



# #MyIBDHistory on Twitter

## Predicting IBD Type From Personal Tweets

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SOTICS 2022



## Maya Stemmer

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- PhD Student in the Department of Industrial Engineering and Management at Ben-Gurion University of the Negev, Israel.
- Research area: social media mining for health insights.

### Recent publications

**Stemmer, M., Parmet, Y., & Ravid, G. (2022).** Identifying Patients With Inflammatory Bowel Disease on Twitter and Learning From Their Personal Experience: Retrospective Cohort Study. *Journal of Medical Internet Research*, 24(8), e29186. <https://doi.org/10.2196/29186>.

**Stemmer, M., Parmet, Y., & Ravid, G. (2021, November).** What Are IBD Patients Talking About on Twitter?. In *International Conference on ICT for Health, Accessibility and Well-being* (pp. 206-220). Springer, Cham. [https://doi.org/10.1007/978-3-030-94209-0\\_18](https://doi.org/10.1007/978-3-030-94209-0_18).

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# Introduction



## Motivation

*"Do any IBD people have experience with/heard of Golimumab for UC? It's a biologic and I'm thinking of giving it a go!"*

*"I am living proof that yoga can help [#uchicagoibd](#) [#studiothree](#) [#yoga](#) [#ibd](#)"*



## Learning from Patients' Personal Experience

- Social networks serve as alternative information sources for patients.
- Patients use social media to share **daily experiences** including health and treatment information.
- Chronically ill patients exchange experiential knowledge about their everyday life with the disease that extends far beyond medical care.
- Mining these informative conversations may shed some light on patients' ways of life and **support the research of chronic conditions.**

# Inflammatory Bowel Disease (IBD)

- Chronic inflammation condition of the digestive system
- Flares and remissions
- Two main diseases: Crohn's Disease (CD), Ulcerative Colitis (UC)
- Inconclusive cases: IBD Unclassified (IBD-U)

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## Characteristics

Chronic and incurable

Lifestyle changes can help with symptoms

Diversity in treatments' effectiveness

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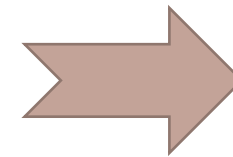
## Social Implications

Disruption of daily activities

Embarrassment

Lack of public awareness

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Mining  
social  
media

## #MyIBDHistory on Twitter

- The hashtag #MyIBDHistory was initiated in 2018 by a Twitter account promoting IBD-related discussion called @bottomlineibd.
- Patients with IBD wrote their own medical history in a single tweet and signed it with the hashtag #MyIBDHistory.
- In their tweets, patients mentioned their disease type (CD or UC), their age at diagnosis, the medications they have tried over the years, whether they underwent any surgeries, and more.

*“ UC, diagnosed 2011 (age 30). Colonoscopy showed severe ulceration. Asacol didn't work, pred did. Tried Pentasa, more pred, Balsalazide (still on 9/day). 3 flares in a year lead to Aza and Mercap but intolerant to both. On Golimumab for a year, still seems to work. #MyIBDHistory ”*

## Research questions

Is it possible to derive insights into the well-being of patients with IBD by mining Twitter data?

Can we use the information shared by patients with IBD on Twitter to determine whether a patient with IBD suffers from CD or UC?

What are the key features that help to distinguish between CD and UC?





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# Methodology





## Overview

-  This research aimed to analyze patients' tweets containing the hashtag #MyIBDHistory and to determine the disease type of an IBD patient based on their symptoms and treatments.
-  We constructed a list of classification features and used LASSO logistic regression to predict whether a patient suffered from CD or UC.
-  We identified key features and our results correlated with IBD-related research.
-  To adhere to ethical norms and maintain user privacy, we publish aggregated results that do not reveal the specific users. Directed quotes are presented here after we obtained informed consent from their authors.

