic diseases. So, something is in the genes. right?	1	2				1.7	2
As soon as I ask for side effects, I am tolled to ask someone else - being thrown around the system			2	1		3.3	3
It takes a lot of energy to get to medical consultations because I myself have to keep track of my medical history			2			3	3
You sometimes feel that it is about economics					2	5	5
Is it worth giving this type of treatment?			1		1	4	4
Sometimes I think who sees all the blood samples I get taken? Are they prepared for me to come in for a consultation?				1	1	4.5	4.5
I feel that I myself must point out that I must have a treatment				2		4	4
Have the experience that medication change is the doctors' solution to my pain problems			1	1	2	4.3	4.5
Lack of flexibility							
Considering new job but considering a lot if it will fit logistically with all my appointments at the hospital		1	1	1		3	3
I wish some of the meetings could be done electronically				1	3	4.8	5
Timing of treatment in relation to jobs. Have had to make appointments several times (have many appointments)	1	1		1		2.3	2

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Distance to treatment site in regards to choice of place of residence	1	1	1			2	2
I have time off every Thursday where all my visits are booked. If I did not have that it would be stressful				3		4	4
The earliest you can get appointment is at 9 and no later than 14 o'clock. I have to take a day off every time I go to Herlev			1	2		3.7	4
Relationships to healthcare professionals							
Relationships to healthcare professionals. It is important it's a positive experience to meet the people you meet				2	1	4.3	4
Doctors have good persuasive skills; you might think afterwards			1	1		3.5	3.5
The doctors give a hope, but what is the ulterior motive				2		4	4
The meeting with healthcare professionals must not only be purely professional, but also personal			1	1	1	4	4
At Gentofte I got a permanent contact nurse who I could call to create a better relationship				2	1	4.3	4
It is very nice that it is the same doctor / nurse you meet				2	1	4.3	4
I have the opportunity to talk about everything at the doctor's appointment because it is one to one (time out where you can ask questions)				3		4	4
I have had many different doctors		1	2			2.7	3
Lack of interest for patient wishes							
Staff should gather information from patients about how experiences have been in connection with examinations		1	1	1		3	3
It could be an idea that doctors could refer to a dietitian			3			3	3
When I tell from my own experiences to hear if others experience the same thing - the answer is 'it is individual' (being shut down)				2		4	4
It's a lot about medicine when I go to consultations			1	1		3.5	3.5
If you have symptoms. it is nice to have help to be able to try dietary changes			3			3	3
COMMUNICATION WITH HEALTHCARE PROFESSIONALS							
lack of information							
There should be better information and the opportunity to give constructive criticism in connection with bad experiences – colonoscopy		1			2	4	5
I thought it was an advantage to be told in advance that one should eat pills for the rest of life (clarity about length of treatment)		1	2	1		3	3

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Have symptoms that I still cannot get an answer to	1		1	1		2.7	3
There is a lack of information that imurel has side effects such as increased sensitivity to the sun. which I would like to have from the hospital				1	3	4.8	5
minSP - lacks information about what causes a giant questionnaire	2			2		2.5	2.5
It is especially important in the beginning with solid points of reference and good information				1	2	4.7	5
Do not always get a response / information on the questions I actually have			2	1		3.3	3
The first time I heard Crohn referred to as a disease was in the meeting with a dietitian	1		2	1		2.8	3
Is there enough research in the field?					3	5	5
lack of cooperation							
It is an advantage to have the course of surgery described when you are ready / fresh to receive the description			2	1	1	3.8	3.5
You must have control of your journal yourself				2	2	4.5	4.5
I do not feel that I am heard by the doctors when you say you are in pain				1	3	4.8	5
Blood test results are too black and white: Doctors need to involve me in what I need to do to move my blood test values close to the limit values		2	1		1	3	2.5
An experience of lack of collaboration between hospital and own doctor				2	2	4.5	4.5
I do not get heard							
I found it frustrating that doctors do not believe that my sleep problems are related to my biological medicine					4	5	5
I thought you should have an overview of your illness from the start of treatment		1	1	2		3.3	3.5
I feel like I have to hit the table and say I'm still in pain				2	2	4.5	4.5
Dietitian meeting was a good initiative		1		2	1	3.8	4
I get angry when there are no public toilets compared to before where there were many more options				2	2	4.5	4.5
I have learned that all referrals start with your own doctor	1	2			1	2.5	2
There are 2 different doctor conversations: 1) about the number of treatments 2) holistic approach		1		2	1	3.8	4
I prefer a holistic doctor talk			1		3	4.5	5
Is there anything to do with my air in my stomach. I am missing answers			1	2		3.7	4
Was told I did not have that much. but with me it felt different		1	1	1		3	3

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The hospital - I do not always feel seen as a whole person			1	1		3.5	3.5
Good initiatives							
R1 = exclusive experience (professionally skilled and helpful staff)			1	1	2	4.3	4.5
Relationship with healthcare professionals is important				1	1	4.5	4.5
It creates safety to meet the same people who knows me				1	1	4.5	4.5
Lacks support from health professionals in relation to own experiences			1	1		3.5	3.5
PERSONAL EXPERIENCE WITH CROHN'S DISEASE						4	4
Clarification of my situation							
The long wait did not affect my education	1				2	3.7	5
I had a long course of illness before diagnosis. It was pure survival				1	2	4.7	5
Was very affected by fatigue but did what I was supposed to				1	2	4.7	5
I do not want generations after me to go through the same thing as me				1	2	4.7	5
Relief from being diagnosed in relation to uncertainty				1	1	4.5	4.5
Uncertainty in the time between sampling and result			1		1	4	4
How can I optimize my own experience of my visit to the hospital (my colonoscopy)			1		1	4	4
To meet other people like me							
I would had liked to meet others with the disease and the same age when I got the disease			2		1	3.7	3
Today is the first time I meet others in the same situation as my	1			2		3	4
If I had met others like me I would not have being hiding myself	1			1	1	3.3	4
Knowledge-sharing							
What can I eat and what can I drink. What should I avoid?				2	1	4.3	4
It has become easier to get answers to now what I can eat and drink		1		1	1	3.7	4
Get answers to more questions on social media				1	2	4.7	5
Knowledge sharing/collection among people with the disease				1	2	4.7	5
What works for me might works for others					3	5	5
We need to get better at sharing knowledge					3	5	5
I find it strange that I have not been offered good house advice - flea seed shells			1		2	4.3	5
I lacked good advice when I got sick				1	2	4.7	5
I was told that I should try a little to see what worked for me in terms of diet				1	2	4.7	5
It takes time and energy to seek good advice yourself. Do I have a energy to do it?	1		1	1		2.7	3

