Patient attitudes towards faecal sampling for gut microbiome studies and clinical care reveal positive engagement and room for improvement

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Abstract

Background: Faecal sample collection is crucial for gut microbiome research and its clinical applications. However, while patients and healthy volunteers are routinely asked to provide stool samples, their attitudes towards sampling remain largely unknown. Here we investigate the attitudes of 780 Dutch patients, including participants in a large Inflammatory Bowel Disease (IBD) gut microbiome cohort, and population controls, to identify barriers to sample collection and provide recommendations for gut microbiome researchers and clinicians.

Methods: We sent questionnaires to 660 IBD patients and 112 patients with other disorders who had previously been approached to participate in gut microbiome studies. We also conducted 478 brief interviews with participants in our general population cohort who had collected stool samples. Statistical analysis of the data was performed using R.

Results: 97.4% of respondents reported that they had willingly participated in stool sample collection for gut microbiome research, and most respondents (82.9%) and interviewees (95.6%) indicated willingness to participate again, with motivations for participating being mainly altruistic (57.0%). Responses indicated that storing stool samples in the home freezer for a prolonged time was the main barrier to participation (52.6%), but clear explanations of the sampling procedures and their purpose increased willingness to collect and freeze samples (P=0.046, P=0.003).

Conclusions: To account for participant concerns, gut microbiome researchers establishing cohorts and clinicians trying new faecal tests should provide clear instructions, explain the rationale behind their protocol, consider providing a small freezer, and inform patients about study outcomes. By assessing the attitudes to, motives for and barriers to participation in faecal sample collection, we can provide important information that will contribute to the success of gut microbiome research and its near-future clinical applications.

Background

Gut microbiome research is being conducted using ever greater sample sizes to elucidate the role of gut microbiota in the pathogenesis of Inflammatory Bowel Diseases (IBD).[1–4] The results of these studies hold great promise for clinical applications that include the use of microbiome features as diagnostic biomarkers, determinants of disease activity, and predictors of individual drug response. The microbiome itself may also be a treatment target for prebiotic, probiotic, antibiotic and dietary interventions.[2,5–7] As a consequence, there is a growing demand for stool samples collected by both patients and healthy volunteers. However, little is known about participant perspectives on collecting faecal samples for microbiome research and future care, with available literature currently limited to several studies examining participant experiences with the faecal occult blood test (*FOBT)* used in colorectal cancer screening, the results of which mainly capture experiences coloured by the fear of having cancer.[8,9]

In contrast to the FOBT and other clinical tests, at-home collection of faecal sample for microbiome research requires participants to follow sampling protocols and to store the sample in their home freezer in order to avoid post-collection bias in microbial composition. Accepted best-practices for microbiome studies involve freezing the sample to –80°C within 15 minutes and storage in a domestic frost-free freezer for fewer than 3 days, and samples taken for metabolomics studies, in particular, require stool frozen without preservatives and freezing live bacteria in glycerol preservative for culturing.[10–12] Since stool samples are collected by IBD patients at home, researchers need these patients to fully understand how to collect the sample. However, patient willingness to provide a faecal sample or to store it in the home freezer for research, their motives for and experiences with participation in microbiome research, and the potential barriers they encounter or how these barriers can be overcome have thus far not been described.

Here we explore the motives for and barriers to faecal sample collection given by 780 patients and healthy volunteers, including participants of one of the largest IBD gut microbiome cohorts. Our findings allow us to make recommendations for researchers and clinicians that will allow them to better account for participant attitudes when designing gut microbiome studies for research and clinical applications.

Methods

Cohorts and participants

In total, we contacted 1250 individuals, including IBD patients, patients with other disorders and healthy volunteers. A questionnaire (*Supplementary Table 1)* was sent in January 2017 to 772 patients who had previously been approached by the University Medical Center Groningen, the Netherlands, to participate in gut microbiome studies for which they needed to provide a faecal sample. These patients had been included in four disease-specific cohorts for IBD (n = 660), melanoma (n = 9), Sjögren's syndrome (n = 55) and systemic lupus erythematosus (SLE) (n = 48) (*Figure 1).*. The questionnaire recipients in the IBD cohort comprised both patients previously willing to collect a stool sample for research (n = 577, IBD-Willing) and patients previously not willing to do so (n = 83, IBD-Unwilling), indicating a willingness rate of 87.4% in IBD patients.

