

POLITECNICO DI TORINO

Master's Degree in ICT for smart societies



Politecnico di Torino

Master's Degree Thesis

Study of bowel urgency using telemedical
tool(IBD tool)

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Abstract

The IBD (Inflammatory Bowel Disease) tool web application is a collaboration of the Mauriziano Hospital in Turin and the Links Foundation designed to support the monitoring of patients affected by IBD.

IBD is a chronic condition composed of Crohn's Disease and Ulcerative Colitis and is characterized by abdominal pain, diarrhea, and bowel urgency that significantly influences the quality of life of the patients.

Therefore, the primary agenda of the research is to test the performance of the IBD tool in a follow-up and monitor the symptoms of IBD through broad data analysis. The tool helps the doctor stay connected with the patient through a string of questionnaires to be filled by patients at regular intervals. These questionnaires are automatically scheduled but can also be manually completed and, thus, serve as an alert to the physician promptly to new or current symptoms. Notifications alert physicians upon questionnaire submission, enabling prompt assessment and evaluation.

These data, which include answers to questionnaires and clinical records, are saved in a MongoDB database. This study consists of connection to the MongoDB database with authentication, retrieval of data, cleaning and preparing said data and conducting in-depth analysis. Different statistical analysis and visualization techniques are explained through which insights can be gained in the relation of IBD symptoms with the profile of patients.

The results include the demographic profiles of patients, statistical distributions of pathology duration and patient ages, changes in UC metrics over time for each patient, and distributions of bowel urgency across various categories. These analyses help doctors significantly by providing them with detailed insights into the progression and management of IBD, especially in cases of Ulcerative Colitis and bowel urgency, enabling more informed decision-making and personalized treatment plans.

This thesis highlights how telemedicine and advanced database technologies can improve care for chronic diseases. It shows how the IBD tool uses data to better understand how patients and doctors interact, leading to improved healthcare outcomes.

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Acronyms

IBD Inflammatory bowel disease

CD Chronic Disease

UC Ulcerative Colitis

ICT Information and Communication Technology

SCCAI Simple Clinical Colitis Activity Index

MIAH-UC Monitor IBD at Home-Ulcerative Colitis

IBD-DISK Inflammation-Bowel-Disease Disability Index

DB DataBase

SSN Servizio Sanitario Nazionale

DBMS Database Management System

Chapter 1

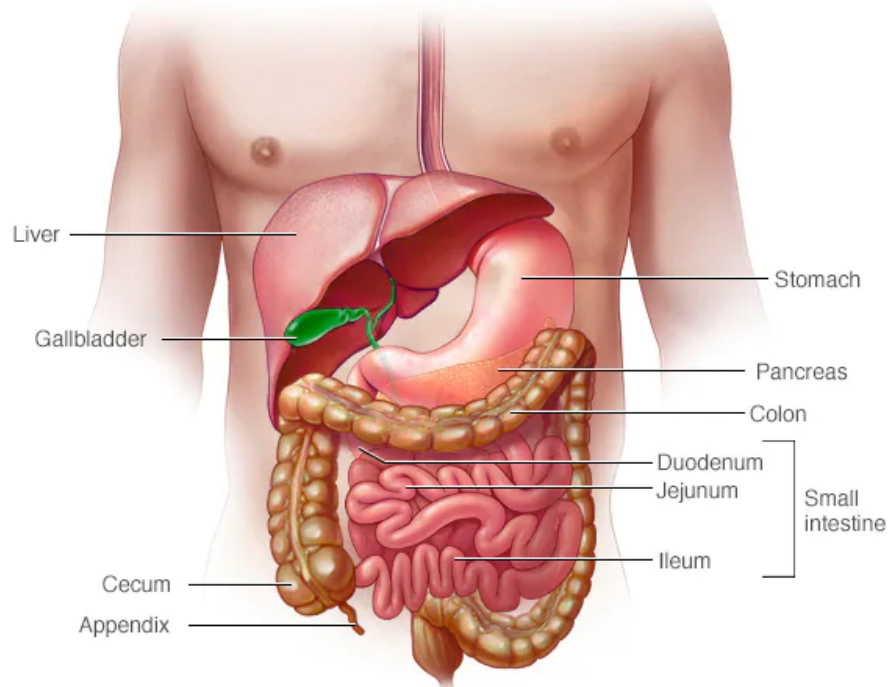
Introduction

1 Inflammatory bowel disease (IBD)

Inflammatory Bowel Disease (IBD) encompasses a group of chronic inflammatory conditions affecting the gastrointestinal (GI) tract, primarily including Crohn's disease (CD) and ulcerative colitis (UC). These disorders are characterized by an intermittent course marked by periods of remission and unpredictable recurrences, necessitating lifelong management to control symptoms and improve quality of life.[1][2][3]

Ulcerative colitis: Ulcerative colitis, on the other hand, is confined to the colon and rectum, causing continuous inflammation and ulceration of the innermost lining of the colon.[4][2][5]

Crohn's disease: Crohn's disease can affect any part of the GI tract from mouth to anus, with inflammation often spreading deep into the affected tissues, leading to a variety of complications such as strictures, fistulas, and abscesses (Academic OUP). Ulcerative colitis, on the other hand, is confined to the colon and rectum, causing continuous inflammation and ulceration of the innermost lining of the colon.[4][3][5]



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Figure 1.1: Digestive System[4]

1.1 Symptoms

Inflammatory bowel disease symptoms vary, depending on the severity of inflammation and where it occurs. Symptoms may range from mild to severe. You are likely to have periods of active illness followed by periods of remission.

Common symptoms of both Crohn's disease (CD) and ulcerative colitis (UC), the two primary forms of Inflammatory Bowel Disease (IBD), include diarrhea, abdominal pain, and fatigue. Both conditions often lead to chronic inflammation in the gastrointestinal tract, resulting in these overlapping symptoms:[2] [6]

- Diarrhea
- Fatigue
- Abdominal pain and cramping
- Blood in your stool
- Reduced appetite
- Unintended weight loss

1.2 Complications

Complications of both Crohn's disease (CD) and ulcerative colitis (UC), the primary forms of Inflammatory Bowel Disease (IBD), can be extensive and severe, affecting various parts of the body and overall health. Here are some common complications shared by both conditions:

- **Intestinal Obstruction:** This occurs when chronic inflammation and scarring cause narrowing of the intestinal passages, leading to partial or complete blockage of the bowel, which can require surgical intervention [7].
- **Fistulas:** These are abnormal connections that can form between different parts of the intestine or between the intestine and other organs, such as the bladder, vagina, or skin. Fistulas can lead to severe infections and abscesses if left untreated [7].
- **Abscesses:** Collections of pus caused by infections within the abdominal cavity or other areas can develop due to fistulas or deep inflammation. Abscesses are often painful and can be life-threatening without proper treatment [7].
- **Malnutrition:** Due to the chronic inflammation and frequent diarrhea associated with IBD, patients often suffer from malnutrition. This can lead to deficiencies in essential nutrients and contribute to overall poor health and fatigue [8].
- **Anemia:** Chronic blood loss from the inflamed intestinal lining can lead to anemia. This condition is characterized by a reduced number of red blood cells, causing fatigue, weakness, and other symptoms [8].
- **Extraintestinal Manifestations:** IBD can affect organs outside the digestive tract, leading to complications such as arthritis, skin conditions (e.g., erythema nodosum, pyoderma gangrenosum), eye inflammation (e.g., uveitis, episcleritis), and liver disorders (e.g., primary sclerosing cholangitis) [2][8].

These complications significantly impact the quality of life for IBD patients, emphasizing the need for comprehensive treatment plans and ongoing monitoring by healthcare providers.

1.3 Causes

The exact cause of inflammatory bowel disease (IBD), which includes Crohn's disease (CD) and ulcerative colitis (UC), remains unknown. While factors like diet and stress were once thought to be primary causes, it is now understood that these factors may aggravate but do not cause IBD.[4]

- **Immune System Malfunction:** One possible cause of IBD is an immune system malfunction. Normally, the immune system protects the body from pathogens such as viruses and bacteria. In individuals with IBD, an abnormal immune response leads to the immune system attacking the cells of the digestive tract. This chronic inflammation causes the characteristic symptoms of IBD. [4][9].
- **Genetic Factors:** Several gene mutations have been associated with IBD. Genetic studies have identified over 200 genetic variants linked to IBD, highlighting its hereditary component. People with first-degree relatives who have IBD are at a higher risk of developing the disease themselves. However, the majority of IBD patients do not have a family history of the condition. [10][11]

- **Environmental Factors:** Environmental factors also play a significant role. The incidence of IBD is higher in industrialized countries and urban areas. Factors such as a Western diet, high in fat and low in fiber, and smoking have been associated with the development and exacerbation of IBD symptoms.[9][11]

1.4 Risk Factors

- **Age**

Most people who develop IBD are diagnosed before they're 30 years old. But some people don't develop the disease until their 50s or 60s [9].

- **Race or Ethnicity**

Although IBD is more common in white people, it can occur in any race. Cases are also increasing in other races and ethnicities [9] [12]

- **Family History**

You are at higher risk if you have a close relative — such as a parent, sibling, or child — with the disease. Genetic predisposition plays a crucial role, though most people with IBD do not have a family history [13].

- **Cigarette Smoking**

Cigarette smoking is the most important controllable risk factor for developing Crohn's disease. Smoking may help prevent ulcerative colitis. However, its harm to overall health outweighs any benefit, and quitting smoking can improve the general health of your digestive tract, as well as provide many other health benefits [13].

- **Nonsteroidal Anti-inflammatory Medication**

These include ibuprofen (Advil, Motrin IB, others), naproxen sodium (Aleve), diclofenac sodium and others. These medications may increase the risk of developing IBD or worsen the disease in people who have IBD. [13].

2 Crohn's Disease

Crohn's disease is a type of inflammatory bowel disease (IBD). It causes swelling of the tissues (inflammation) in your digestive tract, which can lead to abdominal pain, severe diarrhea, fatigue, weight loss and malnutrition.

It is named after Dr. Burrill B. Crohn, who first described the disease in 1932 along with his colleagues, Dr. Leon Ginzburg and Dr. Gordon D. Oppenheimer.[14]

Inflammation caused by Crohn's disease can involve different areas of the digestive tract in different people, most commonly the small intestine. This inflammation often spreads into the deeper layers of the bowel.

Crohn's disease can be both painful and debilitating, and sometimes may lead to life-threatening complications.

There's no known cure for Crohn's disease, but therapies can greatly reduce its signs and symptoms and even bring about long-term remission and healing of inflammation. With treatment, many people with Crohn's disease are able to function well.

Crohn's Disease

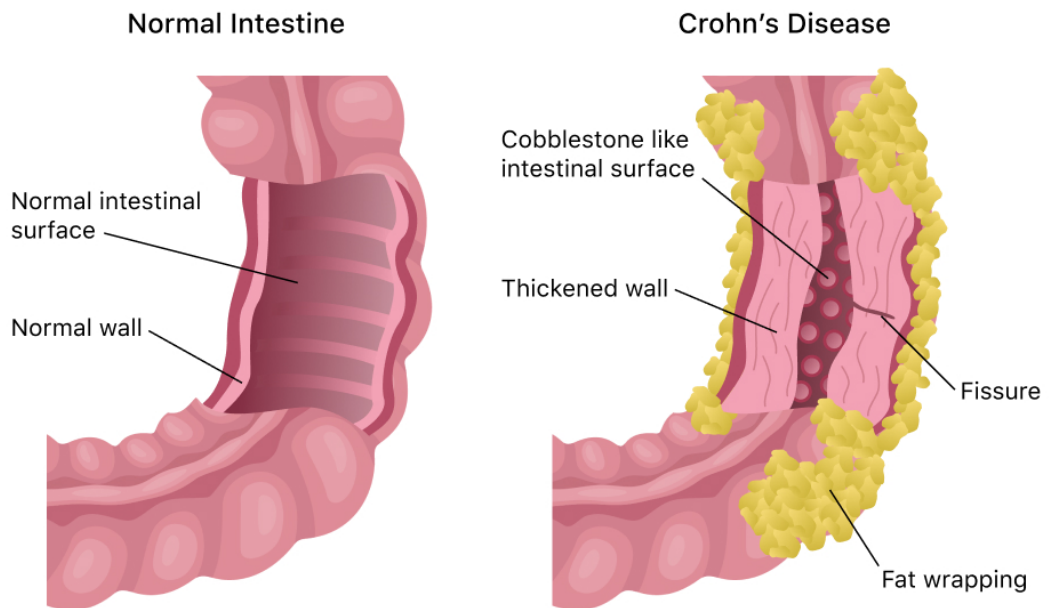


Figure 1.2: Crohn's Disease [15]

Complications

Crohn's disease (CD) can lead to various complications, both within the gastrointestinal (GI) tract and affecting other parts of the body. Here are some of the primary complications associated with CD:

Intestinal Obstruction

Chronic inflammation from Crohn's disease can cause scarring and thickening of the intestinal walls, leading to strictures. These strictures can result in partial or complete intestinal obstruction, which may require surgical intervention to remove or bypass the affected segments [16].