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Online journal access can be both good and bad		1			1	3.5	3.5
What is bad for me it not necessary bad for others			1		1	4	4
I interpret my test results (using google)		1			1	3.5	3.5
My test results do not always reflect how I feel					2	5	5
I feel diet has an impact on my illness and life - for consultations I get shut down when I talk about it		1		1		3	3
It takes a long time to get acquainted with search results and figure out what to go up and down		1	1	1		3	3
Part of every day							
Constant pain			1	1	1	4	4
Do not go a day without I mark for discomfort and pain	1		1	1		2.7	3
I have been embarrassed in various situations including at work			1	2		3.7	4
It does not really matter what you eat. It's hard to figure out what makes it worse		1	2			2.7	3
POSITIVE ATTITUDES						4.3	4.5
A positive approach to life							
I am relieved to have received my diagnosis			1	1	2	4.3	4.5
I'm relieved I've got my diagnosis so I can do something about it			1		3	4.5	5
It's easier to get sick as a child because you do not think about things or take a stand	1		1	1	1	3.3	3.5
As an adult. I have been given a different approach to stoma and what comes with it after surgery				2	2	4.5	4.5
I do not take into account what I eat at all even though I know the consequence. I take the consequence of what I eat / drink		2		1	1	3.3	3
Crohn's is a disease, but I do not feel sick (not "flu-sick")			2		2	4	4
I am unstoppable							
I'm a very positive human being					4	5	5
I always turn the negative into something positive				2	2	4.5	4.5
I have no worries				3	1	4.3	4
I cannot change my disease		1	1		2	3.8	4
Food / drink should not be a limitation for me at social events				1	3	4.8	5
I decide over my stomach and me				1	5	4.8	5
I do not see flexjobs, retirement and retraining as an option for me	1				3	4	5

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The future is bright, and I will not let myself be ruled by my illness	5	5		5	4	5	5
I am not a victim				1	1	4.5	4.5
SPECULATIONS AND THOUGHTS; LIFE NOW AND IN THE FUTURE						3.9	4
Worries							
I'm worried about having a chronic illness	2		2			2	2
I worry about my daughter (UC) and whether she will get as sick as me			1	3		3.8	4
I'm worried about the future	2	1			1	2.3	1.5
I'm nervous about whether my youngest daughter also gets Crohns (my second daughter has UC)		1		2	1	3.8	4
I have been nervous about whether my disease is hereditary	1			2	1	3.5	4
Do I get the old age I want?			2	1		3.3	3
How will I feel in 10 and 20 years compared to now			1	2		3.7	4
Do I get a stoma - I do not want that!			1	1	1	4	4
Do my children get it?			1	1	1	4	4
I have told my son that he should be aware of symptoms		1	2			2.7	3
It is an autoimmune disease - it can be elsewhere as well (have had it in both joints and eyes)		2		1		2.7	2
What if I get sick abroad? Both in relation to medicine or if I need surgery	1	2	3			2	2
Colonoscopes. There is always a risk associated with them - is always worried about getting them done		1	1	1		3	3
It can take two days without me going to the toilet. so why do I have to be nervous about it all the time			2	4		3.3	3
My thoughts / worries go straight to my stomach				2		4	4
Have had symptoms from other organs as well - is it something that shows up later		1	2			2.7	3
Concerns about comorbidities			1		1	4	4
Concerns about the future - how will it go?				1	1	4.5	4.5
Are even more operations expected in the future?					2	5	5
It may be that things are going well now - will it continue?				2		4	4
Do I pass the disease on to my children?					2	5	5
I'm going on a ski holiday and am worried if I can get my ski pants off before I go to the toilet			1		1	4	4

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Uncertainty haunts me - when will the disease flare up?					2	5	5
I think a lot about my illness being recurrent especially when I go for colonoscopies					2	5	5
Lack of understanding of the disease							
People's attention to my illness was fierce		1	1	2		3.3	3.5
I have never considered that fatigue can be due to my illness	1	2				1.7	2
Tired of comments like 'did you fall in the barrel' - people do not think about the meaning of it			2			3	3
I experience embarrassment when I go out of the toilet and there are others				1	1	4.5	4.5
The worst thing is that I have a couple of friends who do not have a key to the toilet					2	5	5
Worries about the future					2	5	5
According to my blood tests. I've gotten sicker. but I do not feel sick anymore	1				1	3	3
Unnecessary stress							
It's stressful that it's in your head all the time				2	1	4.3	4
It sits in my head as soon as I walk out the door				2	1	4.3	4
The family is affected by the disease							
Family. When I was hospitalized with intestinal fluke. it was the first time my children saw me sick					2	5	5
It was traumatic for my children					2	5	5
My daughter is often worried about me					2	5	5
The challenge for me is how to tackle my children's reaction to my illness					2	5	5
I could have used help in the course of the disease in relation to my children					2	5	5
My husband sees sides of me that he would not have seen if I did not have my illness				2		4	4
When it comes to intimacy with my husband. I sometimes feel disgusting when I have been to the toilet many times (minus the shower)				2		4	4
I was never naked when I had a stoma and was with my boyfriend				1	1	4.5	4.5
When I'm intimate with my husband - think if I'm going to the bathroom in the middle of it all				1	1	4.5	4.5
PHYSICAL AND MENTAL CHALLENGES/CONSEQUENCES						3.9	4
Mental influence							