In addition, a random selection of participants from the general population cohort Lifelines, of whom 9,547 individuals participated in the faecal sample collection project DAG3, were interviewed using a brief questionnaire (n = 478) to analyse their opinions in the faecal sampling collection process (*Supplementary Table 2).*.[13]

Figure 1: Cohort selection and responses. **Chart depicts cohorts, diseases, departments and respondents in this study.**

Questionnaire design and processing

In collaboration with a psychologist from the IBD Centre in Groningen, we designed a questionnaire covering eight distinct areas: (A) general information including living situation, (B) prior experiences with faecal sample collection, (C) information about the type of toilet and freezer at home, (D) perceptions of the collection process, (E) perceptions of storing faecal samples in their freezer, (F) experience with the pick-up of the faecal samples from the participant's home by hospital employees, (G) satisfaction about information provided by our university medical centre, and (H) future willingness to collect faecal samples for clinical care purposes. An English translation of the Dutch questions and the answers to the questionnaire and the interview can be found in *Supplementary Tables 1* and *2,* respectively.

In our questionnaire we addressed both patients previously willing to participate in faecal sample collection for microbiome research (IBD-Willing, melanoma, SLE, and Sjögren's Syndrome) and patients not willing to participate (IBD-Unwilling). The IBD-Unwilling cohort was asked to answer questions about their reasons for not participating despite their willingness to participate in research in general. Patients who had participated in faecal sample collection for research were asked about their experiences.

Of the 347 respondents to our questionnaire, 45 gave answers to questions that were inconsistent, indicating they had not correctly understood the instructions. We chose to exclude these 45 questionnaires for a final sample of 302 respondents (a 39.1% response rate). To ensure that exclusion of these 45 questionnaires did not introduce bias, we performed our analyses on both the full set (347) and the final set (302) for comparison purposes and found similar results.

Statistical analyses

Descriptive statistics were determined for each question using the statistical software package R[14] (*Supplementary Table 1).*. Chi-Square tests and Fisher's exact tests were performed to determine statistically significant differences between counts (*Table 1).*.

The following five associations were calculated:

1. Willingness to collect faecal samples for future screening and care vs. Gastrointestinal disease (Fisher's exact test), to test if disease location (gastro-intestinal or extra-intestinal) is associated to willingness;
2. Willingness to collect faecal samples for future screening and care vs. Home situation (Fisher's exact test), to test if having co-habitants is associated to willingness;
3. Willingness to collect faecal samples for future screening and care vs. Clarity of the instruction manual (Fisher's exact test), to test if understanding the protocol properly is associated to willingness;
4. Willingness to collect faecal samples for future screening and care vs. Clarity of oral instruction (Fisher's exact test), to test if understanding the protocol properly is associated to willingness;

5. Willingness to store faecal samples in the home freezer for future screening and care vs. Knowing the purpose of freezing the samples (Chi-Square test of independence with Yate's continuity correction), to test if understanding the reason for freezing is associated to increased willingness of storing the samples in the home freezer.

Results

Of the 772 patients who received the questionnaire, 302 patients responded (39.1%). When combined with the 478 Lifelines interviewees, we had information from 780 individuals in total (*Figure 1).*.

Of the patients who responded to the written questionnaire, 97.4% had collected a faecal sample for prior gut microbiome research projects. Unfortunately, response from the IBD patients who did not want to participate in gut microbiome research was very low: only three of the 83 IBD-Unwilling patients responded to the questionnaire, making it hard to draw broad conclusions from their answers. Nevertheless, extensive and valuable information could be obtained from the participants who did respond (*Table 1, Supplementary Table 1).*.