Fistulas

Fistulas are abnormal connections that can form between different parts of the intestine or between the intestine and other organs, such as the bladder, vagina, or skin. These can lead to infections and abscesses, which are collections of pus that can be life-threatening if not treated [16].

Abscesses

An abscess is a pocket of pus caused by infection. In Crohn's disease, abscesses can form in the abdominal cavity, pelvis, or around the anus. These abscesses can cause significant pain and may require drainage and antibiotic treatment [16].

Malnutrition

Due to chronic inflammation and malabsorption, patients with Crohn's disease often suffer from malnutrition. This is compounded by reduced appetite, diarrhea, and increased nutritional needs during periods of active inflammation. Malnutrition can lead to deficiencies in essential nutrients and overall poor health [16].

Osteoporosis

Patients with Crohn's disease are at an increased risk of developing osteoporosis, a condition characterized by weakened bones and a higher risk of fractures. This is often due to chronic inflammation, corticosteroid use, and poor absorption of calcium and vitamin D [16].

Thrombosis

There is an increased risk of venous and arterial thrombosis in individuals with Crohn's disease. This includes a higher likelihood of developing blood clots, which can lead to serious complications such as deep vein thrombosis (DVT) or pulmonary embolism (PE) [16].

Extraintestinal Manifestations

Crohn's disease can also cause complications outside the GI tract. Common extraintestinal manifestations include arthritis, skin conditions (such as erythema nodosum and pyoderma gangrenosum), eye inflammation (such as uveitis), and liver disorders (such as primary sclerosing cholangitis) [16].

3 Ulcerative Colitis

Ulcerative colitis is an inflammatory bowel disease (IBD) that causes inflammation and ulcers (sores) in your digestive tract. Ulcerative colitis affects the innermost lining of your large intestine, also called the colon, and rectum. In most people, symptoms usually develop over time, rather than suddenly.

Ulcerative colitis can be draining and can sometimes lead to life-threatening complications. While it has no known cure, there are several new treatments that can greatly reduce signs and symptoms of the disease and bring about long-term remission.

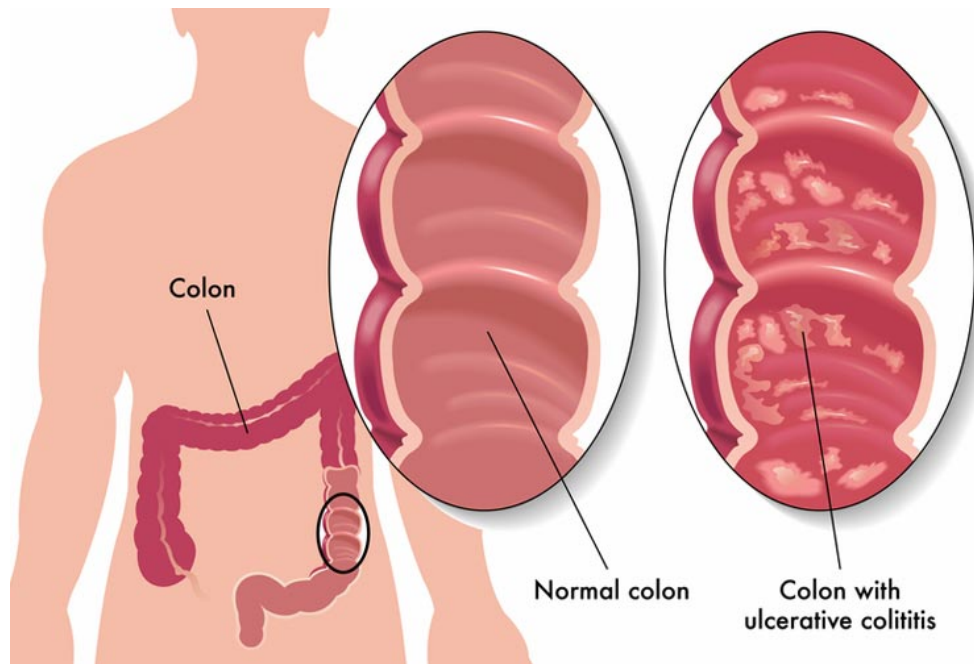


Figure 1.3: Ulcerative Colitis[17]

Complications

Ulcerative colitis (UC) is a chronic inflammatory condition of the colon and rectum that can lead to various complications both within and outside the gastrointestinal (GI) tract. Here are some of the primary complications associated with UC:

Toxic Megacolon

Toxic megacolon is a severe, life-threatening complication where inflammation extends through the entire wall of the colon, causing it to expand and potentially rupture. This condition requires immediate medical attention and often necessitates surgery [18].

Perforated Colon

A perforated colon occurs when a hole forms in the wall of the intestine. This can lead to the contents of the intestine leaking into the abdominal cavity, causing peritonitis, a serious infection that requires emergency surgery [18].

Severe Bleeding

Chronic inflammation and ulceration in the colon can lead to significant bleeding, resulting in anemia and necessitating blood transfusions in severe cases. This complication often requires hospitalization and intensive management [18].

Dehydration and Malnutrition

Due to chronic diarrhea and the inability to absorb nutrients effectively, patients with UC can suffer from severe dehydration and malnutrition. This can lead to weight loss, fatigue, and a general decline in overall health [18].

Increased Risk of Colon Cancer

Long-standing inflammation in UC increases the risk of developing colon cancer. Regular screenings and colonoscopies are essential for early detection and prevention of colorectal cancer in UC patients [18].

Extraintestinal Manifestations

UC can also cause complications outside the GI tract. These include:

- **Arthritis:** Inflammation of the joints causing pain and stiffness.
- **Skin Conditions:** Such as erythema nodosum (red, tender nodules) and pyoderma gangrenosum (painful ulcers).
- **Eye Inflammation:** Conditions like uveitis and episcleritis.
- **Liver Disorders:** Such as primary sclerosing cholangitis, a disease of the bile ducts [18].

Chapter 2

Architecture

1 Questionnaires

The structure of the questionnaires and the methodology for calculating the final score discussed in this section are based on the guidelines provided by the Link Foundation. The relevant pages from the Link Foundation's PDF, which outline the required information, have been attached in the appendix. Although they are in Italian, we have translated and adapted them for use in this section.

1.1 SCCAI

The aim of SCCAI is to devise an accurate, easily calculated index of disease activity using a small number of clinical criteria. The index should be readily calculated by a family practitioner or physician at an outpatient consultation and should not require physical examination, sigmoidoscopic evaluation, or laboratory indices. The final index could then act as an initial guide to appropriate changes in treatment and be an aid in identifying those patients requiring more detailed assessment.[19]

The Simple Clinical Colitis Activity Index (SCCAI) is a tool used to assess the activity of ulcerative colitis. It takes into account both clinical symptoms reported by the patient and findings from a physical examination. The SCCAI includes thirteen questions, covering factors such as stool frequency, urgency, blood in stool and general well-being.

The total score can show the patient status. Higher scores indicating more severe disease activity. It is a helpful tool for clinicians to monitor and evaluate the status of Ulcerative colitis in patients, guiding treatment decisions and assessing response to therapy. If you or someone you know is dealing with Ulcerative colitis, it is essential to keep an open line of communication with healthcare professionals to ensure effective management of the condition.

Questionnaire Structure

1. How many bowel movements did you have on average during the day (i.e. from when you woke up to when you went to sleep) in the last week?

Evacuations of mucus or blood only should also be considered.

- 0-3 evacuations : 0
 - 4-6 evacuations: 1
 - 7-9 evacuations: 2
 - over 9 evacuations: 3
2. How many bowel movements did you have during the night on average (from when you went to sleep to when you woke up, how many times did you have to get up to go to the bathroom) in the last week?
- nothing : 0
 - 1-3 evacuations : 1
 - 4 or more evacuations: 2
3. In the past week, have you been able to hold your stool for 15 minutes or longer when you felt the urge to go to the bathroom? (or to evacuate)
- Yes : 0
 - No: 1
4. In the last week, have you had to adjust your activities to make sure there is a bathroom nearby?
- Yes : 1
 - No: 0
5. In the last week, have you had any episodes of fecal incontinence?
- Yes : 1
 - No: 0
6. In the last week, have you had any episodes of fecal incontinence?
- Yes : 1
 - No: 0
7. If you had to measure your overall health by assigning a number, which number would you choose? (0=very bad, 10=perfect , VAS 1-10)
- VAS \geq 7 : 0
 - VAS = 6 : 1
 - VAS = 5 : 2
 - VAS = 4 : 3
 - VAS < 4 : 4
8. In the past week, have you had joint pain that was worse with rest rather than movement?

- Yes : 1
 - No: 0
9. In the past week, have you had any joint redness or swelling?
- Yes : 1
 - No: 0
10. In the past week, have you ever woken up with joint pain?
- Yes : 1
 - No: 0
11. In the past week, have you had a skin problem that was diagnosed as erythema nodosum by your dermatologist?
- Yes : 1
 - No: 0
12. In the last week, you have had a skin problem that has been diagnosed as pyoderma gangrenosum by your dermatologist?
- Yes : 1
 - No: 0
13. Are you currently suffering from an eye infection, for which you have consulted an ophthalmologist and the diagnosis of uveitis has been made?
- Yes : 1
 - No: 0

Final score

Final score = sum of the all questions scores

Health status:

The final score indicates a health status:

- **Remission:** final score < 5
- **Relapse:** final score > 5

Patient status:

Variance between the final score of the current month and the final score of the previous month is calculated and used to define patient status (e.g., final score April – final score March):

- **Patient health is improving:** final score variance ≤ -2
- **Patient health is worsening:** final score variance $\geq +2$
- **Patient health is stable:** $-2 < \text{variance final score} < +2$

Bowel urgency score

The parameter for bowel urgency is derived by assigning numerical values to the responses of questions 3, 4, and 5 in the Simple Clinical Colitis Activity Index (SCCAI). For each affirmative response (indicating the presence of symptoms), a value of 1 is assigned, while a negative response receives a value of 0. The final parameter score is obtained by summing these individual values, resulting in a range from 0 to 3.

This condensed scoring system effectively captures the severity of bowel urgency, offering a concise yet informative measure for clinicians to assess and monitor ulcerative colitis activity, particularly in the realm of urgency-related symptoms.

Bowel urgency score = sum of the question 3,4,5 scores

1.2 MIAH-UC

The Monitor IBD At Home-Ulcerative Colitis (MIAH-UC) questionnaire is designed for monthly assessment, consisting of 5 concise questions. Each question is associated with a specific score based on the response provided by the individual. These questions are strategically formulated to capture key aspects of inflammatory bowel disease (IBD) activity, allowing for a quick yet comprehensive self-assessment.

Questionnaire Structure

1. If you had to measure your overall health by assigning a number, which number would you choose? (0=very bad, 10=perfect)

VAS scale 0 to 10

- min:0 : VAS=10
- max:10 : VAS=0

2. Rectal bleeding:

- Yes: 1
- No : 0

3. Number of evacuations per day:

- <4 : 0
- >3 :10

4. (a) Evacuation urgency:

- No : 0
- Yes,Urgent : 5
- Yes,very Urgent : 10

(b) Abdominal pain

- 0 = no abdominal pain
- 10 = worst abdominal pain

answer domain 4 = 0,5 * answer subdomain 4.a + 0,5 * answer subdomain 4.b

Score: 0-10.

