

Ontology-based interactive visualization of patient-generated research questions

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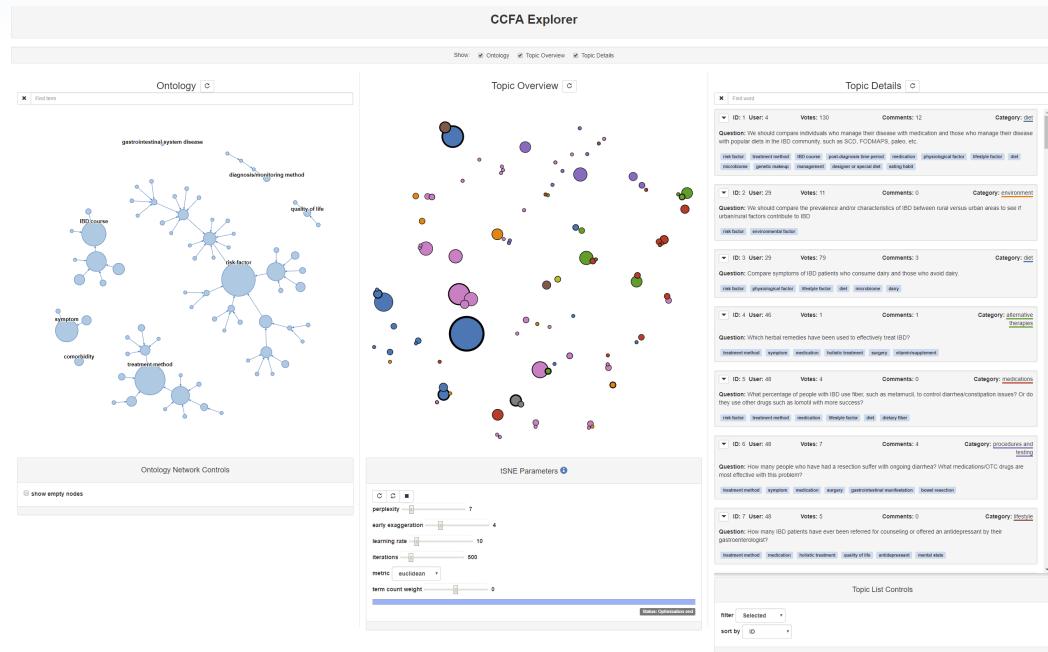
THE UNIVERSITY
of NORTH CAROLINA
at CHAPEL HILL



National Institute of Environmental Health Sciences
Your Environment. Your Health.

Overview

- **Background**
 - Crohn's disease & colitis
 - IBD Partners discussion forum
- **Ontology creation**
- **CCFA Explorer**
 - Ontology visualization
 - Research topic visualization
 - Overview
 - Details
- **Example scenario**
- **Feedback and future work**



Crohn's Disease and Colitis

- **Crohn's disease**
 - Inflammatory bowel disease (IBD)
 - Chronic
 - Diverse set of symptoms
 - Diarrhea
 - Inflammation (gut and other body parts)
 - Fatigue
 - Abdominal pain
 - Weight loss
 - Etc.
- **Colitis**
 - Inflammation of the inner lining of the colon
 - Commonly co-occurs with Crohn's disease

Crohn's Disease and Colitis

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 - **Colitis**
 - Inflammation of the inner lining of the colon
 - Commonly co-occurs with Crohn's disease
- 
- No known cure
- Certain therapies can help treat *symptoms*
- Treatment largely consists of *disease management*

IBD Partners

(formerly CCFA Partners)

- Patient-powered online research network
 - Crohn's and Colitis Foundation
 - UNC-Chapel Hill School of Medicine
- Discussion forum
 - Patients propose and discuss research ideas
 - Researchers engage in discussion

The screenshot shows the top navigation bar of the IBD Partners website. It includes the logo "IBD PARTNERS" with a stylized blue and green icon, followed by links for "About", "Resources", "For Researchers", "For Kids & Teens", "Help", and "Sign In". Below the main navigation, there is a secondary navigation bar with links for "Home", "Research Ideas", "My Health Data", "My Contributions", "Members", and "Blog".