Respondent motivations for participating in research projects were mainly altruistic, as future benefits for other patients (57.0%) were mentioned much more often than future benefits for themselves (12.8%) or future benefits for both themselves and others (16.1%). Most of the patients who responded (82.9%) and the population controls who were interviewed (95.6%) indicated that they were willing to collect faecal samples for future screening or research. We had anticipated that respondents with gastrointestinal disorders, who are more accustomed to handling stool, would be more willing to collect a stool sample. However, we found that having a gastrointestinal disorder was not related to the willingness to do so, with all groups showing similarly high levels of willingness to participate in future collections (GI-disorder, willing: 224 of 250 (89.6%) vs. no GI-disorder, willing: 43 of 48 (89.6%), P = 0.673, Fisher's exact test). Only 26.2% of the patients who responded felt the collection of faecal samples was dirty and most of the population controls interviewed perceived faecal sample collection as 'not inconvenient at all' (49.8%) or 'not inconvenient' (28.7%).

Most patients thought the collection process was easy (84.9%), immediately succeeded in collecting the sample (89.0%), and were able to store their faecal sample in the freezer within 15 minutes (93.9%) as required, with 62.4% of these respondents reporting only needing 5 minutes to do so. A majority of respondents (72.1%) did not mind storing the stool samples in their home freezer. However, while most patients were willing to store a stool sample in their freezer, many were only willing to do so for a brief period of time: maximum 1 to 3 days (21.8%), 1 week (22.1%), or 2 to 4 weeks (8.7%). Just 32.2% said that they did not mind storing faecal samples for a longer time. Some patients even reported clearing the entire freezer before the stool sample collection and keeping it empty until the sample was picked up on dry ice by our collection team.

Household composition did not influence willingness to collect and store stool samples in a home freezer, as we saw no difference in attitude between participants living alone versus those living with a partner,

children, parents or roommates (P = 0.543, Fisher's exact test). A minority of respondents (19.1%) did not understand why the faecal sample needed to be frozen. This is an important observation because the clarity of the written instructions was associated with future willingness to collect stool samples (P = 0.046, Fisher's test), and knowing the purpose of freezing stool (stopping bacterial growth) was associated with future willingness to freeze the stool samples (P = 0.003, Chi-square test). More than half of the patients (58.3%) did not know how the stool samples would be processed and investigated, even though most patients (80.2%) indicated that they would like to learn more about the results of the gut microbiome research they were participating in, and some felt very disappointed about not being briefed afterwards.

Discussion

In this study, we investigated the attitudes towards faecal sampling of participants in one of the largest IBD gut microbiome cohorts and compared them to those of other patient cohorts and healthy volunteers.[15] By assessing the attitudes to, motives for and barriers to participation in faecal sample collection, we can provide important information that will contribute to the success of gut microbiome research and its near-future clinical applications. Targeting the gut microbiome will be part of the diagnostic process and treatment of IBD.[3,16] For this to be successful, close monitoring of the faecal gut microbiome will be necessary, requiring frequent stool sampling.

So far, several strategies have already been developed to reshape the microbiome of IBD patients with the aim of ameliorating intestinal inflammation. Several trials are ongoing on faecal microbiota transplantation in IBD, the transfer of faecal material containing microbiota from a healthy donor into a diseased patient, and some trials have already been able to induce clinical remission in ulcerative colitis patients.[17–19] Other studies have shown that tailored probiotics can target specific microbial pathways.[20–22] In one example, treatment with tungstate, which selectively inhibits microbial respiratory pathways active during inflammation, decreased the expansion of *Enterobacteriaceae,* thereby ameliorating intestinal inflammation.[22] Dietary interventions and supplements have also been shown to effectively alter gut microbiota. For example, prebiotic fibres increase the abundance of gut microbes capable of fermenting fibre into short-chain fatty acids, which exerts anti-inflammatory effects.[21] Several companies are now developing probiotic mixtures containing combinations of live bacteria that showed anti-inflammatory effects in pre-clinical experiments, and some of these probiotics are already being tested in clinical trials.[23]

It is thus very likely that reshaping the gut microbiome by specific microbiota-targeted therapies, faecal transplantation, probiotics, prebiotics and dietary interventions will be part of the treatment of IBD. In addition to modifying the microbiome, the faecal gut microbiome can also be used in the management of IBD as a biomarker for disease activity[24] or disease outcome[25] and as a predictor of clinical drug response.[6] All the aforementioned IBD diagnostic and treatment strategies require repeated sampling from IBD patients.[26]