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I'm afraid of getting tired which makes me sad		1		2	1	3.8	4
Periods with an insane amount of air in the stomach. It makes me isolate myself				2	1	4.3	4
I'm nervous every day that there will be air (flatulence)			1	2		3.7	4
When I get hospitalized. put on hospital clothes. I become a little girl				1	1	4.5	4.5
Hospital odor / clinical odor triggers my vomiting center			1		1	4	4
Is in a constant state of malaise due to flatulence				3		4	4
It's mentally hard for others to finish their studies and I could not finish with them				1	1	4.5	4.5
I was diagnosed with Crohn's when I went to high school. I was told I was bored. it was hard				1	1	4.5	4.5
Physical sequelae							
Lymphangiomas that liquefied - it does not look nice (it looked like I had peed in my pants)				1	2	4.7	5
One of the things that has bothered me the most is flatulence				2	1	4.3	4
Feeling constipated and that the intestinal system is completely locked. It is uncomfortable to be at a party.				2	1	4.3	4
Stomach cramps come on suddenly and it rarely comes in handy			1	2		3.7	4
Fistulas were the big problem for me	1				1	3	3
Got my fallopian tube removed due to the size of my fistulas	1			1		2.5	2.5
Fatigue and sleep							
Fatigue			2	1		3.3	3
I also has Bectherew Disease - could also be a cause of fatigue		2	1			2.3	2
Can sleep 7-8 hours. and still be tired when I several times a day		1	2			2.7	3
Waking up several times at night			2	1		3.3	3
Advices for recovery							
You do not recover from dietary changes, but it can help with symptoms			3			3	3
Consequences of the disease							
I cannot have children because I had my fallopian tube removed	1				1	3	3
I took an extra year of high school because I got sick				1	1	4.5	4.5
Feeling of injustice							
Experience of injustice when I am really affected by my symptoms					2	5	5
When I'm in a lot of pain - why does it hit me					2	5	5
When my medication has not worked. I get angry because I have become more ill			1	1		3.5	3.5

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I am good at being a chronic patient except when I am sick					2	5	5
I felt like I was getting older in a short time when I got sick (necessity)					2	5	5

Table A4: All statements divided in clusters and concepts from ulcerative colitis workshops

	Ratings				mean	median
	A	B	C	D		
COMMUNICATION WITH HEALTHCARE PROFESSIONALS					3.2	3
Lack of understanding						
Hard to explain to the doctors what they cannot see on the tests	3	2	5	5	3.8	4
The doctor must be able to understand my situation and give me personal advice on alternative options	3	4	5	5	4.3	4.5
Doctors do not acknowledge personal stories	1	3	5	5	3.5	4
The doctor must understand what it means to be ill.	1	4	5	5	3.8	4
Lack of understanding from doctors about the importance of diet	2	5	5	5	4.3	5
One must be aware of what consequences a dialogue can have	2	5	5	1	4.0	5
Necessary not to create unnecessary worry	1	1	5	5	3.0	1
Dialogue / form of communication. You have to understand who you are talking to.	1	2	5	5	3.3	2
Frustration over lack of understanding of my situation from the doctors in the outpatient clinic	4	5	5		4.7	5
Have had all experiences with the doctors - from arrogance to empathy	3	3	4		3.3	3
Lack of information						
Overview of help (public services) that can make my life easier - where can it be found	2	2	2	5	2.8	2
I do not think I have been informed about the possibilities for the chronically ill	1	1	2	2	1.5	1.5
Lack of information about plan	2	4	4	5	3.8	4
Wish I had a plan for how long I should have my medication?	2	3	4	5	3.5	3.5
Lack of information creates unnecessary worries	1	1	2	3	1.8	1.5
Information on the significance of pregnancy for the disease	1	1	1	3	1.5	1
Begins to bleed immediately upon ingestion of lactose - tried explained to the doctors	1	1	1	5	2.0	1
More clear communication to patients regarding what is "moving" in the health area	2	2	4		2.7	2
Important with information about the staff at the hospital - to create a relationship / security	2	2	4		2.7	2

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Lacks information on what is happening in the field in terms of research and treatment	3	3	4		3.3	3
The good conversation						
There has always been time to talk about something other than illness (in hospital)	3	3	4		3.3	3
It is important that there is also time to talk about other illnesses	3	3	4		3.3	3
The most important thing for me in examinations is that my doctors listen to my needs.	3	5	5		4.3	5
The dialogue with the hospital must be about something other than the treatment.	3	4	5		4.0	4
The dialogue must also be about prevention, life in general and other alternatives	4	4	5		4.3	4
Lack of communication						
Do I have to control the disease and its impact myself?	1	1	1	1	1.0	1
It does not take much before I get worried	1	1	2	4	2.0	1.5
Why does the doctor ask me what treatment I should have? (It's not me who's a doctor)	1	2	3	5	2.8	2.5
Focus on dialogue in e.g. meeting with the health service	1	4	4	5	3.5	4
I have the impression that I cannot talk to the doctors about it if I want to try cannabis oil	3	3	5		3.7	3
I do not mind different doctors if they just want to behave properly and followed the same strategy (3 doctors 3 strategies)	1	4	5		3.3	4
MEETING THE HOSPITAL					3.5	4
alternative options						
Are there alternatives to endoscopies? Would be nice to get rid of them	3	3	4	5	3.8	3.5
I must go to Herlev to have my blood samples taken - twice a week. It would save me both time and money if I could take them to Glostrup	1	4	5		3.3	4
I would like to see research done on acupuncture. Alternative treatments	3	3	4		3.3	3
The negative meeting						
Today I have changing doctors	1	1	3	4	2.3	2
Have the feeling that the doctors are not familiar with my history	1	2	2	4	2.3	2
I have been used to having a nurse. and now I have many different and it is a challenge / have to get used to it	2	4	5		3.7	4
My biggest frustration is that I see a new doctor every time I'm in the outpatient clinic. As a patient. I feel it is an production chain	3	4	5		4.0	4
At time I have seen the doctors as enemies	2	4	5		3.7	4
There is a lot of money in the pharmaceutical industry. I have doubts about the doctors want the best for me	1	2	4		2.3	2