An IBD Patient-Powered Research Network

IBD Partners (formerly known as CCFA Partners) is an online research network brought to you by the Crohn's and Colitis Foundation and the University of North Carolina School of Medicine. We bring together inflammatory bowel disease (IBD) patients and researchers in a revolutionary partnership aimed at optimizing treatment of IBD.



Want to learn more? [View infographic](#)

Join IBD Partners to start collaborating with researchers today.

[Join](#)

We believe that when patients and researchers work together we learn so much more about how to better treat inflammatory bowel diseases (IBD).

Patients understand their own body and disease best and have valuable information to share. We provide a way for researchers to listen to patients about their experiences with IBD. By working together, we can answer the questions that are most important to patients.

Our Community

We are one of the largest IBD research networks in the world.

[See Our Community](#)



15,680

We are now 15,680 patients strong.



300+

There are over 300 IBD researchers involved in our network.

How It Works



Patients Propose Research Ideas

Patients come up with insightful research ideas. We invite you to propose, vote, and discuss research ideas. IBD researchers will review these ideas. Your idea may even lead to a study!

Popular Research Ideas

We should compare individuals who manage their disease with medication and those who manage their disease with popular diets in the IBD

Discussion Forum Data



Research topic

Research question

Description

User ID, Votes, Category

Comment

User ID

Comment

User ID



Discussion Forum Data



Research topic

Research question

Description

User ID, Votes, Category

Comment

User ID

Comment

User ID



Forum snapshot:

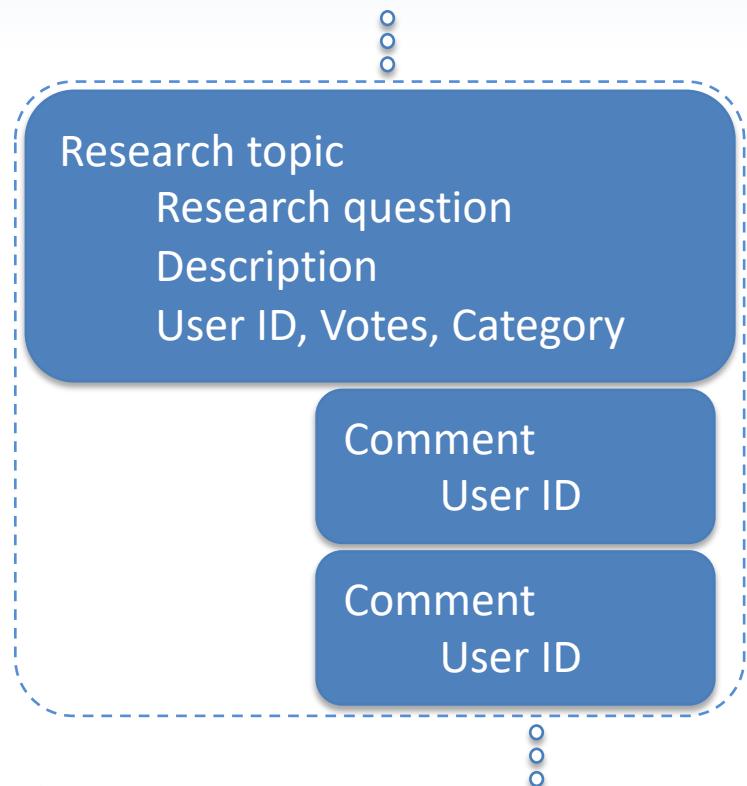
97 research topics

121 total comments

400 unique users

1246 total votes

Discussion Forum Data



Example topic post:

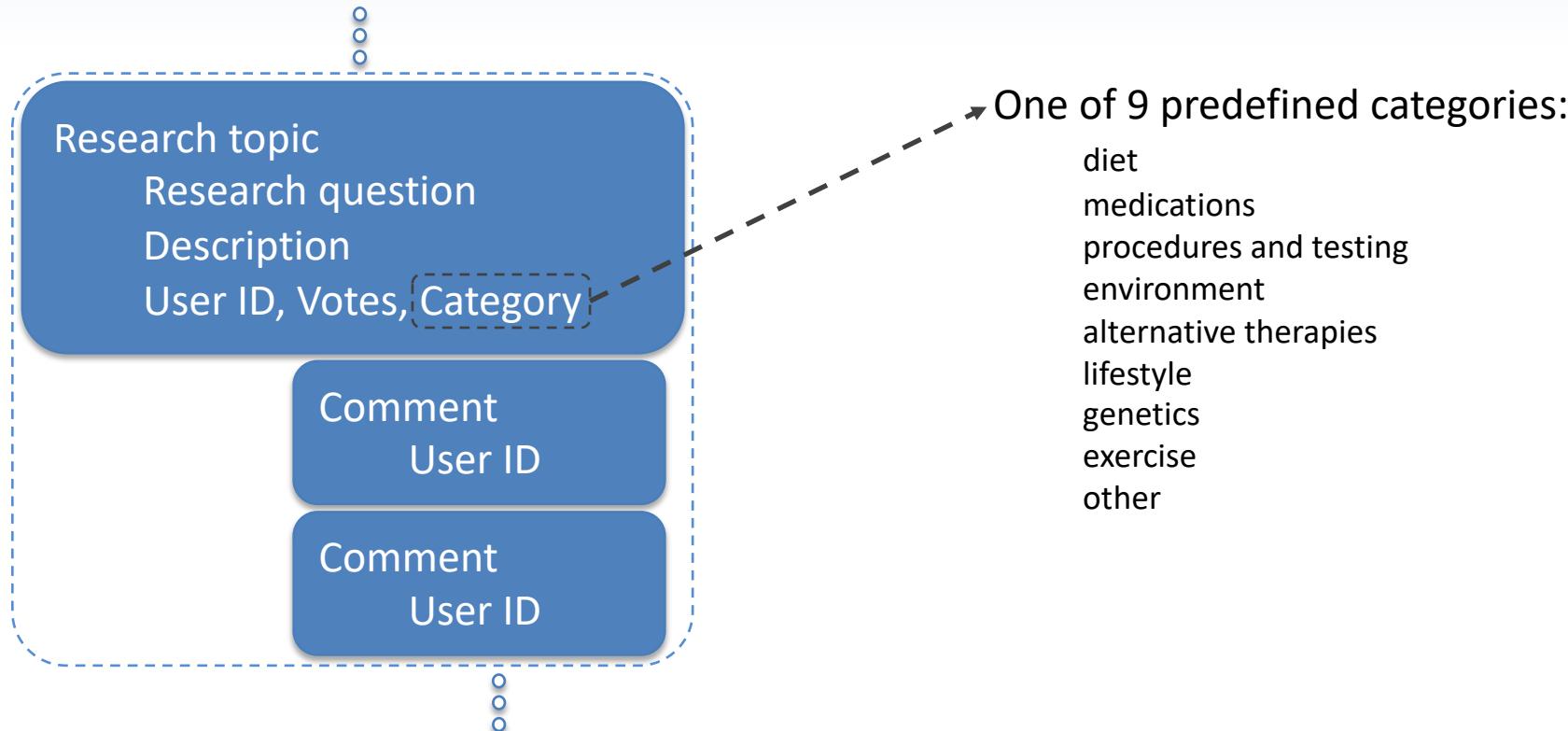
Question:

Nicotine has shown to be effective for UC [ulcerative colitis] in some individuals, both prior- and nonsmokers. What is the mechanism? Does nicotine affect the microbiome, the immune system or both?

Description:

Big Pharma will not take on the role of studying nicotine as there is no \$\$\$ in it. Few studies with small sample sizes have been done but more research is needed.