## Data collection and preparation

Twitter  
Academic API:  
#MyIBDHistory  
tweets

Self-reported  
medical history  
of 125 IBD  
patients

Conversion to a  
tabular  
database with  
IBD features

## Data collection and preparation – example

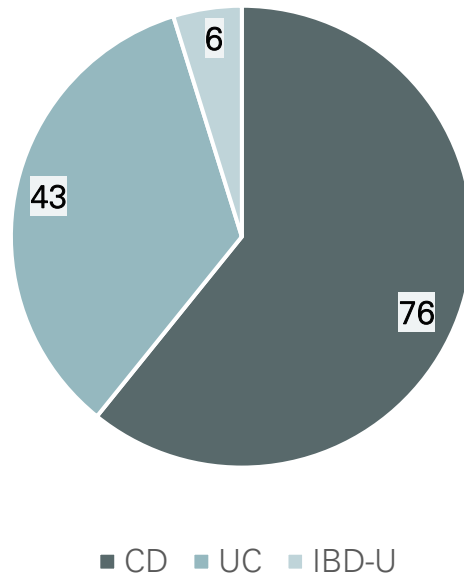
*“ UC, diagnosed 2011 (age 30). Colonoscopy showed severe ulceration. Asacol didn’t work, pred did. Tried Pentasa, more pred, Balsalazide (still on 9/day). 3 flares in a year lead to Aza and Mercap but intolerant to both. On Golimumab for a year, still seems to work. #MyIBDHistory ”*



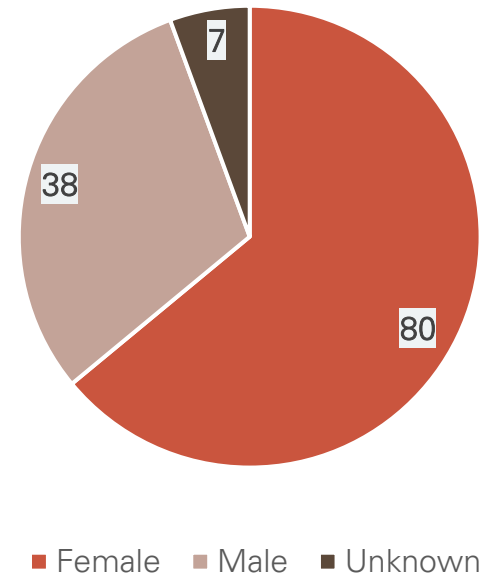
Disease type	Gender	Age group	Meds: anti-inflammatory	Meds: steroids	Meds: antibiotics	Meds: biologics	Meds: Immune suppressors	Meds: others	Wrong diagnosis	Fistula	Weight	Diet	Pre-diagnosis	Hospital
UC	M	15-35	1	1	0	1	1	0	0	0	0	0	0	0

# A bit of descriptive statistic...

Disease type



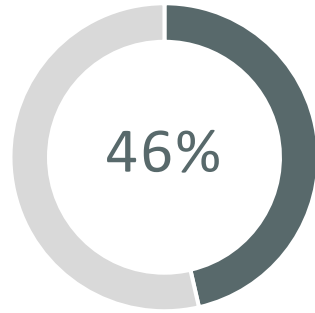
Gender



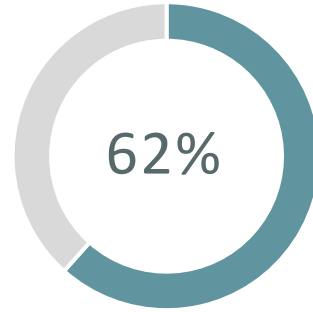
# A bit of descriptive statistic...