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Lack of control over the medicine (when I was hospitalized - the systems do not talk to each other)	2	3	4		3.0	3
General concern for hospitals (what one might come across)	2	2	3		2.3	2
I'm really happy with "my" doctor. but was sorry that he was not the one to give me the results (since he knew my story)	2	3	4		3.0	3
I had an emergency visit and was met by a doctor who did not act on my problem	1	5	5		3.7	5
Was sent on (the emergency room), when she "the doctor" thought I came faster - but it did not happen (waited 6-7 hours)	1	3	5		3.0	3
Lack of cooperation between staff - were forgotten when they talked past each other	1	5	5		3.7	5
Becoming a "throwing ball" in our system (sees a new one every time)	1	4	4		3.0	4
I juggle between different doctors at the beginning of my course - who do not know me	3	4	5		4.0	4
Lack of collaboration between hospitals and hospitals / general practitioners	1	2	3		2.0	2
Internally in the ward. different doctors tell something different - creates insecurity	3	3	3		3.0	3
Before there was "control over me" I had to try all sorts of pill cures. which I had to pay for myself - very expensive	3	3	4		3.3	3
It shocked me to experience how little doctors do not keep up with new knowledge (research / experiments around the world)	2	2	3		2.3	2
the positive meeting						
There are sweet nurses on the ward	4	4	5		4.3	4
Feeling safe and well treated in the outpatient clinic	2	3	5	5	3.8	4
Important with security and closeness in the treatment	3	3	4	5	3.8	3.5
I had an ultrasound done. Nice experience that I could avoid endoscopy in the situation.	1	3	4	5	3.3	3.5
I have never experienced at Herlev that there was no time for me (doctors and nurses)	4	4	5		4.3	4
I am really happy to be at Herlev / department	3	5	5		4.3	5
Feeling cared for by coming to the ward (Herlev)	4	4	4		4.0	4
Grateful that my "needs" are recognized	5	5	5		5.0	5
In the IBD Clinic they are good at asking how "I" feel	4	4	4		4.0	4
I am seen and heard and action is taken according to what is good for me	4	4	5		4.3	4
Grateful to be able to get biological medicine	4	5	5		4.7	5
I love Ebbe - he is interested in "me" and what is important to me	1	2	3		2.0	2
After I started on biological medicine. the disease does not take up much space in my life	4	5	5		4.7	5
Creates safety						

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In the old days. I had the same doctor. Knows me. Creates security.	3	1	5	1	2.5	2
I'm glad it is the same nurses I meet	4	5	5		4.7	5
I thought there are some nurses who have been easier to work with than others	1	2	5		2.7	2
I experienced when I was diagnosed that it was the same nurse who treated me (it was reassuring)	3	4	5		4.0	4
There are no psychologists associated with this disease. It could be a good idea for a teenager who needs one to talk to	4	5	5		4.7	5
It creates security when you know the staff	3	5	5		4.3	5
Must work towards getting the same doctor	4	4	4		4.0	4
It is only after I have entered biological treatment (outpatient clinic) that I have become safe	4	4	4		4.0	4
In the outpatient clinic. it is familiar faces I meet - create security for me	4	4	4		4.0	4
At the beginning of the process. you do not "necessarily" know what you need (mentally - in terms of what it is about)	3	4	5		4.0	4
Opportunity to get affiliated with a psychologist	3	3	3		3.0	3
I also have low metabolism and am not fully aware of what is what (side effects)	1	3	4		2.7	3
I have to feel like they want the best for me	3	4	5		4.0	4
CONCERNS AND CONSEQUENCES					3.2	4
Worries about the future						
Do I need to choose not to have children due to my illness - can I handle it?	1	1	3	4	2.3	2
Constant worry about when the disease will return	3	4	5	5	4.3	4.5
I'm worried about whether I can have children / have more children	1	1	3	4	2.3	2
You are very worried about a lot of things when you have the disease	2	2	3	4	2.8	2
What are the treatment options in the future	2	4	4	5	3.8	4
I think more about the future now than I did before I got sick	1	3	4		2.7	3
What does my future look like?	3	4	4		3.7	4
I may be worried about my children getting the same disease as me	1	3	5		3.0	3
It's not a disease that has been in my family before me, so I'm worried about my children being at risk	3	4	5		4.0	4
I prefer not to hear about bad stories because they affect me and I can get scared	1	1	3		1.7	1
How do I feel, when I get old in 20 years?	1	5	5	5	4.0	5
The worries can have a negative effect on your illness	4	4	5		4.3	4
Worries about symptoms						

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Worries about blood in the stool	1	2	2	5	2.5	2
Great pain due to air in the intestines. Why do I get it. Missing answer	1	1	1	5	2.0	1
Googled symptoms that told that blood in the stool could be internal bleeding and became concerned	1	1	1	1	1.0	1
Worries about medicine						
What if my medication does not work? What is the next step?	1	4	4	5	3.5	4
Sequelea						
Is there a connection between my diseases?	1	1	3	5	2.5	2
Concerns about sequelae	2	3	5	5	3.8	4
I worry about whether it develops into more / other autoimmune diseases	2	4	4		3.3	4
What other things do I attract when I'm already sick (when I receive immunosuppressive medication)	2	3	4		3.0	3
Consequences at worsening						
Concern for my health. What does the disease bring (surgery)?	2	4	5	5	4.0	4.5
Concern for surgery. Does it heal? Or do I get other diseases?	1	4	5	5	3.8	4.5
If the disease develops. what then?	2	3	5	5	3.8	4
If I get a really big outbreak I can then risk dying if I do not get the right help in time	4	4	5		4.3	4
Can I plan ahead? I do not know what triggers a flare	1	2	5		2.7	2
Anxiety about surgeries and being hospitalized	2	2	5		3.0	2
The fear of ending up in another ward (possibly medical)	1	2	2		1.7	2
Uncertainty about the disease						
Anxiety about increased risk of bowel cancer	2	3	4		3.0	3
What triggers the disease?	1	5	5	5	4.0	5
The uncertainty about where I am in my course of illness and treatment - how many shots are in the box?	4	4	5	5	4.5	4.5
Intestinal force?	1	3	3		2.3	3
Stoma?	3	3	3		3.0	3
I'm wondering if my illness can develop into cancer	2	4	4		3.3	4
Biggest fear is stoma	2	5	5		4.0	5
I'm worried about whether it's going to develop into cancer - do not any more	1	4	5		3.3	4
Is it hereditary? Am very afraid that my children will get the disease	4	5	5		4.7	5
Do you pass on the disease?	4	5	5		4.7	5