Final score

Final score = $10 - (10 * (e^{-0.611 - 0.160 * (\text{answer domain 1}) + 2.103 * (\text{answer domain 2}) + 0.167 * \text{answer domain 3} - 0.184 * (\text{answer domain 4})) / (1 + e^{-0.611 - 0.160 * (\text{answer domain 1}) + 2.103 * (\text{answer domain 2}) + 0.167 * (\text{answer domain 3}) - 0.184 * (\text{answer domain 4}))}))$

Health status:

The final score indicates a health status:

- **Remission:** final score < 3.6
- **Relapse:** final score > 3.6

1.3 IBD-DISK

The IBD-DISK (Inflammation-Bowel-Disease Disability Index) is a comprehensive questionnaire for assessing the impact of Inflammatory Bowel Disease on patients' lives. Monthly check-ins with 10 targeted questions and a scoring system can provide valuable insights into the fluctuating nature of CD and UC. Regular monitoring allows for a more nuanced understanding of how the diseases affect individuals over time, helping healthcare providers tailor interventions and support accordingly.

Questionnaire structure

Absolutely disagree		Neither agree or disagree						Absolutely agree				
←								→				
0		1	2	3	4	5	6	7	8	9	10	
In the last week, because of my Crohn's disease or ulcerative colitis...												
Abdominal pain	...I have had aches or pains in my stomach or abdomen											
Regulating defecation	...I have had difficulty coordinating and managing defecation, including choosing and getting to an appropriate place for defecation and cleaning myself afterwards											
Interpersonal interactions	...I have had difficulty with personal relationships and/or difficulty participating in the community											
Education and work	...I have had difficulty with school or studying activities, and/or difficulty with work or household activities											
Sleep	...I have had difficulty sleeping, such as falling asleep, waking up frequently during the night or waking up too early in the morning											
Energy	...I have not felt rested and refreshed during the day, and have felt tired and without energy											
Emotions	...I have felt sad, low or depressed, and/or worried or anxious											
Body image	...I have not liked the way my body or body parts look											
Sexual functions	...I have had difficulty with the mental and/or physical aspects of sex											
Joint pain	...I have had pains in the joints of my body											

Figure 2.1: IBD-Disk questionnaire[20]

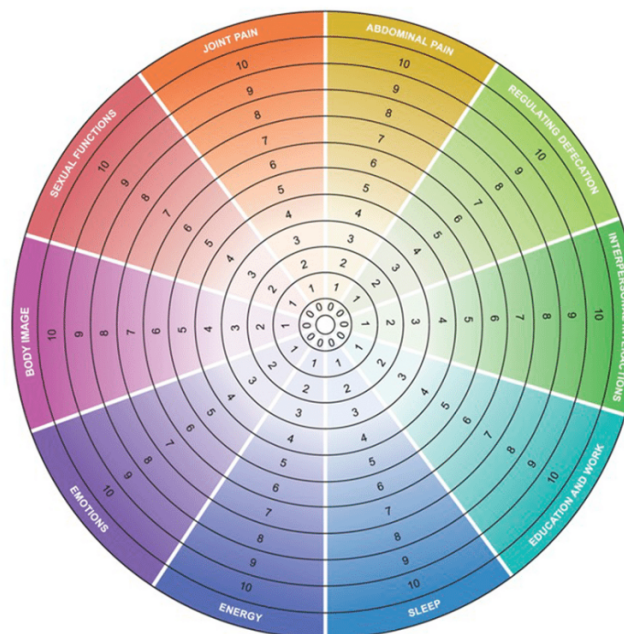


Figure 2.2: IBD-Disk scoring disk[20]

Final score

Final score = sum of the ten answers scores (0 to 100)

2 Database

Selecting the right database management system is crucial for the efficient handling of data. Effective data management is essential for the advancement of medical research and improving patient care.

This chapter delves into the fundamental aspects of our IBD tool, which serves as a crucial instrument in understanding and managing this complex condition. Central to our tool's architecture is the choice of a robust Database Management System (DBMS), a decision that profoundly influences the system's efficiency and scalability. By selecting MongoDB as the backbone of our data infrastructure, We chose a modern approach designed specifically for managing medical data effectively.

2.1 MongoDB

The relational database has been the foundation of enterprise applications for decades, and since MySQL's release in 1995 it has been a popular and inexpensive option. Due the explosion of large volume and variety of datas in recent years, non-relational database technologies like MongoDB become useful to address the problems faced by traditional databases. MongoDB is very useful for new applications as well as to augment or replace existing relational infrastructure.[21]

MySQL is a popular open-source relational database management system (RDBMS) that is distributed, developed, and supported by Oracle Corporation. The relational systems like, MySQL stores data in tabular form and uses structured query language (SQL) for accessing of data. In MySQL, we should pre-define the schema based on requirements and set up rules to control the relationships between fields in the record. In MySQL, related informations may be stored in different tables, but they are associated by the use of joins. Thus, data duplication can be minimized.[21]

MongoDB is an open-source database developed by MongoDB,Inc. MongoDB stores data in JSON-like documents that can vary in structure. Related information can be stored together for fast query access through the MongoDB query language. MongoDB uses dynamic schemas,which helps to create records without first defining the structure, such as the attributes or the datatypes. It is possible to change the structure of records by simply adding new attributes or deletingexisting fields. This model helps to represent hierarchical relationships, to store arrays, and other more complex structures very easily. Documents in a record need not have an identical set of fields. MongoDB is designed with high availability and scalability includes replication and autosharding.[21]

Advantages

- **Flexibility**

MongoDB stores data in document format using JSON. It is a schema less document and maps to native programming language types.[22]

In the context of medical data management, flexibility is essential for integrating new data types and attributes as medical knowledge evolves and new research findings emerge.

- **Scalability**

MongoDB's horizontal scaling capabilities enable the seamless expansion of database systems to handle growing volumes of medical data. By distributing workload across multiple nodes, MongoDB ensures that performance remains consistent even as data volume and user concurrency increase. This scalability is particularly critical in healthcare settings where the volume of patient data continues to grow exponentially, necessitating a scalable infrastructure to support research and clinical operations.

- **Performance**

It provides high performance data persistence. It reduces I/O activity on database system by supporting embedded documents. Use of indexing supports faster queries.[22]

By indexing frequently queried fields and leveraging query optimization techniques, MongoDB minimizes query latency and enhances overall system responsiveness. This performance optimization is crucial in healthcare applications where timely access to patient data is essential for making informed clinical decisions and conducting research studies.

- **Rich query language:**

It gives the feature of RDBMS what we are used to with additional features of its own. Dynamic queries, sorting, secondary indexes, rich updates, easy aggregation, upsert (update if document exists and insert if it does not) are few RDBMS features and flexibility and scalability are the additional ones.[22]

- **Sharding:**

Autosharding allow us to scale our cluster linearly by adding more machines. It is possible to increase the efficiency which is very important on the web when load can increase suddenly and bring down the website.[22]

- **Ease of use:**

It is very easy to install, use, maintain and configure.[22]

- **High availability:**

MongoDB support replication facility called, replica set. Replica set is a group of servers that maintains same dataset. It provides automatic failover, redundancy and increased data availability.[22]

- **Agility**

MongoDB's agile development capabilities facilitate rapid prototyping and iteration in the development of medical data management systems. With its schema-less design and support for dynamic schema evolution, MongoDB enables developers to quickly adapt to changing requirements and iterate on data models without disrupting existing workflows. This agility accelerates the development lifecycle of healthcare applications, allowing organizations to respond promptly to evolving regulatory requirements and clinical needs.

- **Community Support and Ecosystem**

MongoDB boasts a vibrant community of developers, contributors, and users who actively contribute to its development and support ecosystem. With extensive documentation, online forums, and user groups, MongoDB provides robust community support to help organizations troubleshoot issues, share best practices, and leverage the full potential of the platform. This community-driven ecosystem fosters collaboration and knowledge sharing, empowering healthcare organizations to harness MongoDB's capabilities effectively in their data management initiatives.

- **Support for multiple storage engines:**

It supports multiple storage engines such as WiredTiger storage engine, MMAPv1 storage engine. It also supports pluggable storage engine API that allows third party to develop storage engine for MongoDB.[22]

Choosing MongoDB: A Flexible Solution for Data-Intensive Applications

At the end the developers is responsible to decide which database should be used in a particular application, depending on its requirements. For this application, the most suitable non-relational database was MongoDB, because the forum will have thousands of users and MongoDB has enabled its customization to suit each user by creating private forums, each with its own flexible and dynamic structure.

MongoDB provided lower execution times than MySQL, which is essential when an application should provide support to thousands of users simultaneously. We can choose MongoDB instead of MySQL if the application is data intensive and stores many data and queries lots of data.

It is also important to note that within the same application, sometimes each user is likely to need its own custom settings and relational databases do not allow total customization that is based solely on the needs of users. Thus, more and more applications are beginning to use a non-relational database because they provide a more flexible structure that can shape after each user' needs; they are designed to store large amounts of data and they are denormalized databases, which increases performance.[23]

2.2 Data Collections

MongoDB allows to compartmentalize data into collections in order to divide data logically. Thus, the speed of queries can increase dramatically by querying on a subset of the data instead of all it. Collections are analogous to tables in a relational database. Each collection contains documents that can be nested in complex hierarchies but still easy to query and index. A document is seen as a set of fields, each one being a key-value pair.[24]

This section focuses on nine distinct data collections housed within the MongoDB database. Each collection serves a unique purpose in supporting our research objectives. In the upcoming sections, we will provide a detailed examination of each collection, unraveling their individual contributions to the functionality of the IBDtool. This exploration aims to offer a comprehensive understanding of the role played by each data collection in shaping the landscape of our research infrastructure.

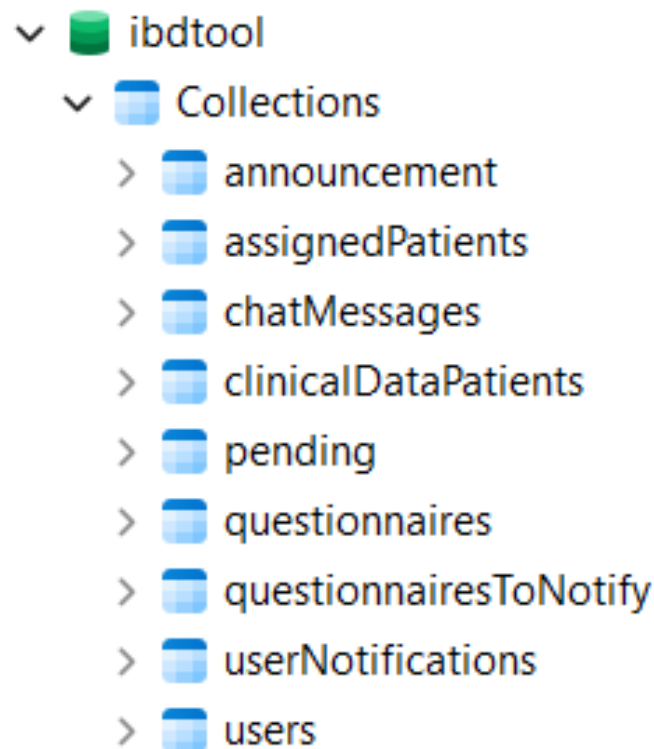


Figure 2.3: IBD_tool mongoDB Data collections

- **Announcement**

The "Announcement" collection displays messages that are broadcasted to all users within the IBDtool.

Each document within this collection follows a structured format, starting with a unique identifier (`_id`) automatically generated by MongoDB.

The "doctorName" and "doctorSurname" fields store the name and surname of the healthcare professional who authored the announcement, respectively. This provides attribution to the message and helps users identify the source of the information.

The "date" field records the timestamp of when the announcement was broadcast, using the ISODate format to capture both date and time components accurately.

The core content of the announcement is encapsulated within the "text" field, which contains the message's textual content.

Finally, the "class" field indicates the specific class or type of entity represented by the document, facilitating internal application logic and data management processes.

```
{
  "_id" : ,
  "doctorName" : ,
  "doctorSurname" : ,
  "date" : ISODate("2022-10-26T19:21:01.921+0000"),
  "text" : "Gentile utente,..."
  "_class" : "com.backend.web.ibdtool.entity.Announcement"
}
```

- **Assigned Patients**

The "Assigned Patient" collection provides a comprehensive overview of patients assigned to each doctor within the IBDtool database. Here's an expanded explanation of the data structure:

Each document in the "Assigned Patient" collection is uniquely identified by the email address of the doctor to whom the patients are assigned (`_id` field). This allows for efficient organization and retrieval of patient data based on the doctor's identity.