Medications

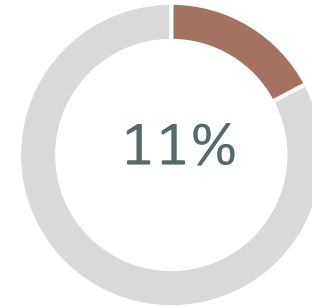
Anti-inflammatory



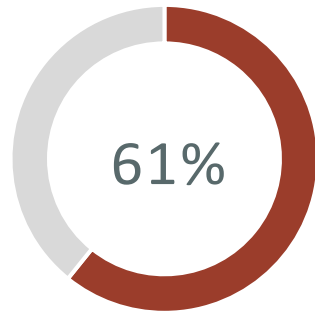
Steroids



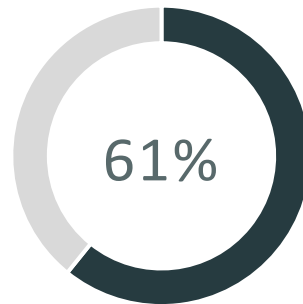
Antibiotics



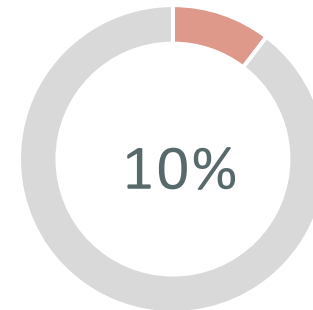
Biologics



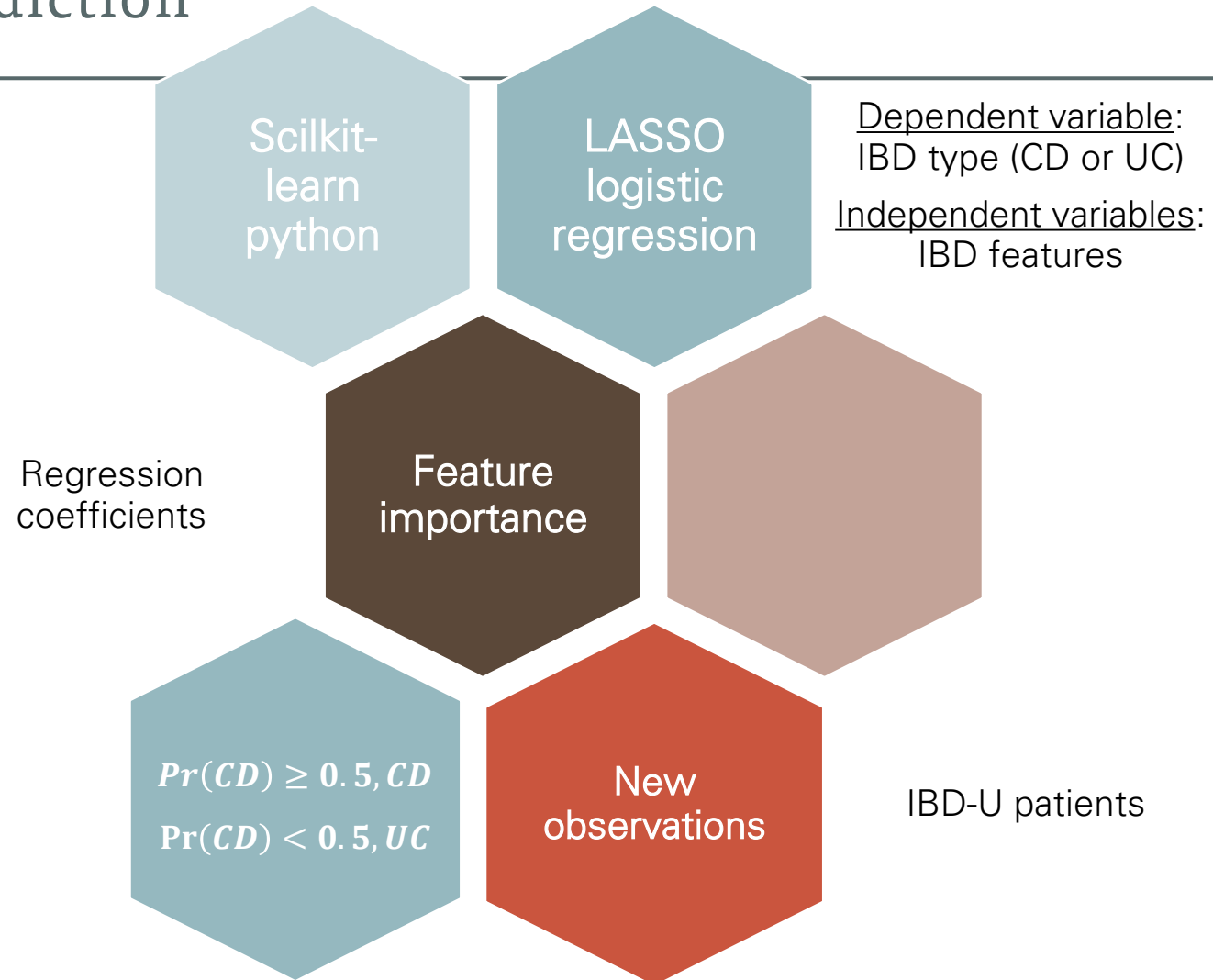
Immune suppressors



Others



# Disease type prediction



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## Results



# Disease type prediction

Regression model evaluation results

Evaluation Measure	Evaluation Data	
	Test Set	Entire Dataset
Accuracy	0.75	0.7563
Precision	0.7273	0.7527
Recall	1.0	0.9211
F1	0.8421	0.8284
Area Under the Receiver Operating Characteristic Curve (AUC ROC)	0.625	0.6931

Confusion matrices for the regression model

Evaluation Data	Predictions		
	Predicted UC	Predicted CD	
Test Set	True UC	2	6
	True CD	0	16
Entire Dataset	True UC	20	23
	True CD	6	70