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In the past. I was afraid that my illness would control my future plans. Christmas Eve.	3	4	4		3.7	4
Worry about what is the worst thing that can happen	2	3	4		3.0	3
I worry if it's hereditary - my children	2	2	4		2.7	2
WORKING LIFE					3.4	4
Worries about working life						
When should I tell my employer that I have my illness ("should" vs. "have to" say it)	1	1	2	3	1.8	1.5
Concerns for my future working life	1	4	4	5	3.5	4
Concerns about future job opportunities	1	4	4	5	3.5	4
Flexjob (disability job) - whether it is an option in the future	2	2	4		2.7	2
Can I do a normal job - full time in communication	3	5	5		4.33	5
I can imagine that it is a challenge to get a new job due to section 56	1	4	4		3.0	4
When I have to look for a new job - will someone hire me with my illness?	3	4	4		3.7	4
It is worrying that you do not know how flexjobs (disability job) will be distributed (are you entitled to it)	3	4	5		4.0	4
I'm worried about my retirement fund	2	3	5		3.3	3
I do not think I can work until I turn 72 due to challenges with my illness	2	3	4		3.0	3
Even though I do not have a physically hard job. I am chronically ill and therefore it feels like a long prospect of retirement	3	4	5		4.0	4
How does the disease develop - can I take care of my work / career	4	4	5		4.3	4
Can I keep working?	3	5	5		4.3	5
What can I do. if I can't keep my job... the future.	3	4	5		4.0	4
How do I explain to a new employer that I am chronically ill?	2	3	4		3.0	3
No consequences for working life						
The disease has not had a consequence for my work	1	3	4	5	3.3	3.5
Public services relations						
You cannot see my disease (opportunity for flex jobs and cooperation with the public services)	3	3	4		3.3	3
Paragraph 56: my place of work is reimbursed when I am unable to work	3	4	5		4.0	4
I have to write a lot with the public services	1	3	3		2.3	3
The demand from the unemployment system meant that I could not find myself in it at all - the demands were too great in terms of having a chronic illness	1	2	2		1.7	2
Consequences for working life						
I have realized that I am losing my job	2	5	5		4.0	5

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I really want to work. almost more after I got sick	2	3	4		3.0	3
I want to show that I can still and will strike	4	4	5		4.3	4
I work twice as hard after my illness (I have to put more work into it)	3	4	5		4.0	4
I always have to think one extra time	3	4	4		3.7	4
Negative/bad coworker relationships						
After many years at the same workplace. I have experienced that I have now got an incomprehensible boss who has led me to go to sick calls	4	4	5		4.3	4
My workplace questions my illness	2	3	4		3.0	3
My workplace does not use their option (section 56 (extra work pressure on employees))	2	3	5		3.3	3
I have experienced a work pressure which has meant that I have been reported sick	2	3	4		3.0	3
Positive relationships to coworkers/work place						
I have a good and flexible workplace which is understandable (I can work from home)	4	5	5		4.7	5
My colleagues/work place are considered for me	3	4	5		4.0	4
I have a very understanding workplace	4	4	5		4.3	4
I can always get time off if I need treatment etc.	4	4	5		4.3	4
It should not affect others that I am ill, so it should not be a problem that I should have a job	3	3	4		3.3	3
I cannot stand others have to pay for me to go home	2	2	3		2.3	2
The influence of the disease on working life						
I cannot do the same things I could	3	3	4		3.3	3
Memory is a challenge compared to before (before illness I had sticky brain)	3	3	5		3.7	3
Before I could do everything at once. I can no longer do that	3	4	4		3.7	4
Influenced me (I was broken down) by being a part of unemployment (became more and more ill)	1	2	3		2.0	2
I work hard and I'm done when I get home	3	3	4		3.3	3
Irritation about being the one who is often sick	2	2	3		2.3	2
EVERYDAY LIFE WITH COLITIS					3.6	4
To live with the disease						
Has been on off sick for 10 years	2	5	5	5	4.3	5
You can feel your body in a completely different way - you get to know your body	1	4	4	4	3.3	4
Constant strain on the body and psyche to be on off sick	2	3	5	5	3.8	4
I do not have to go to the toilet so often after I have received my medicine - I am no longer dependent on nappies	1	1	5	3	2.5	2

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The disease is involved in many considerations - everyday life. travel. vacation	2	3	4	5	3.5	3.5
I am reminded of my illness every day	3	4	5		4.0	4
I thought it went better in the summer (it's rare I'm erupting in the summer)	1	4	5		3.3	4
I often have flare-up in the winter	1	4	5		3.3	4
I cannot contain negative stories (facebook)	1	2	4		2.3	2
Pain affects me mentally every single day	3	5	5		4.3	5
Football was my identity	4	5	5		4.7	5
It is individual how the disease affects one	4	4	5		4.3	4
I think about the situations I put myself in	4	4	5		4.3	4
I can get very frustrated when I cannot find cause for exacerbation	4	4	5		4.3	4
When you are a teenager. it should be fun. It's not fun to be sick.	4	4	5		4.3	4
Teenagers do not have the empathy to understand me and put themselves in my place	3	4	5		4.0	4
Feeling limited by my illness	3	4	4	5	4.0	4
Why it is important to want to be near a toilet or why you eat what you do.	2	3	4		3.0	3
Limitations due to the disease						
I may feel limited even though I am well treated	1	1	3	4	2.3	2
I have many toilet visits (45-47 times a day)	2	5	5		4.0	5
Is completely drained of energy to hold	1	2	4	5	3.0	3
I'm not going anywhere if I'm having a flare	3	4	4		3.7	4
I feel limited by my illness	1	4	5		3.3	4
I can no longer play football due to my illness	3	4	5		4.0	4
My daily life is interrupted by all my hospital visits	2	4	5		3.7	4
The time spent in hospital I never get back	4	5	5		4.7	5
Family life						
What do my children think about the diseases - why should my father go to the hospital	1	4	4	4	3.3	4
I have no energy when I get home to be with family	3	4	4		3.7	4
It feels like a defeat I will have to hire cleaning help to make everyday life work	1	1	3		1.7	1
I am a mother who would like to be able to handle it all myself. home baking. etc.	3	4	5		4.0	4
Practical issues						
The disease is very unpredictable in terms of organization	1	3	4	5	3.3	3.5
The disease requires daily organization	1	3	4	5	3.3	3.5
Can I go to the toilet? I should have had a diaper with me	1	1	3	5	2.5	2