The "patients" field is an array containing detailed information about each patient assigned to the doctor. For each patient, the following attributes are stored:

- Email: The email address of the patient, serving as a unique identifier.
- name: The first name of the patient.
- surname: The last name of the patient.

- SSN: servizio sanitario nazionale number serves as another unique identifier for the patient.
- birthDate: The date of birth of the patient.
- birthPlace: The place of birth of the patient.
- phoneNumber: The contact phone number of the patient.
- doctor: An embedded document containing information about the doctor responsible for the patient's care, including the doctor's email, name, surname, SSN, phone number, and doctorID.
- pathology: Specifies which disease the patient has.
- checkClinicalData: A boolean value indicating whether clinical data for the patient has been reviewed.
- questionnaires: An array containing a list of questionnaires associated with the patient, such as "CLINICAL-SCCAI" or "IBD-DISK" and ...
- category: The classification of the patient.

```

{
  "_id" : Email of the doctor,
  "patients" : [
    {
      "email" : Email of patient ,
      "name" : ,
      "surname" : ,
      "SSN" : ,
      "birthDate" : ,
      "birthPlace" : ,
      "phoneNumber" : ,
      "doctor" : {
        "email" : ,
        "name" : ,
        "surname" : ,
        "SSN" : ,
        "phoneNumber" : ,
        "doctorID" :
      },
      "pathology" : "Colite ulcerosa",
      "checkClinicalData" : false,
      "questionnaires" : [
        "CLINICAL-SCCAI",
        "CLINICAL-PRISM",
        "IBD-DISK",
        "PRISM",
        "PATIENT-SCCAI",
        "MIAH-UC"
      ],
      "category" : "STANDARD"},
  ]
}

```

- **Chat Messages**

It showcases all chat messages, along with details such as the sender, recipient, their names, email addresses, and the respective date and time of each message.

```
{
  "_id" : ,
  "sender" : Email of the sender ,
  "recipient" : Email of the recipient,
  "patientEmail" : ,
  "patientName" : ,
  "patientSurname" : ,
  "doctorName" : ,
  "doctorSurname" : ,
  "date" : ISODate("2021-04-22T23:17:56.015+0000"),
  "text" : "Buona sera dott, la situazione è sempre la stessa,..."
  "read" : true,
  "_class" : "com.backend.web.ibdtool.entity.ChatMessage"
}
```

- **Clinical Data Patients**

Clinical data of a patient refers to a comprehensive set of information related to the individual's health and medical history. This data typically includes details such as diagnoses, treatments, medications, laboratory results, vital signs, and other relevant healthcare information. Clinical data is crucial for healthcare professionals to assess a patient's health status, plan appropriate interventions, and track the effectiveness of medical care over time. It forms the foundation for informed decision-making and continuity of care in the medical field.

This collection presents the clinical data of each patient, encompassing essential physical aspects such as weight, height, age, and gender. Additionally, it provides insights into the disease pathology of each patient, detailing the date, time, and duration of the pathology. Moreover, the collection includes records of therapeutic interventions, specifying the date and time of each therapy session. This comprehensive dataset offers understanding of the patients' health status, facilitating medical analysis and decision-making.

```
{
  "_id" : patientSSN,
  "bodyStat" : {
    "weight" : "51",
    "height" : "160",
    "pathology" : "Malattia di Crohn",
    "age" : "28",
    "sex" : "1",
    "dateOfDiagnosis" : "",
  }
}
```

```

    "ageOfDiagnosis" : "13",
    "familiarity" : "0",
    "pathologyDuration" : "13",
    "infiammatorioCD" :
    "stenosanteCD" :
    "penetranteCD" :
    "malattiaPerianaleCD" :
    "locatColonCD" :
    "locatIleumCD" :
    "locatUpperGI" :
    "localizzazioneUC" :
    "storicheEIMS" :
    "attiveEIMS" :
    "interventi" : "1",
    "numResezioni" : "1",
    "stomia" :
    "therapy5ASAOS" :
    "therapyTOPICA" :
    "therapyGCSOS" :
    "therapyIMM" :
    "therapyBIO" :
    "notes" :
    "therapies" :
    "lastLogin" : ISODate("2022-06-22T20:55:43.042+0000"),
    "category" : "TELEMEDICINA",
    "registrationTime" : NumberLong(1596823125),
    "_class" : "com.backend.web.ibdtool.entity.ClinicalDataPatients"
}

```

- **Pending**

The "Pending Questionnaires" collection within our database serves as a dynamic repository, capturing pending questionnaires along with pertinent details. This includes information on the doctor who initiated the questionnaire, the designated patient recipient, and the corresponding date and time of the pending task. This collection plays a crucial role in tracking and managing the flow of questionnaire-related activities, ensuring timely and organized interactions between healthcare professionals and patients.

```

{
  "_id" : ,
  "uuid" : ,
  "type" : "PATIENT-SCCAI",
  "doctorID" : ,
  "patientSSN" : ,
  "date" : ISODate("2020-08-14T16:43:56.220+0000"),
  "_class" : "com.backend.web.ibdtool.entity.Pending"
}

```

- **Questionnaires**

The "Questionnaires" collection is a comprehensive repository encompassing all completed questionnaires by patients. It incorporates essential details such as the doctor's ID, patient's SSN (Servizio sanitario nazionale), the specific questionnaire name, and the corresponding date and time of completion. Furthermore, this collection includes record of all responses to the questionnaire's queries. Notably, it calculates and stores a final score, representing the cumulative result derived from the patient's answers to the questionnaire. This dataset provides an overview of patient responses and their overall assessment.

```
{
  "_id" : ,
  "type" : "PATIENT-SCCAI",
  "doctorID" : ,
  "patientSSN" : ,
  "compiled" : true,
  "date" : ISODate("2020-08-14T16:56:42.057+0000"),
  "results" : [
    "0-3 evacuazioni","1-3evacuazioni","Si","Si","No",
    "Mai""5","No","No","Si","No","No","No"
  ],
  "finalScore" : NumberInt(5),
  "read" : true,
  "evaluation" : false,
  "warning" : false,
  "_class" : "com.backend.web.ibdtool.entity.
  QuestionnairePatientSCCAI"
}
```

- **Questionnaires to notify**

This collection includes the doctor's identification, the patientSSN, the patient's name and surname, and details regarding the questionnaire itself. This encompasses the questionnaire's name, the final score derived from the patient's responses. Effectively, this collection facilitates communication by tracking essential information, ensuring timely notifications for both healthcare professionals and patients.

```
{
  "_id" : ,
  "type" : "PSQI",
  "score" : 0.0,
  "doctorID" : ,
  "patientSSN" : ,
  "patientName" : ,
  "patientSurname" : ,
  "ripresaAttivita" : false,
  "_class" : "com.backend.web.ibdtool.entity.QuestionnaireToNotify}
```

- **User Notification**

The "User Notifications" collection encapsulates notifications intended for all users, encompassing both the title and body of each notification. This compilation provides a comprehensive record of the information disseminated to users, allowing for a detailed overview of the content and context of notifications within our system.

```
{
  "_id" : ,
  "notifications" : [
    {
      "title" : "15/12/2023 15:31:40 Nuovo questionario
      CLINICAL-SCCAI
      compilato relativo a Alessandro ..."
      "body" : "Hai appena compilato un questionario
      CLINICAL-SCCAI
      relativo al paziente Alessandro..."
      "read" : false
    },
    {
      "title" : "15/12/2023 16:11:42 IBD Tool - Nuovo
      questionario CLINICAL-PRISM
      da compilare",
      "body" : "Gentile Marco nè disponibile un nuovo
      questionario CLINICAL-PRISM
      da compilare relativo al paziente Paolo.
      "read" : false
    },
  ],
  "_class" : "com.backend.web.ibdtool.entity.UserNotifications"
}
```

- **Users**

The "Users" database collection serves as a comprehensive repository containing detailed information about all users, encompassing both doctors and patients. The dataset includes crucial personal details such as name, surname, date, and place of birth, as well as contact information such as phone number and email (which serves as their user ID). Additional information comprises the user's registration timestamp on the website, timestamps for monthly and three-monthly questionnaires, and, if applicable, details specific to patients. For patients, this includes the name of their assigned doctor, specifications related to their assigned healthcare professional, and an indication of their category—whether they fall under standard care or telemedication. This collection forms the foundational structure for user management within our system, providing a comprehensive overview of both doctors and patients participating in our research initiative.

```
{
  "_id" : ,
  "name" : ,
  "surname" : ,
  "SSN" : ,
  "phoneNumber" : ,
  "role" : {"userRole" : "DOTTORE"},
  "enabled" : true,
  "emailValid" : true,
  "registrationTime" : NumberLong(1592242851),
  "doctorID" : ,
  "chatNotificationEnabled" : false,
  "birthDate" : ISODate("1989-05-07T00:00:00.000+0000"),
  "birthPlace" : ,
  "deadlineQuestionnaireModified" : false,
  "timestampLastMonthlyQuestionnaire" : NumberLong(0),
  "timestampLastThreeMonthlyQuestionnaire" : NumberLong(0),
  "timestampLastBiannualQuestionnaire" : NumberLong(0),
  "doctorRole" : "JUNIOR",
  "tokens" : [ ],
  "lastLogin" : ISODate("2023-06-08T18:57:17.605+0000"),
  "usageTime" : NumberLong(920918),
  "_class" : "com.backend.web.ibdtool.entity.UserEntity"
}
```

Chapter 3

Methods

1 Including and Excluding Criteria

To ensure precision and inclusivity, each SCCAI questionnaire is paired with at least one MIAH-UC questionnaire within a 7-day window. The SCCAI questionnaire serves as the reference date :

- **UC Diagnosis (Excluding Crohn's):**

Patients must have a documented diagnosis of UC or another relevant condition, the crohn's disease ones are excluded from our research.

- **SCCAI Reference Date:**

The SCCAI questionnaire serves as the reference point, initiating the temporal window for our criteria.

- **Pairing of SCCAI and MIAH-UC (± 7 days):**

Both SCCAI and MIAH-UC questionnaires must be completed within a ± 7 -day window to ensure a focused examination of symptoms and inflammation. Other relevant questionnaires completed within this window are also considered.

- **No Surgery Record:**

Patients must not have a documented history of surgery.

2 Data Extraction

In our research, data extraction is the vital step that turns raw information into useful insights. This involves carefully selecting relevant details from sources like medical records and questionnaires.

Data extraction is more than just gathering data points; it's a careful process that matches the information we collect with our set criteria. This ensures accuracy and helps us find meaningful patterns in the data we have.

In this section, we explain how we extract data, showing how this step is crucial for making our study reliable and thorough. This process helps us uncover important stories within the data, moving us toward well-informed conclusions.

2.1 Connecting and Authentication

Authentication is the process of verifying the identity of a client. When access control (authorization) is enabled, MongoDB requires all clients to authenticate themselves in order to determine their access.[25]

```
myClient = pymongo.MongoClient('mongodb+srv://...')
db = myClient['ibdtool']
questionnairesCollection = db['questionnaires']
clinicalDataPatientsCollection= db['clinicalDataPatients']
Users=db['users']
```

The initiation of this connection is facilitated by the creation of a MongoDB client, encapsulated within the pymongo library, which acts as the bridge between our Python environment and the MongoDB server.

PyMongo is a Python distribution containing tools for working with MongoDB, and is the recommended way to work with MongoDB from Python.[26]

'myClient' establishes a connection to the MongoDB server using the provided connection string. This connection string typically includes authentication details, server location, and other essential parameters.

With the connection in place, we then proceed to define our database and collections within it. In our case, the MongoDB database is named 'ibdtool,' signifying its role as the repository for our study's data.

Within the 'ibdtool' database, we create three distinct collections, each designated for a specific type of data: questionnaires, clinical data of patients, and user-related information.