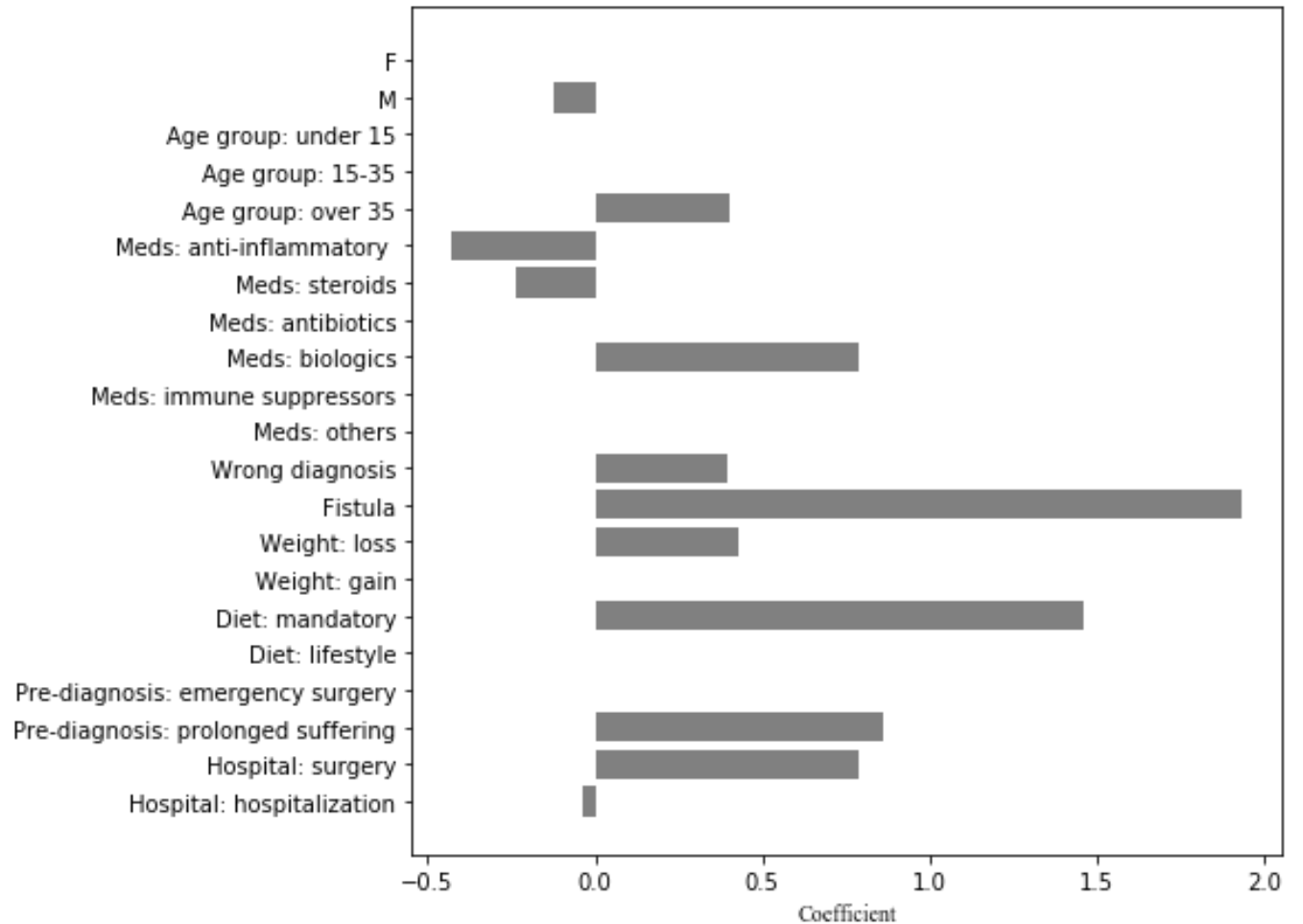


# Feature importance

Strong (CD) features:




1. Fistula
2. Diet: mandatory
3. Pre-diagnosis:  
prolonged suffering
4. Meds: biologics
5. Hospital: surgery

Bar chart of feature importance based on regression coefficients



# IBD-U prediction

Features and predictions for IBD-U patients

-  Highly confident classification
-  Confident classification
-  Inconclusive classification