Our study has demonstrated that stool sample collection for gut microbiome studies and future clinical applications is acceptable to the majority of IBD patients and even to population controls. The main driver for participation in gut microbiome research that our respondents reported was the possibility that the research could benefit others with disease, and this motivation to contribute to research for the next generation of patients affected by disease has been also reported to rank highly in other studies of research participation.[27,28] This shows that an emphasis on the public benefit of the research could help with establishing large cohorts for microbiome research.[28] Most of our participants also indicated a desire to know more about the study and its outcome. This is in line with a previous study in which the attitudes of 400 patients towards participation in clinical trials were assessed at their internal medicine ward.[29] We show that understanding the purpose of our procedures is associated with increased willingness to collect and freeze stool samples. Most patients also reported immediately succeeded in collecting the sample and storing it in the freezer within 15 minutes according to the collection protocol, which indicates that faecal sampling does not present a significant logistical challenge for individuals.

Only a minority of our participants felt the collection of faecal samples was dirty or inconvenient. In another study in which patients were interviewed about providing faecal samples to their general practitioner, a much larger proportion of patients mentioned embarrassment, concerns about hygiene and contamination, discretion and privacy, and the lack of adequate information.[9] The positive attitudes towards faecal sample collection in our study may not always be representative of other patients, and attitudes may differ depending on the reason for stool sample collection, e.g. samples collected for research vs. those collected for diagnosis of a potential disease (a process that may be accompanied by fear), or the health care setting, e.g. secondary vs. routine primary care.

Conclusions

Our questionnaire study was limited by knowing only the answers of the respondents and by the low response rate among IBD patients not willing to participate in our previous stool sample collection. However, we obtained enough information to formulate the following conclusions and recommendations for both gut microbiome researchers and clinicians.

(1) *Gut microbiome researchers setting up new cohorts or clinicians trying new faecal tests should not shy away from doing so.*Most IBD patients were willing to participate in our previous stool sample collection, and most respondents and interviewees indicated that they were willing to participate again.

(2) *Gut microbiome researchers and clinicians should explain why their collection protocol was designed in a specific way.* Explaining the procedures and reasons why they were designed in a specific way, increases participant willingness to collect and freeze a faecal sample.

(3) *In studies where a time-series of many stool samples needs to be collected, researchers should consider providing participants with a small freezer.* The need to store samples in a participant's home

freezer can be a barrier to participation in faecal sample collection, especially when participants have to store samples for a prolonged period.

(4) *Researchers and clinicians should inform participating patients and healthy volunteers about the outcome of the research.*Patients were very interested in the outcome of the study they contributed to, and were disappointed when they were not informed. Based on the responses to our questionnaire, our team of microbiome researchers wrote a newsletter for participants about our scientific findings and publications. We recommend future researchers and clinicians provide similar feedback when possible.

List Of Abbreviations

FOBT faecal occult blood test; GI-disorder gastrointestinal disorder; IBD inflammatory bowel disease; SLE systemic lupus erythematosus.

Declarations

Ethics Approval and Consent to Participate

The collection of faecal samples was previously approved by the Institutional Review Board (IRB) of the University Medical Center Groningen (IRB number 2008.338).All participants who participated in the faecal sample collection studies provided a signed informed consent form. For a single questionnaire study, no additional IRB approval was required according to Dutch medical research law. The questionnaire and the interview to assess the attitudes towards faecal sampling of patients and the general population, respectively, have been designed specifically for this study and are not published elsewhere. Consent to participate was integrated in the questionnaire.

Consent for Publication

Not applicable to the nature of this research.

Availability of Data and Material

Supporting data (translation of the questions and descriptive statistics) are included in the Supplementary material. Unprocessed questionnaire data is available on request from the corresponding author: F.Imhann@rug.nl

Competing Interests

Floris Imhann received a speaker fee from *Abbvie.* Rinse Weersma received speaker fees from *Abbvie, MSD,* and *Boston Scientific,* a consulting fee from *Takeda Pharmaceuticals* and unrestricted research

grants from *Pfizer, Takeda, Ferring* and *Tramedico.*

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Authors' contributions

FI designed the study. LAB, MAYK, VC and FI designed the questionnaire. LAB and MAYK collected and processed the data. LAB and MAYK performed the statistical analysis. LAB, MAYK and FI wrote the manuscript. Collij V, AVV, JF, TAVDM, JJDH, GJV, AD, AZ, CW, and RKW critically reviewed the manuscript.