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General challenge in everyday life. Where is the toilet.	3	4	5	5	4.3	4.5
Open toilet stalls are degrading to us	2	3	4	5	3.5	3.5
Frequent toilet visits	4	5	5		4.7	5
On a normal day I still have to go to the toilet many times (more times than ordinary people)	3	4	5		4.0	4
I must always consider in what situation I put myself in. Use of toilet. Transport	5	5	5		5.0	5
Symptoms						
Fatigue	2	3	4	5	3.5	3.5
Joint pain	2	4	4		3.3	4
Fatigue - gives everything at work. but can no longer bear when I get home	3	4	5		4.0	4
It hurts to refrain from having stool	1	2	4	5	3.0	3
The worst thing about the disease is the pain	1	1	2	5	2.3	1.5
Sore joints and abdominal pain	2	5	5		4.0	5
THE INFLUENCE AND IMPORTANCE OF DIET					3.0	3
The influence on everyday life						
Learn from doctors that diet does not affect the disease	1	2	4	5	3.0	3
When I take lactase pills. lactose is no problem	1	1	1	2	1.3	1
I am overly aware of illness and what I eat and drink - bad conscience	2	4	4	5	3.8	4
I think a lot about what I eat (what foods)	2	3	4		3.0	3
Diet can affect the disease	3	4	5	5	4.3	4
I have never before spent so much time on food before my illness	2	3	4		3.0	3
My relatives cook food that I can eat	1	3	4		2.7	3
I eat lactose free diet (dairy products challenge the stomach)	1	1	4		2.0	1
Lack of understanding						
Confusion about diet. There is a lot of contradictory information	3	4	4		3.7	4
The diet challenges						
I will have to cook all the food from scratch - positively	1	2	4	5	3.0	3
I have to constantly make sure that there is something I can tolerate / eat	2	3	4		3.0	3
I have an illness that makes me need to know what to eat for an event (packed lunch / eat from home)	2	3	4		3.0	3
It is a challenge that the food I can tolerate changes in different outbreaks	2	3	3		2.7	3
There are foods that are a challenge that I avoid eating	3	3	5		3.7	3
Knowledge sharing						

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Lack of knowledge sharing about what other patients experience in relation to diet	3	3	4	5	3.8	3.5
More information on what diet can do	1	3	5	5	3.5	4
I've been advised by the hospital about diet	1	2	3		2.0	2
What alternative options are there (diet. stress. meditation. etc.)	3	4	4		3.7	4
The best advice for me is to try foods on my own body (advice from a dietitian did not work for me)	2	2	3		2.3	2
TAKE RESPONSIBILITY FOR AND CONTROL OF YOUR OWN LIFE					4.0	4
Accept						
I have to accept the things I can no longer do because of my illness	3	4	4		3.7	4
There is no one wiser than myself on my illness.	3	5	5		4.3	5
Calm in life. Calm in the disease.	4	5	5		4.7	5
If the worst happens. it's a condition I can not control. but can I can control how I relate to it	4	5	5		4.7	5
My focus is on a healthier. more balanced life. I am convinced that it has a positive effect on my life regardless of the effect of the medicine	5	5	5		5.0	5
I have to choose the positive things in life	4	5	5		4.7	5
The way you talk about illness is important for how you relate to your illness	4	5	5		4.7	5
How long can one keep the idea that it is "me" who decides over life and not the disease	2	3	5		3.3	3
I have come there to accept my illness	4	4	4		4.0	4
I have learned to live with the fact that there is never anything that is safe (the influence of the disease - had booked travel - did not leave).	3	4	5		4.0	4
Be mentally strong to get a bowel disease	4	4	5		4.3	4
The disease has also been an eye opener - generally in terms of how you want to live your life	4	4	5		4.3	4
No worries						
I'm not worried about my illness (I do not die of it)	2	3	3		2.7	3
I can do it						
Have the experience that I can do something myself that helps with my illness	2	3	5	5	3.8	4
It does not help me to be sad all the time (you have to find something positive)	2	3	4		3.0	3
When I can get rid of all the work and worries. I feel healthier	3	3	5		3.7	3
I do not let the disease stop me in relation to holidays. Assures me that my insurances cover	2	3	4		3.0	3
I do not let my illness limit me in anything	5	5	5		5.0	5
Short vacations, car vacations in Europe. If I get an outbreak. I'm fine	2	4	4		3.3	4
It's not the doctors who give me knowledge.	1	3	4		2.7	3

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I have found all the information about diet, medicine and the psyche myself	2	3	4		3.0	3
For weeks I have written down what I eat / exercise. No pattern if symptoms	1	3	4		2.7	3
I've found a pattern. Work / stress related	4	4	5		4.3	4
I think a lot about whether there is something in life that needs to be changed to make the disease better. Occupation. Family or something.	4	4	4		4.0	4
What can I investigate and do myself	3	3	5		3.7	3
I've been researching cannabis oil	2	3	5		3.3	3
I have had contact with 2 Chinese acupuncturists who think they can help. but there is no subsidy for the treatment - too expensive	2	3	4		3.0	3
I must not just ignore my worries. but must process them. If that happens. then what's the worst?	4	4	4		4.0	4
When the disease breaks out. that's where I'm best at doing something good for myself	4	4	5		4.3	4
Diet, exercise and mindfulness are good for me	4	5	5		4.7	5
I want to prioritize myself more. even in the good times	3	5	5		4.3	5
It has been important for me to find values other than before and in the course of the disease	4	4	5		4.3	4
Laughter is healing	2	5	5		4.0	5
It is important that you get out of the victim role. otherwise you do not have a life	5	5	5		5.0	5
It is the disease that must live with me and not the other way around	5	5	5		5.0	5
The more positive you are the less ill you are	5	5	5		5.0	5
The psyche and the physical are connected	4	5	5		4.7	5
Focus on what makes you happy	5	5	5		5.0	5
Take responsibility for your own life	5	5	5		5.0	5
Refuses to let me be limited	5	5	5		5.0	5
Positive experiences						
I have become calmer after I got my illness	1	1	3		1.7	1
I have become more thoughtful after I got my illness (the boulder bass is tamed)	1	1	3		1.7	1
I have chosen that it is good for me that I am calmer now	1	1	4		2.0	1
The disease has fostered my curiosity and fostered my knowledge	3	4	5		4.0	4
The disease has created self-awareness that has given me completely different values than my peers	1	5	5		3.7	5
I do not want to be without of my course - I take better care of myself.	4	5	5		4.7	5
Worries should not get stuck in your head and make things worse	4	5	5		4.7	5