Feature/ Prediction	Patient					
	IBD1	IBD2	IBD3	IBD4	IBD5	IBD6
Gender: female	0	1	1	0	1	1
Gender: male	1	0	0	1	0	0
Age group: under 15	0	0	1	0	0	0
Age group: 15-35	0	0	0	1	0	0
Age group: over 35	1	0	0	0	1	0
Meds: anti-inflammatory	1	0	0	0	1	0
Meds: steroids	1	0	1	1	1	0
Meds: antibiotics	0	0	1	0	0	0
<b>Meds: biologics</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>
Meds: immune suppressors	1	0	1	0	0	0
Meds: others	0	0	0	0	0	0
Wrong diagnosis	0	0	0	0	0	0
<b>Fistula</b>	0	0	<b>1</b>	0	0	0
Weight: loss	0	0	1	0	0	0
Weight: gain	0	0	0	0	0	0
<b>Diet: mandatory</b>	0	0	<b>1</b>	0	0	0
Diet: lifestyle	0	0	0	0	0	0
Pre-diagnosis: emergency surgery	0	1	0	0	0	0
<b>Pre-diagnosis: prolonged suffering</b>	<b>1</b>	0	0	0	0	0
<b>Hospital: surgery</b>	0	<b>1</b>	<b>1</b>	<b>1</b>	0	0
Hospital: hospitalization	1	0	0	0	0	0
Probability	0.622	0.567	0.994	0.603	0.428	0.589
Class	1	1	1	1	0	1

# IBD-U prediction

- **Patient IBD3:** fistula + mandatory diet change, the two strongest features => unambiguous CD classification.
- **Patients IBD1 and IBD4:** biologic meds + prolonged suffering/ surgery => CD classification.
- **Patients IBD2, IBD5, and IBD6:** only one medium level feature => indecisive classification with probabilities ~0.5.
- **Patient IBD5:** anti-inflammatory meds + steroids, the strongest UC features => UC classification.






Feature/ Prediction	Patient					
	IBD1	IBD2	IBD3	IBD4	IBD5	IBD6
Gender: female	0	1	1	0	1	1
Gender: male	1	0	0	1	0	0
Age group: under 15	0	0	1	0	0	0
Age group: 15-35	0	0	0	1	0	0
Age group: over 35	1	0	0	0	1	0
Meds: anti-inflammatory	1	0	0	0	1	0
Meds: steroids	1	0	1	1	1	0
Meds: antibiotics	0	0	1	0	0	0
<b>Meds: biologics</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>1</b>
Meds: immune suppressors	1	0	1	0	0	0
Meds: others	0	0	0	0	0	0
Wrong diagnosis	0	0	0	0	0	0
<b>Fistula</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>
Weight: loss	0	0	1	0	0	0
Weight: gain	0	0	0	0	0	0
<b>Diet: mandatory</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>
Diet: lifestyle	0	0	0	0	0	0
Pre-diagnosis: emergency surgery	0	1	0	0	0	0
<b>Pre-diagnosis: prolonged suffering</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>
<b>Hospital: surgery</b>	<b>0</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>0</b>	<b>0</b>
Hospital: hospitalization	1	0	0	0	0	0
Probability	0.622	0.567	0.994	0.603	0.428	0.589
Class	1	1	1	1	0	1

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## Discussion



## Principal findings

-  Analysis of #MyIBDHistory tweets: extraction of categorical features from natural language text describing the medical history of IBD patients.
-  LASSO logistic regression: prediction of IBD type (CD or UC) and identification of key features that help distinguish CD from UC.
-  The two strongest CD features – having a fistula and resorting to mandatory diet changes – two common CD phenomena that seldom occurs with UC.
-  The LASSO regulation helped to eliminate unnecessary independent classification variables.
-  Differentiation complexity: with CD distinctive characteristics – confident CD classification. Otherwise, equivocal classification.

## Limitations and future research



Relatively small patient dataset



Enriching the dataset by identifying more patients on Twitter or expanding the search to other social media.



Imbalanced data with 0.5 classification threshold



Balancing the groups by adding more UC patients or changing the classification threshold in favor of UC.

## Contribution and Conclusion



The first study to use social media data for differentiating between CD and UC.



The first study to use the #MyIBDHistory hashtag to scientifically draw conclusions for IBD.



The methods can also help to explore other medical conditions.



Findings from Twitter research on IBD patients correlate with existing medical knowledge regarding the disease => Room for collaboration between physicians and engineers.



Further mining Twitter for health-related data may complement and enhance healthcare research.



Thank you

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