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Tables

Table 1: Patient willingness to collect and freeze faecal samples and associated factors

		n (%)		
Motivation to participate in faecal sample collection for microbiome research		**All patients**		
	Benefit for other patients	170 (57.0%)		
	Both, benefit for self and others	48 (16.1%)		
	Benefit for self	38 (12.8%)		
	Other options/combinations	27 (9.1%)		
	Did not fill in	15 (5.0%)		
	Total	298 (100%)		
Willing to collect faecal samples for future healthcare	**Willing to collect**	**GI disorder**	**No GI disorder**	
	Yes	224 (89.6%)	43 (89.6%)	P = 0.673
	No	15 (6.0%)	4 (8.3%)	
Split by GI disorder/no GI disorder	Did not fill in	11 (4.4%)	1 (2.1%)	
	Total	250 (100%)	48 (100%)	
Willing to collect for future healthcare	**Willing to collect**	**Living alone**	**Living together**	
	Yes	49 (16.4%)	213 (71.5%)	P = 0.543
	No	2 (0.7%)	16 (5.4%)	
Split by living alone/living together	Did not fill in		18 (6.0%)	
	Total		298 (100%)	
Was the collection process easy?		**All patients**		
	Yes	253 (84.9%)		
	No	35 (11.7%)		
	Did not fill in	10 (3.4%)		
	Total	298 (100%)		
Time between sample collection and storage in the freezer		**All patients**		
	1-5 minutes	186 (62.4%)		
	5-10 minutes	74 (24.8%)		
	10-15 minutes	20 (6.7%)		
	>15 minutes	4 (1.3%)		
	Did not fill in	14 (4.7%)		
	Total	298 (100%)		
Unpleasant to store faecal samples in home freezer?		**All patients**		
	Yes	73 (24.5%)		
	No	215 (72.1%)		
	No answer	10 (3.4%)		
	Total	298 (100%)		
Maximum time patients want to store faecal samples in their freezer		**All patients**		
	I do not want that	29 (9.7%)		
	1 to 3 days	65 (21.8%)		
	1 week	66 (22.1%)		
	2 to 4 weeks	26 (8.7%)		

	>1 month	6 (2.0%)		
	I do not mind	96 (32.2%)		
	No answer	10 (3.4%)		
	Total	298 (100%)		
Was it clear why faecal samples need to be frozen?		**All patients**		
	Yes	224 (75.2%)		
	No	57 (19.1%)		
	Did not fill in	17 (5.7%)		
	Total	298 (100%)		
Clarity of instruction manual vs. Willing to collect faecal samples	**Clarity of instruction**	**Willing to collect**	**Not willing to collect**	
	Yes, very clear	95 (31.9%)	5 (1.7%)	
	Yes, clear	157 (52.7%)	11 (3.7%)	
	Neither clear nor unclear	8 (2.7%)	1 (0.3%)	
	No, unclear	4 (1.3%)	1 (0.3%)	P = 0.046
	No, very unclear	0 (0.0%)	1 (0.3%)	
	Did not fill in	15 (5.0%)		
	Total	298 (100%)		
Knowing the purpose of freezing vs. Willing to freeze	**Willing to freeze**	**Knowing the purpose of freezing**	**Not knowing the purpose of freezing**	
	Willing to freeze	200 (67.1%)	42 (14.1%)	P = 0.003
	Not willing to freeze	23 (7.7%)	15 (5.0%)	
	Did not fill in	18 (6.0%)		
	Total	298 (100%)		

IBD inflammatory bowel disease; SLE systemic lupus erythematosus; n number; % percentage of total