2.2 Queries

The MongoDB aggregation framework⁴ is currently the most prominent language providing rich querying capabilities over collections of JSON documents, and hence has become the de-facto standard language for JSON. This language is modeled on the flexible notion of a data processing pipeline, where a query consists of multiple stages, each defining a transformation using a specific operator, applied to the set of documents produced by the previous stage.[27]

Clinical data query

```
query = {
  "$and": [
    {"bodyStat.pathology": {"$in": ["Colite ulcerosa", "Altro"]}},
    {"bodyStat.interventi": "0"}
  ]
}
# Execute the query and convert the result to a DataFrame
cursor = (clinicalDataPatientsCollection.find(query))
df = pd.DataFrame(list(cursor))
```

The query is designed to filter patients based on specific criteria related to their medical history. It selects patients who either have 'Colite ulcerosa' or other diseases ('Altro'), excluding those with 'Crohn's Disease' (CD). Furthermore, the query narrows down the selection further by including only patients with no recorded interventions, denoted by 'interventi=0'. This refined dataset allows for a more targeted analysis of patients with related inclusion and exclusion criteria that have been mentioned before.

Users data query

```
query = {"role.userRole": "PAZIENTE"}
# Execute the query and convert the result to a DataFrame
cursor = (Users.find(query))
df = pd.DataFrame(list(cursor))
```

This query is used to find specific user data in the collection, focusing on individuals with the role of 'PAZIENTE' (patient). By using the filter 'role.userRole': 'PAZIENTE', the query retrieves records where the user's role is labeled as a patient. This data collection contains personal information such as name, surname, date of birth, email, place of birth and ect.

3 Data processing

3.1 Data Filtering and Merging:

The `merge_questionnaire` function processes each row in the SCCAI dataset (`df_sccai`). For each row, it filters another dataset (`df_type`) containing specific questionnaire types (like 'MIAH-UC', 'IBD-DISK', 'PRISM', 'IBDQ', 'PHQ9', 'PSQI', 'MMAS8', 'EQ5D5L', 'LARS'). The function selects rows that match the patient's SSN and are within ± 7 days of the SCCAI questionnaire completion date, then assigns the final score to the corresponding row in `df_sccai`.

This careful timing ensures our dataset includes various questionnaire data aligned with SCCAI assessments. Since including MIAH-UC is crucial, we then drop rows that don't have matching final scores for MIAH-UC.

```
def merge_questionnaire(df_sccai, Type):

    df_type = Questionnaires[Questionnaires['type'] == Type]
    df_sccai[Type] = None
    # Iterate through each row in df_sccai
    for index, row in df_sccai.iterrows():
        closest_rows=df_type[(df_type['patientSSN']==
                               row['patientSSN'])
                              &
                              (df_type['date'] >= row['date'] - pd.Timedelta('7days'))
                              &
                              (df_type['date']<=row['date']+pd.Timedelta('7days'))]

        if not closest_rows.empty:
            closest_row = closest_rows.loc[closest_rows['date'].
                                            idxmin()]
            df_sccai.at[index,Type] = closest_row['finalScore']
    return df_sccai
```

```
Questionnaires['date']=pd.
    to_datetime(Questionnaires['date'])
df=Questionnaires[Questionnaires['type']=='PATIENT-SCCAI']
types=['MIAH-UC', 'IBD-DISK', 'PRISM', 'IBDQ', 'PHQ9', 'PSQI',
       'MMAS8', 'EQ5D5L', 'LARS']
for Type in types :
    df=merge_questionnaire(df,Type)
df=df.dropna(subset=['MIAH-UC'])
```

3.2 Bowel urgency score Calculation

The function `calculate_final_score` converts answers from questions 3, 4, and 5 of the SCCAI questionnaire into a numerical score. 'No' in question 3 and 'Yes' in questions 4 and 5 each add 1 to the final score. The total sum gives the participant's bowel urgency score.

```
df['results'] = df['results'].apply(ast.literal_eval)
def calculate_final_score(row):
    score_question_3 = 1 if row[2] == 'No' else 0
    score_question_4 = 1 if row[3] == 'Si' else 0
    score_question_5 = 1 if row[4] == 'Si' else 0
    final_score = score_question_3 + score_question_4 +
    ↪score_question_5
    return final_score
df['bowel urgency'] = df['results'].apply(calculate_final_score)
```

3.3 Final data collection

Our final data collection is created by extracting final scores from specific questionnaires based on inclusion and exclusion criteria, calculating the bowel urgency score, and merging necessary features from clinical and user data collections. It includes the following features:

```
['patientSSN',
 'name',
 'surname',
 'date',
 'Bowel urgency',
 'SCCAI',
 'MIAH-UC',
 'IBD-DISK',
 'IBDQ',
 'PHQ9',
 'MMAS8',
 'sex',
 'birthDate',
 'age',
 'height',
 'weight',
 'dateOfDiagnosis',
 'ageOfDiagnosis',
 'pathologyDuration',
 'storicheEIMS',
 'attiveEIMS',
 'stomia']
```

Chapter 4

Results

1 Statistics

In this study, we analyzed data from 277 patients with ulcerative colitis (UC) to explore their demographic and clinical characteristics. We found an almost equal gender split, with slightly more males (50.9%) than females (49.1%). The median age of the patients was 42 years, ranging from 16 to 86 years.

Patients were typically diagnosed with UC at a median age of 29 years, with diagnosis ages ranging from 1 to 69 years, showing that UC can start at various life stages. The median duration of UC was 11 years, emphasizing its chronic nature.

We also looked at UC-related surgeries and extraintestinal manifestations (EIMs). About 17.92% of patients had undergone UC-related surgeries, highlighting the significant impact of the disease on the gastrointestinal tract. Additionally, 18.77% of patients had a history of EIMs, indicating that UC can affect other organs beyond the digestive system.

Among patients with a history of EIMs, 15.16% had active EIMs at the time of the study, showing the ongoing challenges in managing UC and its complications.

Item	Value	%
Number of included patients	277	
Gender (male/female)	141/136	50.9/49.1
Age (Median, IQR, Range)	42, 30.5-51.5, 16-86	
Age of Diagnosis (Median, IQR, Range)	29, 22-37, 1-69	
Pathology duration (Median, IQR, Range)	11, 5-21, 0-69	
UC-related surgery	76/342	17.92
EIM history	52	18.77
EIM active	42	15.16

Table 4.1: Demographic and Clinical Characteristics of Patients [28]

2 Pathology Duration distribution

The histogram below depicts the distribution of pathology duration among patients enrolled in the study. Pathology duration refers to the length of time since diagnosis of ulcerative colitis (UC) in each patient. The x-axis represents the duration in years, while the y-axis indicates the number of patients falling within each duration range.

The distribution reveals a diverse spectrum of pathology durations, ranging from 0 to 45 years. The majority of patients appear to have pathology durations concentrated within the lower range, with noticeable peaks around 0 to 10 years. This suggests that a significant portion of UC patients have been living with the disease for a relatively moderate duration.

Quantile lines, denoted by red dashed lines, highlight key percentile values within the distribution. These lines help identify central tendencies and spread within the data. Notably, the median pathology duration falls within the range of 10 to 15 years, indicating that half of the patients have experienced UC for this duration or less.

This visualization offers valuable insights into the chronic nature of UC and the variability in disease duration among patients. Understanding the distribution of pathology duration is essential for clinicians and researchers to tailor treatment approaches, predict disease progression, and assess long-term outcomes in the management of UC.

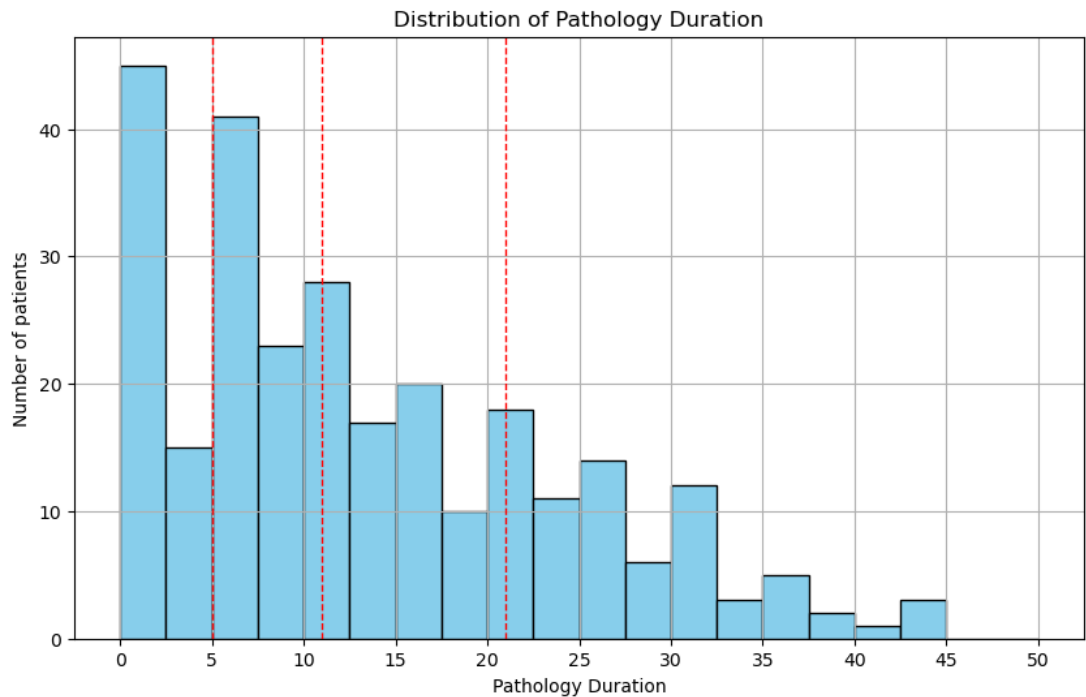


Figure 4.1: Pathology Duration Distribution

3 Age Distribution

The histogram below illustrates the distribution of ages among patients diagnosed with ulcerative colitis (UC). Each bar represents the number of patients falling within a specific age range.

The plot reveals a wide range of ages among the UC patient population, with the majority of patients concentrated within the middle-aged range. Specifically, there are notable peaks in the distribution around the ages of 30 to 50 years, indicating that a significant proportion of UC patients belong to this age group.

Quantile lines, represented by red dashed lines, mark key percentile values within the age distribution. These lines serve as reference points for understanding the central tendencies and variability in patient ages. Notably, the median age falls within the range of 40 to 45 years, indicating that half of the patients are younger than this age and half are older.

This visualization provides valuable insights into the demographic characteristics of UC patients, highlighting the age distribution within the studied population. Understanding the age demographics of UC patients is essential for tailoring interventions, assessing disease risk factors, and predicting disease outcomes in clinical practice.

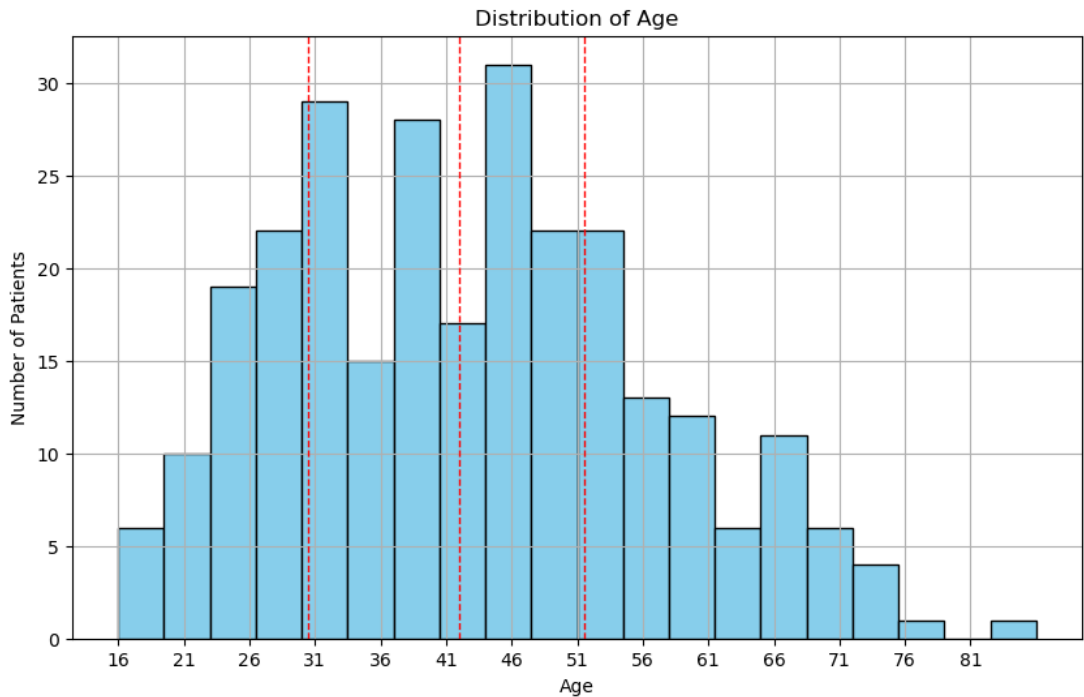


Figure 4.2: Age distribution

4 UC metrics over time

The graph below shows how three important health scores—Bowel Urgency, MIAH-UC, and IBD-DISK—have changed over time for a specific patient. These scores give us insight into how the patient’s health has been affected by their inflammatory bowel disease (IBD) over the months.