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Time is the most precious thing in life	5	5	5		5.0	5
Support is important	4	5	5		4.7	5
It's nice to find out how good you really are	2	4	5		3.7	4
Openness about the disease						
Openness creates strength	4	5	5		4.7	5
At work. in the family. they know when I go to the hospital. the toilet. etc. (openness)	3	4	5		4.0	4
It has given me a great free space that I can talk (humorously and seriously) with my wife about the disease. She is a health professional and understands the seriousness of the disease	5	5	5		5.0	5
It's important to tell the good stories	2	5	5		4.0	5
Important to share that I have a good life and that the medicine helps	3	4	5		4.0	4
It gave me hope to talk to someone else with a similar illness	2	4	5		3.7	4
We need hope	1	5	5		3.7	5
In order to obtain support. one needs to be open	3	4	5		4.0	4
It's nice for me to talk to others with colitis	2	4	5		3.7	4
PROMOTE UNDERSTANDING OF MY DISEASE/SITUATION					3.4	3.25
Feeling alone						
Feeling alone. It is constantly me who feels and feels my illness.	2	3	4	5	3.5	3.5
It is degrading not to be able to hold on	2	4	4	5	3.8	4
People have no understanding that I use the disabled toilet when I do not look handicapped	1	2	4	5	3.0	3
It is a taboo disease	2	3	3	5	3.3	3
Stigmatization. One must be pre-approved by insurance companies in connection with travel	1	2	3	3	2.3	2.5
The more you hide it the more vulnerable you become (risk of being exposed)	3	4	4		3.7	4
No understanding						
Lack of understanding from teachers	3	4	5		4.0	4
Lack of understanding from the outside world. I do not look sick. Stamped. Being put in stalls.	3	3	4	5	3.8	3.5
Importance of relationship						
Important about networking. Understanding of each other's situation.	2	3	4	5	3.5	3
One is surprised of how many people have an intestinal disease	2	3	4		3.0	3
It has actually been a gift for me to be part of the facebook group (openness "together with" other like-minded people)	2	2	2		2.0	2
When I was diagnosed there were no "groups"	1	2	2		1.7	2
There are some strong arms that can "hold" me / grab me (not necessarily health professionals)	3	5	5		4.3	5

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Make a mentor course - one who has been through the process (early in the course - the time of diagnosis)	3	3	5		3.7	3
Openness about the disease						
Promote the understanding of the consequences of the disease (eg toilet visits)	3	4	4		3.7	4
Destroy the taboo around the disease - tell your surroundings about it	3	4	4		3.7	4
Share experiences with like-minded people	4	4	5		4.3	4
It is important to say "how you really feel" - and put all that about toilet visits on the shelf	3	3	4		3.3	3
ACCEPT AND RECOGNITION					3.5	4
Accept						
I do not feel sorry for myself	2	3	5		3.3	3
You must realize that you have to stop being a victim	5	5	5		5.0	5
Accept of what I cannot do when having the disease	3	4	5		4.0	4
Accept can be difficult						
I have to tackle that it's forever. Accept.	3	3	4	5	3.8	3.5
It is hard to take in that the disease is for the rest of your life	3	3	4	5	3.8	3.5
I have built up an inner anger	1	2	5		2.7	2
I have to seek professional help due to my anger	1	1	4		2.0	1
Why me?	2	4	4		3.3	4
I have a hard time accepting that I have a disease that has control over me	5	5	5		5.0	5
I was raised to handle everything myself. It is now difficult for me to ask for help.	3	4	4		3.7	4
Recognition						
I do not feel I am enough	2	3	3		2.7	3
Others who do not have my illness do not understand how I feel	3	4	4		3.7	4
Am I good enough?	5	5	5		5.0	5
Loneliness						
I have never been as sad as I have been in recent years	1	1	5		2.3	1
I feel like I'm a burden	2	4	4		3.3	4
Deep down, you do not want to be left alone with your illness	3	3	5		3.7	3
You're being excluded - also by yourself. You don't feel like there is room for yourself and the disease in other people's life	2	4	5		3.7	4
I can see that it becomes too much for people, so I exclude from my life	3	4	5		4.0	4
Do you ever make close friends? You always have some friends	4	5	5		4.7	5

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Consequences						
My anger goes out to the wrong (my closest)	1	1	5		2.3	1
My illness means I do not live as I would like. Necessarily.	1	5	5		3.7	5
It's hard for me to laugh. My illness has made me withdraw into myself and not express if any funny happens	3	4	5		4.0	4
When I am under pressure. it triggers the disease	4	5	5		4.7	5
It's all the time planning and structuring. It's awful.	1	5	5		3.7	5
The more you say you are sick. the more sick you become	4	5	5		4.7	5
Openess about the disease						
I have never met anyone who has colitis before today	1	4	5		3.3	4
It's hard to talk to others about my illness	2	4	5		3.7	4
I would like to be able to one day write about the good stories	1	1	4		2.0	1
RELATIONSHIPS/FAMILY//SOCIAL LIFE					3.2	3
Vacation limitations						
Concerns about vacations opportunities	1	4	4		3.0	4
Feeling limited by my illness e.g. in connection with the choice of travel destination	1	1	1	4	1.8	1
There are many holidays I cannot go on due to my illness	2	3	4		3.0	3
Concerns about whether I can only go on holiday far away from the toilet and the health service	2	4	4		3.3	4
Travel insurance in connection with travel	3	4	5		4.0	4
Long flights are a challenge	1	3	3		2.3	3
If I am under investigation in the hospital for a (new) medicine. the insurance company have rules on where I can go on holiday	1	3	3		2.3	3
I am often reminded of my illness as there are places, I am not allowed to go	2	4	5		3.7	4
Long travels in the world where the hospital system is not near by give many worries / thoughts every day	3	4	5		4.0	4
Influencing social events - Traveling to New York (Insurance Challenges / Limitations)	2	3	3		2.7	3
Have not previously thought about possible restrictions on freedom (activities. etc.)	1	4	4		3.0	4
Everyday life						
Not a day goes by where I do not think about my illness	3	5	5		4.3	5
I can see how much the disease has affected my life (negative)	1	2	2		1.7	2
Guts are just not sexy	1	3	3		2.3	3
Except it's getting it now?	3	3	4		3.3	3