Figures

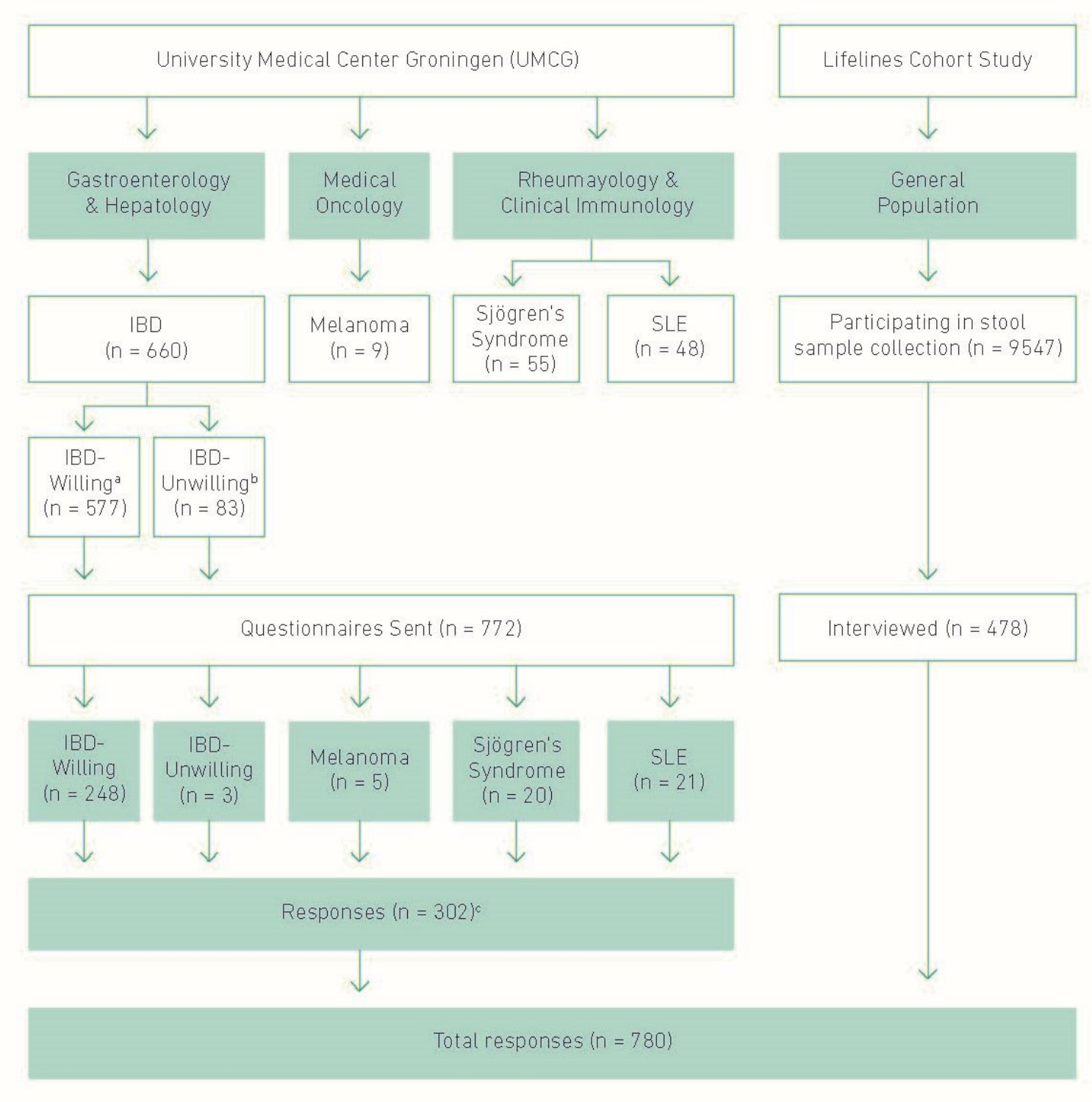

Figure 1

Cohort selection and responses. Chart depicts cohorts, diseases, departments and respondents in this study. IBD inflammatory bowel disease; SLE systemic lupus erythematosus; n number. From top to bottom: Source, Department, Cohort, Sub-cohort, Assessment Method, Responses by Cohort, Responses to Questionnaire, Total Responses. a IBD-Willing: patients previously indicated willingness to collect faecal samples for research b IBD-Unwilling: patients previously indicated that they were not willing to

collect faecal samples for research c Total responses include 5 individuals who did not fill in their participation number and could not be assigned to a cohort.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- SupplementaryTable2.xlsx
- SupplementaryTable1.xlsx
- ADDITIONALFILES.docx