Each line on the graph represents one of these health scores. For example, the Bowel Urgency score tells us how urgently the patient needs to use the bathroom, while IBD-DISK gives us an idea of their emotional well-being and how their social life is impacted by their IBD. The MIAH-UC score shows how severe the disease is at different times.

By looking at how these scores go up and down over time, we can see patterns and trends in the patient’s health. For instance, if a score suddenly spikes, it might mean the patient is experiencing a flare-up of their IBD symptoms. If a score stays low for a while, it could mean the patient is doing well and their symptoms are under control.

Understanding these patterns helps doctors and patients make better decisions about treatment and care. By paying attention to changes in these scores, we can adjust medications, lifestyle habits, and other factors to improve the patient’s health and quality of life..

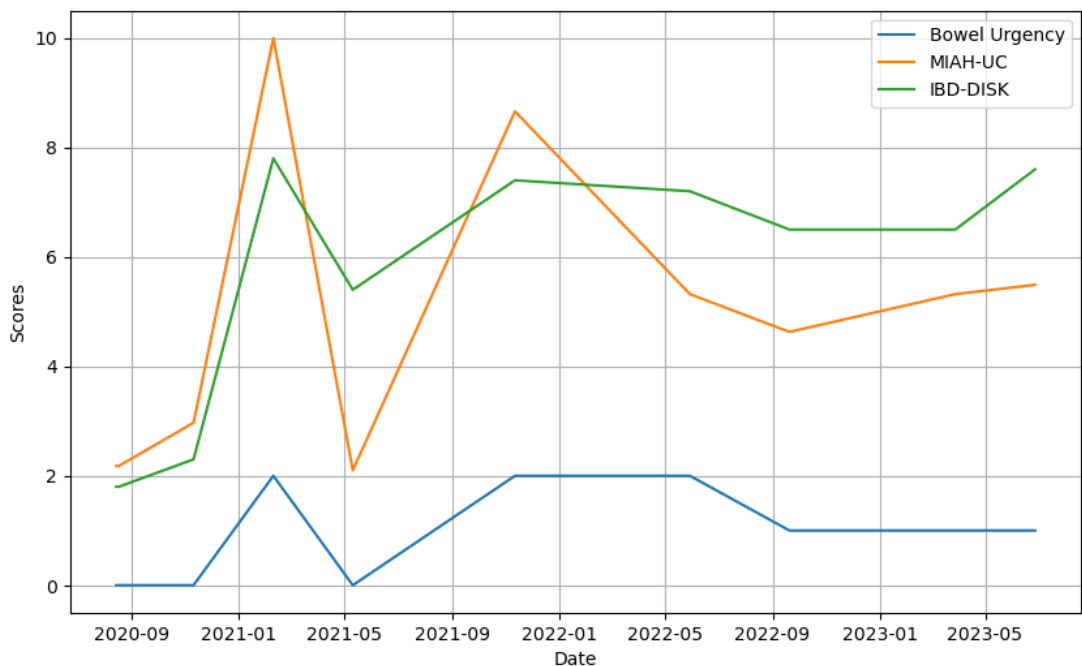


Figure 4.3: UC metrics over time

5 Bowel Urgency Distributions

Bowel Urgency general Distribution

The bar diagram below provides a clear visual representation of the distribution of cases based on their bowel urgency scores. Each bar on the graph corresponds to a specific bowel urgency score, ranging from 0 to 3, representing varying degrees of urgency experienced by patients with inflammatory bowel disease (IBD).

It is important to note that only the latest recorded score for each patient's unique identifier (PatientSSN) has been considered in this analysis. By focusing exclusively on the most recent data, we obtain a snapshot of the current state of bowel urgency across the patient population, offering insights into the prevalence and severity of this symptom at a given point in time.

The height of each bar corresponds to the percentage of cases exhibiting a particular bowel urgency score. For instance, a higher bar indicates a higher percentage of patients experiencing greater bowel urgency, while a lower bar signifies a lower prevalence of this symptom among the patient cohort.

By quantifying the distribution of bowel urgency scores and visualizing it in this manner, healthcare providers gain valuable insights into the prevalence and severity of this symptom within the IBD patient population. Such insights are instrumental in guiding treatment decisions, monitoring disease progression, and optimizing patient care strategies to address the specific needs and challenges associated with bowel urgency in IBD.

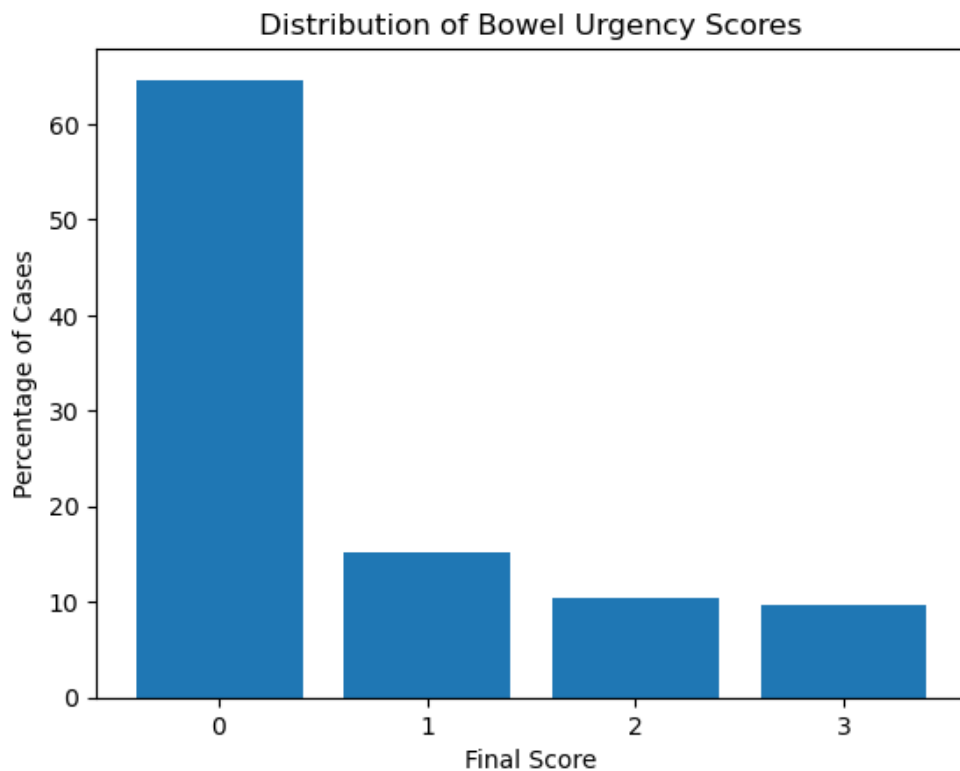


Figure 4.4: Bowel Urgency distribution

Bowel Urgency Distribution categorized by gender

The bar diagram below shows the distribution of bowel urgency scores among patients with inflammatory bowel disease (IBD), categorized by gender. Each bar represents the total percentage of cases for a specific urgency score, with segments indicating the proportion contributed by each gender.

The stacked bars provide a visual comparison of urgency scores between genders, showing the prevalence and severity of bowel urgency in male and female populations. The height of each bar reflects the total percentage of cases for each score, while the segments within the bars show the contribution of each gender.

This visualization helps understand how bowel urgency differs between genders, offering insights into potential gender-specific patterns in IBD symptoms. By analyzing these distributions, healthcare providers can tailor treatments to better address the needs of male and female patients.

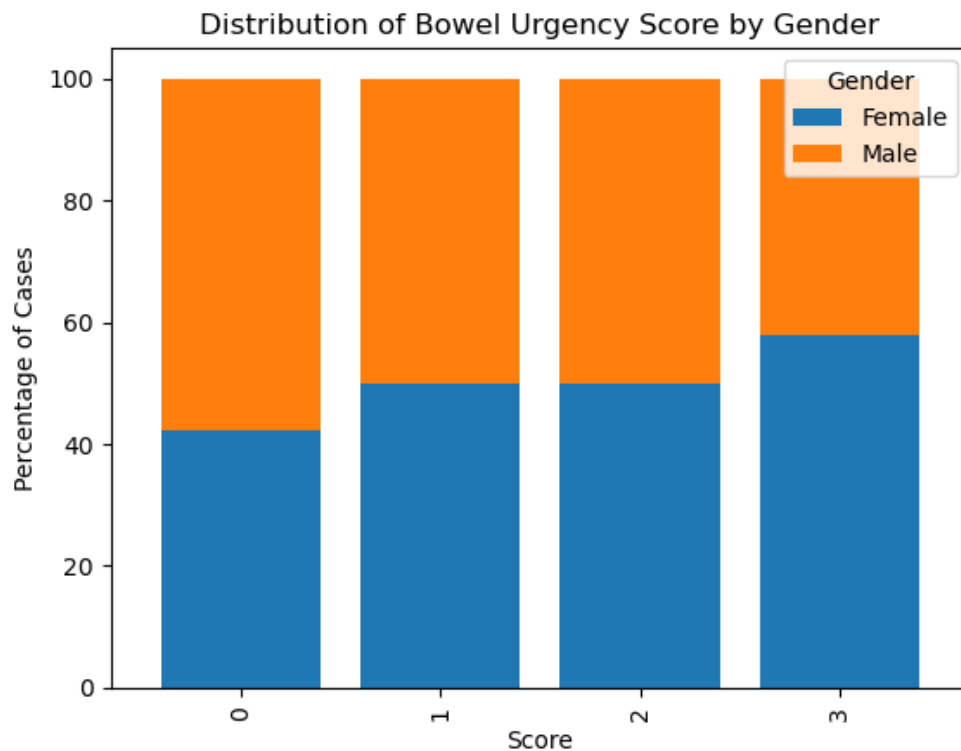


Figure 4.5: Bowel Urgency Distribution categorized by gender

Bowel Urgency Distribution categorized by age

This diagram breaks down bowel urgency scores into four age groups: <20, 20-40, 41-60, and 60+ years. Each urgency level has its own set of bars, one for each age group.

By grouping the data this way, the chart shows how bowel urgency patterns vary across different life stages. It helps us understand how age influences urgency scores and highlights trends related to age and bowel health.

The four bars for each urgency level make it easy to compare the prevalence and severity of bowel urgency across age groups. For example, by looking at the height of the bars, we can see which age groups have higher or lower percentages of specific urgency scores.

The stacked bar chart uses different colors for each age group, making it clear and easy to distinguish the contributions of each group to the overall distribution of urgency scores.