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Influence on family life						
I'm worried when my kids just have a stomach infection even though it's not dangerous	3	3	3		3.0	3
It is a pressure on my family that I have a chronic illness	2	4	4		3.3	4
I do not have the same energy when I come home from work. to do extra other than prioritize the family (no trip to the amusement park in the evenings)	3	3	4		3.3	3
Feeling that the disease has made me an adult prematurely. but is still dependent on my parents	1	3	5		3.0	3
My brothers are more independent than me. The disease has limited me to being completely self-sufficient	1	3	4		2.7	3
I cannot talk about everything with my family. They are family. They have no choice but to love and include me	3	3	5		3.7	3
In my family you are not allowed to say that you do not "feel like it"	3	5	5		4.3	5
Family and friends may push in the right direction	4	4	5		4.3	4
Worry about whether I can take good care of my children	4	4	4		4.0	4
Lack of understanding						
My peers have not been through similar difficult phases as I did. They are not yet aware of serious situations	3	4	5		4.0	4
I'm not embarrassed. but I do not like that people are curious. and that they really do not want the best for me	3	3	5		3.7	3
My illness is being used as an excuse for "not wanting to"	3	4	5		4.0	4
Social events can be a challenging						
Family events with accommodation I say no to	2	3	5		3.3	3
I'm not spending the night out anymore	1	2	5		2.7	2
It can be difficult with social activities during periods (during outbreaks)	4	4	5		4.3	4
Cycling and everyday activities are a challenge	1	3	4		2.7	3
I am constantly on the lookout for activities and foods in my everyday life (can I handle this excursion)	3	4	4		3.7	4
I always have to pay attention to where there is a toilet and it limits me	3	4	4		3.7	4
I'm not going to the cafe if I'm in an outburst	3	3	4		3.3	3
Influence on love life - is one attractive?	2	3	3		2.7	3
What to do from here - is it easier to be alone (single)?	2	2	2		2.0	2
Circus around finding a new boyfriend - I could hardly stand it	1	2	2		1.7	2
Are you good enough to get a new boyfriend/girlfriend?	2	2	3		2.3	2

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When and how to tell it - takes up a lot of space	1	2	3		2.0	2
This is not the first thing you talk about at a social event	1	4	4		3.0	4
Influence on leisure activities - considerations regarding sailing (toilet access etc.)	3	3	3		3.0	3
Have had to stay home in stead of going to social events	4	4	4		4.0	4
I like to sign up for events. but I am aware that I may need to stay home	1	4	4		3.0	4
Openness about the disease						
Only after a few years could I speak openly about my illness and ask others for help	3	5	5		4.3	5
People who are not sick need to hear about the disease from someone other than the sick person to understand the situation	3	4	5		4.0	4
MEDICATION					3.9	5
Side effects						
Thinking about if medication has an impact on a poor memory	3	3	4		3.3	3
Concerned about long-term drug side effects	3	5	5		4.3	5
I am worried that if my liver numbers get elevated by my medication and whether my liver stays damaged if I stop my medication	3	4	5		4.0	4
Imurel increases time to healing. The physicians cannot answer whether it also prolongs recovery of other tissues (muscles / training). Persistent concerns.	1	2	3		2.0	2
The future						
Future treatment options - I do not know which opportunities I have in the future	3	5	5		4.3	5
Do you run out of treatment options (medicine)?	4	5	5		4.7	5
When I switched to my current medication I was told that it was the last option (luckily there is more on the way)	3	5	5		4.3	5
I am hoping for a miracle - a cure!	5	5	5		5.0	5
I hope I can get well again	5	5	5		5.0	5
Worried that the medicine will stop working. as my friend has experienced this after 2 years with good effect	5	5	5		5.0	5
My biggest concern is whether it will be taken from me again (the medicine)	3	4	5		4.0	4
I have been told that I may have to stop taking the medicine - I do not want that at all	4	5	5		4.7	5
Afraid to stop taking the medicine - think if it comes back	4	5	5		4.7	5
Avoid medication						
Is willing to do and try a lot to get rid of medication	3	4	5	5	4.3	4.5
I get a lot of medicine every day that I would like to be without	3	5	5		4.3	5

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All that rubbish (medicine is annoying)	3	5	5		4.3	5
If I can get rid of Imurel then it's going to be great. Possibly try something else	2	3	5		3.3	3
The effect of the medication on the body						
What effect will the medicine have on my future health? Concerns.	1	3	3		2.3	3
Because the medicine is new, we do not know how it will affect my body in 20 years	1	3	3		2.3	3
We get medication that only relieves symptoms. It does not cure the disease. It is frustrating.	4	4	5		4.3	4
Positive attitudes towards medication						
I'm fine with the medicine I'm getting	1	2	4	5	3.0	3
Infliximab helps a lot	1	4	5		3.3	4
I am very happy with Imurel (asymptomatic)	1	1	4		2.0	1
Very happy with the existing medicines	4	5	5		4.7	5
The medicine worked	4	5	5		4.7	5
Had tried a lot before (other than biological) which did not work	3	4	5		4.0	4
Does the medication work?						
I do not know how I can tell if my medicine is working or not	1	1	1	5	2.0	1
I worry about whether my medication will continue to work	5	5	5		5.0	5
If my medication does not continue to work - what then?	4	5	5		4.7	5
When does the medicine stop working?	5	5	5		5.0	5
What will another outbreak phase mean for family, work life and social life? Concerned about the medication stops working.	2	3	5		3.3	3
Is there any other medicine that is better for me and works just as well	3	3	3		3.0	3
I'm worried if the medicine stops working	5	5	5		5.0	5