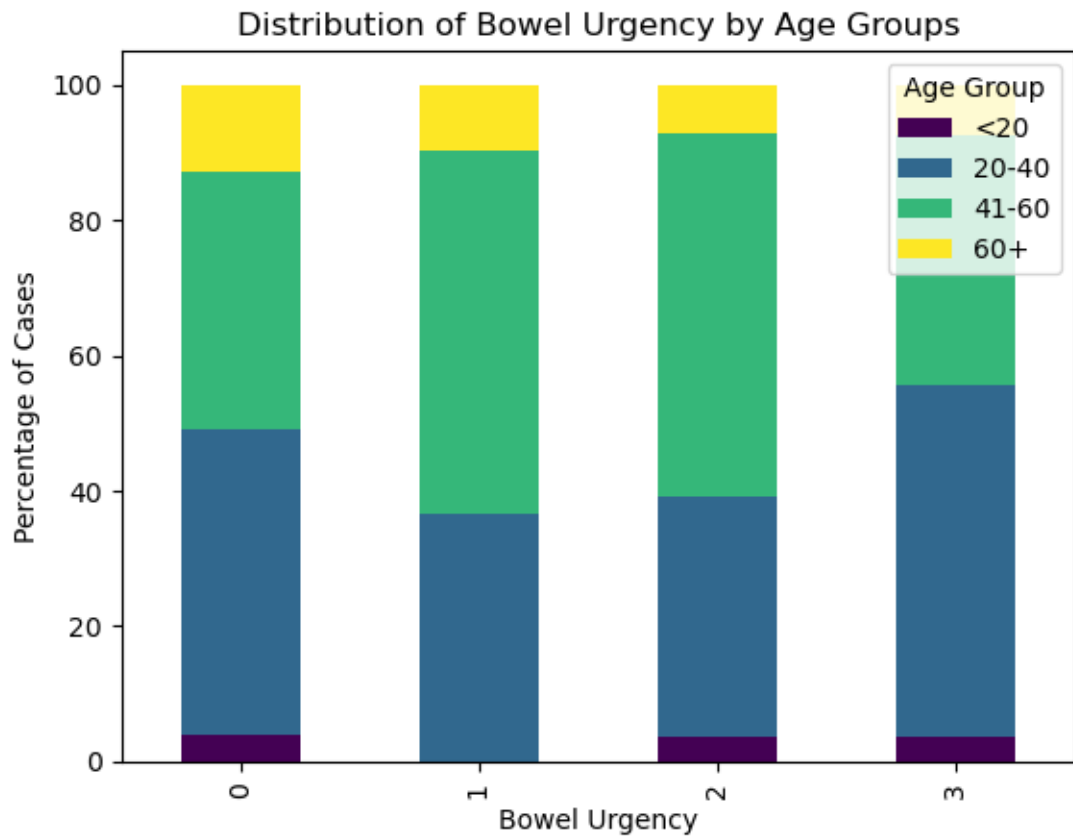


Figure 4.6: Bowel Urgency Distribution categorized by age

Bowel Urgency Distribution categorized by BMI

This diagram breaks down bowel urgency scores by BMI groups—underweight, normal weight, overweight, and obese. Each bar represents a specific BMI group and shows the percentage of cases with different bowel urgency scores.

By categorizing the data this way, the chart reveals how bowel urgency varies with body weight. The height of each bar shows the proportion of cases within each BMI group, while the segments within the bars represent different urgency scores.

This approach helps us understand the link between BMI and bowel urgency, highlighting whether certain weight statuses are associated with higher or lower urgency levels. By comparing these distributions, we gain insights into how body weight affects bowel health.

The stacked bar chart uses distinct colors for each BMI group, making it easy to see the contributions of different BMI categories to the overall urgency scores.

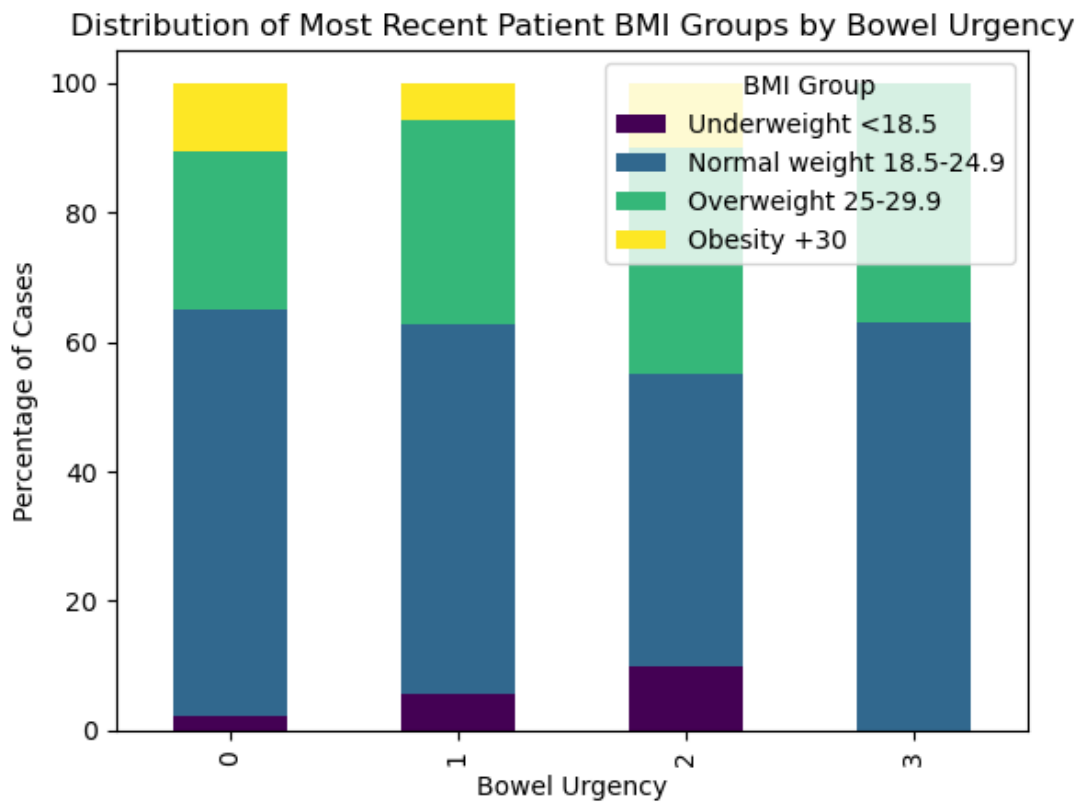


Figure 4.7: Bowel Urgency Distribution categorized by BMI

Bowel Urgency Distribution categorized by MIAH-UC score

This diagram presents a detailed exploration of the distribution of cases based on bowel urgency scores, categorized across three distinct bars, each representing a specific MIAH-UC final score group. By stratifying the data according to MIAH-UC outcomes, the chart unveils distinctive patterns in bowel urgency across different levels of disease severity.

Each bar within the chart corresponds to the percentage of cases within a particular MIAH-UC score group exhibiting a specific bowel urgency score. The height of each bar reflects the proportion of cases within the MIAH-UC group, with segments within the bar delineating the contribution of each urgency score.

This stratified approach enables us to examine how MIAH-UC final scores relate to the prevalence of specific urgency scores within the studied population. By comparing the distribution of urgency scores across MIAH-UC groups, we gain insights into the impact of disease severity on bowel urgency patterns.

The utilization of a stacked bar chart enhances the clarity of the visualization, with distinct colors representing each MIAH-UC group. This color-coded representation aids in distinguishing between the contributions of different disease severity levels to the overall distribution of urgency scores.

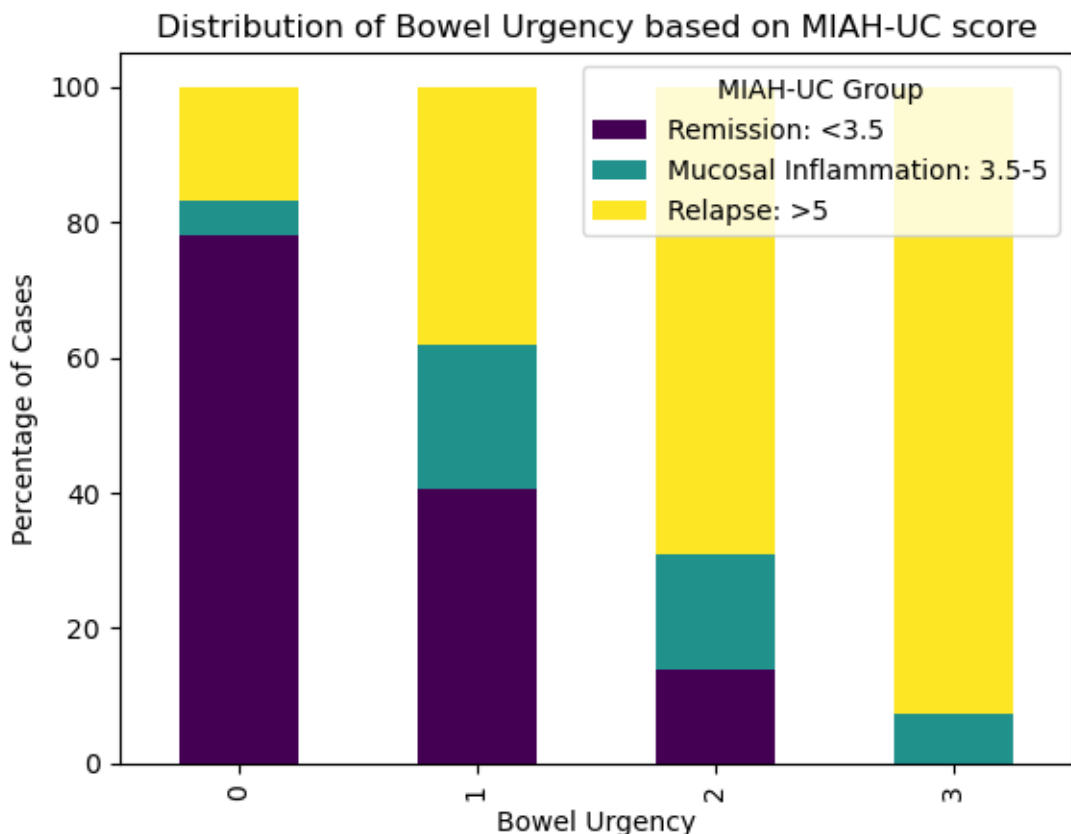


Figure 4.8: Bowel Urgency Distribution categorized by MIAH-UC score

Chapter 5

Conclusion

This is a thesis on a research project that encompasses the uses and effects of an IBD tool: a telemedical web application created to assist patients in monitoring and managing inflammatory bowel disease, which comprises Crohn's and ulcerative colitis. This will generally try to test for an effective increase in the interaction between the patient and doctor about healthcare outcomes.

It is possible to demonstrate the architecture and the main features of the IBD tool by concentrating on a comprehensive questionnaire system and secure communication functions. They allow timely and detailed reports of patient symptoms, while physicians can monitor the disease progression and see whether the treatment should be revised. Additionally, when working with massive amounts of information related to patients and stored and processed with the help of MongoDB, it is scalable and flexible enough.

Data analysis findings of the essential studies consist of patient demographics, statistical distribution of pathology duration and patient ages, and change in trend of metrics of UC over time. These analyses also helped to gain insight into the distribution of bowel urgency within and between groups by gender, age, BMI, and MIAH-UC scores. This further underpins the point that IBD symptoms are so variable and indicate the need for personalized therapeutic strategies.

Data-driven insights with the use of an IBD tool have great importance in managing IBD, especially in cases when UC and bowel urgency are prevailing. Physicians get profound and timely data from the tool to enable them to make better decisions on altering treatment plans for the benefit of individual patient needs, leading to improved outcomes in the end. Remote monitoring of symptoms also reduces the patient's frequency of visits to the hospital, improves quality of life, and optimizes the overuse of health resources.

Ultimately, the IBD tool represents the potential that telemedicine and advanced database technologies bear for overhauling chronic disease management, making care effective and personalized through continuous monitoring and a close patient-physician relationship. Thus, this research highlights the importance of the integration of new technologies into the practice of medicine and sets the path for further innovations regarding managing chronic diseases.

Future improvements

The study is cautious about some pitfalls present in patient-reported data that can easily lead to bias and generalization of the findings concerning the population under study. Moreover, this was a very sparse dataset, and insufficient features were available for applying advanced analytic techniques. For better improvement, we would take into account the development of machine learning techniques to understand the progression of bowel urgency over time when the situation is stable, ameliorated, or worsened; however, this is subject to having a more complete dataset with a rich set of features. Further research in data enrichment and validation for these advanced analytical methods will make it possible to establish further improvement in the prediction accuracy and clinical utility of the tool.

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Project Title: Progetto Telemonitoraggio

Deliverable Title: Trasferimento dell'architettura del servizio di telemonitoraggio precedentemente sviluppato (IBD Tool)

Lead beneficiary: IKINOVA

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Date: 07 June 2023

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- **Relapse:** final score > 3.6

Only for patients with Ulcerative Colitis (UC):

Clinical based SCCAI (Simple Clinical Colitis Activity Index)

Frequency: monthly

Short description: 13 questions, a score is associated at each answer, then a final score is calculated. This questionnaire is compiled by both physician (CLINICAL-SCCAI) and patient (PATIENT-SCCAI).

In details:

Questions	Answers	Scores
1. Quante evacuazioni ha avuto durante il giorno (cioè da quando si è svegliato a quando è andato a dormire) negli ultimi 3 giorni? Vanno considerate anche le evacuazioni solo di muco o di sangue.	<ul style="list-style-type: none">• 0-3 evacuazioni• 4-6 evacuazioni• 7-9 evacuazioni• oltre 9 evacuazioni	0 1 2 3
2. Quante evacuazioni ha avuto durante la notte (da quando si è coricato per dormire al risveglio, quante volte si è dovuto alzare per andare in bagno) nelle ultime 3 notti?	<ul style="list-style-type: none">• nessuna• 1-3 evacuazioni• 4 o più evacuazioni	0 1 2
3. Quanta urgenza all'evacuazione ha accusato negli ultimi 3 giorni? (Cioè, quanto deve correre quando ha lo stimolo ad evacuare)	<ul style="list-style-type: none">• non ho alcuna urgenza evacuativa• devo andare velocemente in bagno• non posso aspettare per andare in bagno• ho episodi di incontinenza (non riesco a controllare l'urgenza e mi è capitato di perdere le feci)	0 1 2 3
4. Quanto sangue ha visto nelle feci negli ultimi 3 giorni?	<ul style="list-style-type: none">• Nulla• Sangue in tracce (una macchia o una piccola quantità)• Sangue più abbondante (talvolta abbondante o anche solo sangue)	0 1 2 3



	<ul style="list-style-type: none">• Sanguinamento grave (sangue sempre abbondante o evacuazioni solo di sangue)	
5. Benessere generale (come si sente in generale con la Sua salute? (VAS 1-10)	<ul style="list-style-type: none">• Molto bene (VAS ≥ 7)• Un po' meno bene del solito (VAS 6)• Male (VAS 5)• Piuttosto male (VAS 4)• Malissimo (VAS < 4)	0 1 2 3 4
6. A parte i Suoi sintomi intestinali, ha avuto qualcuno dei sintomi elencati a seguire?	<p>b) Problemi articolari (ha avuto dolore, arrossamento o gonfiore articolare)?</p> <ul style="list-style-type: none">◦ Sì <p>b) Problemi oculari (occhi rossi, dolorosi o fastidiosi)? Altri sintomi possono essere visione offuscata, sensibilità alla luce, carenza o eccesso di lacrimazione*</p> <ul style="list-style-type: none">◦ Sì (1 punto) <p>Nota: Se ha avuto arrossamento dell'occhio ed ha avuto in precedenza una diagnosi di uveite, episclerite o sclerite, ed ha una recidiva dei sintomi avvertiti, proceda con una visita Oculistica urgentemente</p> <p>c) Problemi orali (ha avuto afte in bocca)? Le afte sono aree giallastre rotonde, circondate da un alone rosso</p> <ul style="list-style-type: none">◦ Sì (1 punto) <p>d) Problemi cutanei:</p> <ul style="list-style-type: none">◦ Ha avuto delle ulcerazioni in genere profonde, violacee che si sono sviluppate improvvisamente (o le è stata fatta diagnosi di pioderma gangrenoso)?▪ Sì (1 punto)◦ Ha avuto delle sorte di lividi rilevati molto dolenti, soprattutto agli arti inferiori (o le è stata	Each Sì = 1 No = 0



	<p>fatta diagnosi di eritema nodoso?</p> <ul style="list-style-type: none"> ▪ Sì (1 punto) <p>e) Problemi perianali (ha avuto ferite o fissurazioni della pelle anale o ascessi (aree arrossate dolenti perianali)</p> <ul style="list-style-type: none"> • Sì (1 punto) 	
Final score	sum of the five questions and sub questions scores	

Final score

The final score indicates a health status:

- **Remission:** final score <5
- **Relapse:** final score >= 5

Variance between the final score of the current month and the final score of the previous month is calculated and used to define patient status (e.g., final score April – final score March):

- **Paziente in miglioramento:** final score variance <= -2
- **Paziente in peggioramento:** final score variance >= +2
- **Paziente stabile:** -2< variance final score <+2

The final score of PATIENT-SCCAI is taken in account.

MIAH-UC (Monitor IBD At Home)

Frequency: monthly

Short description: 5 questions, a score is associated at each answer, then a final score is calculated.

In details:

Questions	Answers	Scores
1. Se dovesse misurare il Suo stato di salute generale attribuendo un numero, quale numero sceglierebbe?	Barra di scorrimento (0=malissimo, 10=perfetto)	VAS scale 0 to 10
2. Sanguinamento rettale	<ul style="list-style-type: none"> • Sì • No 	10 0
3. Numero di evacuazioni al giorno:	Campo vuoto, possibilità di indicare un numero intero	<4 = 0, >3=10
4. Urgenza evacuativa	<ul style="list-style-type: none"> • No • Sì, urgente 	0 10



	• Sì, molto urgente	10
5. Dolore addominale	Barra di scorrimento (0=malissimo, 10=perfetto)	0 to 10
Final score	Solve the algorithm	

Question 1:

Patient-reported disease activity

Scoring VAS scale 0-10: 0 = very poor, 10 = very well.

Question 2:

Rectal bleeding

Scoring (yes/no): No= 0, Yes= 10.

Question 3:

Stool frequency (per day)

Scoring: <4 = 0, >3=10.

Question 4:

Subdomain 4.1 Urgency (last 24 hours)

Scoring (3 options): No = 0. Yes, quite urgent/Yes, very urgent = 10.

Intra-domain weightfactor: 0.5

Sub-question 4.2 Abdominal pain (last 24 hours)

Scoring VAS scale 0-10: 0 = no abdominal pain, 10 = worst abdominal pain.

Intra-domain weightfactor: 0.5

0,5 * answer subdomain 2.1 + 0,5 * answer subdomain 2.2. Score: 0-10.

Algorithm

$$X = 10 * \left(\frac{e^{-0.611 - 0.160 * (\text{answer domain 1}) + 2.103 * (\text{answer domain 2}) + 0.167 * (\text{answer domain 3}) - 0.184 * (\text{answer domain 4})}}{1 + e^{-0.611 - 0.160 * (\text{answer domain 1}) + 2.103 * (\text{answer domain 2}) + 0.167 * (\text{answer domain 3}) - 0.184 * (\text{answer domain 4})}} \right)$$

Cut-off = 3,542150 → X > 3,542150 → mucosal inflammation

For use in myIBDcoach, we reversed the formula (X < 6,5 = mucosal inflammation)

$$X = 10 - \left(10 * \left(\frac{e^{-0.611 - 0.160 * (\text{answer domain 1}) + 2.103 * (\text{answer domain 2}) + 0.167 * (\text{answer domain 3}) - 0.184 * (\text{answer domain 4})}}{1 + e^{-0.611 - 0.160 * (\text{answer domain 1}) + 2.103 * (\text{answer domain 2}) + 0.167 * (\text{answer domain 3}) - 0.184 * (\text{answer domain 4})}} \right) \right)$$

Cut-off = 6.45785 → X < 6.45785 → mucosal inflammation

The final score indicates a health status:

- **Remission:** final score < 3.6
- **Relapse:** final score > 3.6



For both CD and UC patients:

IBD-DISK (Inflammation-Bowel-Disease Disability Index)

Frequency: monthly

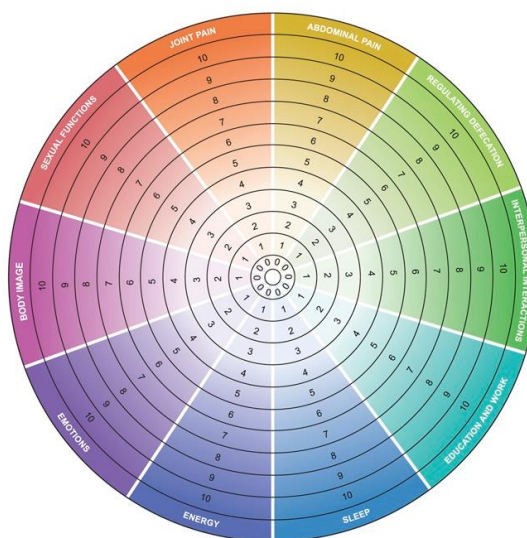
Short description: 10 questions, a score (from 0 to 10) is associated at each answer. The result is expressed in terms of a score disk.

Questions	Answers	Scores
1. Dolori addominali: Ho avuto dolori allo stomaco o addominali	Barra di scorrimento (0: Totalmente in disaccordo, 5: Né d'accordo né in disaccordo, 10: Totalmente d'accordo)	0 to 10
2. Controllo evacuazioni: Ho avuto difficoltà nel coordinare e controllare le evacuazioni, incluso la scelta di un posto appropriato per la defecazione e la successiva pulizia personale	Barra di scorrimento (0: Totalmente in disaccordo, 5: Né d'accordo né in disaccordo, 10: Totalmente d'accordo)	0 to 10
3. Interazioni interpersonali: Ho avuto difficoltà con le relazioni personali e/o difficoltà a partecipare nella comunità	Barra di scorrimento (0: Totalmente in disaccordo, 5: Né d'accordo né in disaccordo, 10: Totalmente d'accordo)	0 to 10
4. Educazione e lavoro: Ho avuto difficoltà con le attività scolastiche o di studio, e/o difficoltà con il lavoro o con le faccende domestiche	Barra di scorrimento (0: Totalmente in disaccordo, 5: Né d'accordo né in disaccordo, 10: Totalmente d'accordo)	0 to 10
5. Sonno: Ho avuto difficoltà nel dormire, ad esempio con l'addormentarmi, svegliandomi frequentemente la notte o svegliandomi troppo presto la mattina	Barra di scorrimento (0: Totalmente in disaccordo, 5: Né d'accordo né in disaccordo, 10: Totalmente d'accordo)	0 to 10
6. Energia: Non mi sono sentito riposato durante la giornata, e mi sono sentito stanco e senza energie	Barra di scorrimento (0: Totalmente in disaccordo, 5: Né d'accordo né in disaccordo, 10: Totalmente d'accordo)	0 to 10
7. Emozioni: Mi sono sentito triste, giù di morale o depresso, e/o preoccupato o ansioso	Barra di scorrimento (0: Totalmente in disaccordo, 5: Né d'accordo né in disaccordo, 10: Totalmente d'accordo)	0 to 10
8. Visione del proprio corpo: Non mi è piaciuto il modo in cui appare il mio corpo o parti del mio corpo	Barra di scorrimento (0: Totalmente in disaccordo, 5: Né d'accordo né in disaccordo, 10: Totalmente d'accordo)	0 to 10



9. Funzioni sessuali: Ho avuto difficoltà con aspetti sessuali mentali e/o fisici	Barra di scorrimento (0: Totalmente in disaccordo, 5: Né d'accordo né in disaccordo, 10: Totalmente d'accordo)	0 to 10
10. Dolori articolari: Ho avuto dolore alle articolazioni del mio corpo	Barra di scorrimento (0: Totalmente in disaccordo, 5: Né d'accordo né in disaccordo, 10: Totalmente d'accordo)	0 to 10
Final score	sum of the ten answers scores	0 to 100

Final score disk:



PHQ9 (Patient Health Questionnaire-9)

Frequency: 3 months

Short description: 2 questions. The first question evaluates the symptoms of depression with 9 sub questions, at each sub questions a score between 0 and 3 is associated, the second question evaluates the effect of depression on the patient quality of life, then a final score is calculated.

In details:

Instructions and general informations		
Il presente questionario è importante perché ci consente di fornirLe la miglior assistenza possibile. Le Sue risposte ci aiuteranno a capire i problemi che Lei può avere. La preghiamo, perciò, di rispondere con la massima precisione possibile.		
Questions	Answers	Scores
1. Durante le ultime due settimane, per quanti giorni...		