Discussion Forum Data



Discussion Forum Data



Research topic

Research question

Description

User ID, Votes, Category

Comment

User ID

Comment

User ID

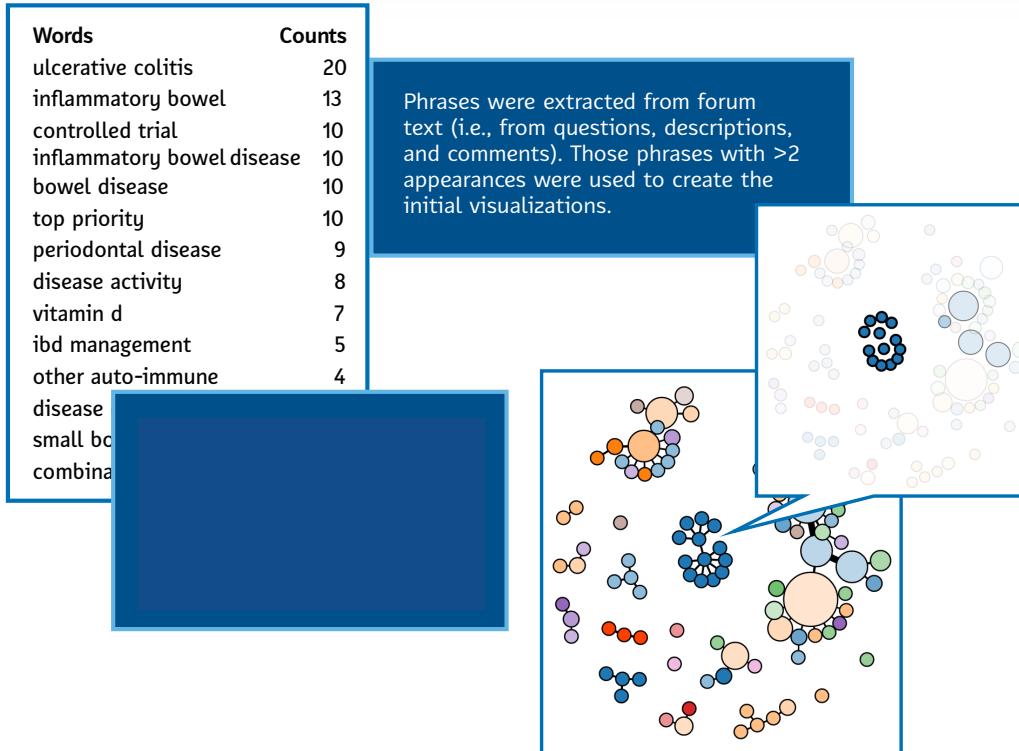
Goals:

Identify common themes

Prioritize patient-generated
research questions



Initial Approach

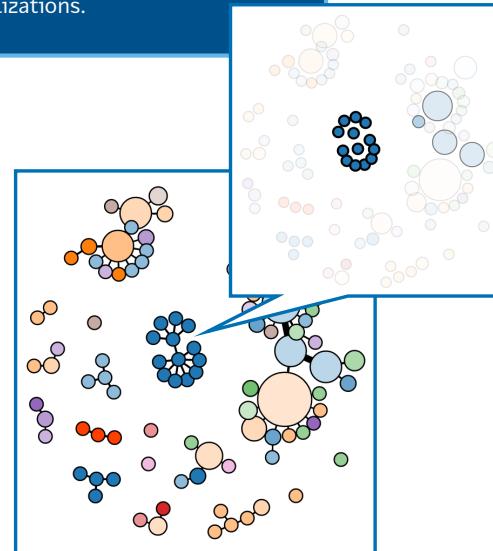


Initial Approach

Words	Counts
ulcerative colitis	20
inflammatory bowel	13
controlled trial	10
inflammatory bowel disease	10
bowel disease	10
top priority	10
periodontal disease	9
disease activity	8
vitamin d	7
ibd management	5
other auto-immune	4

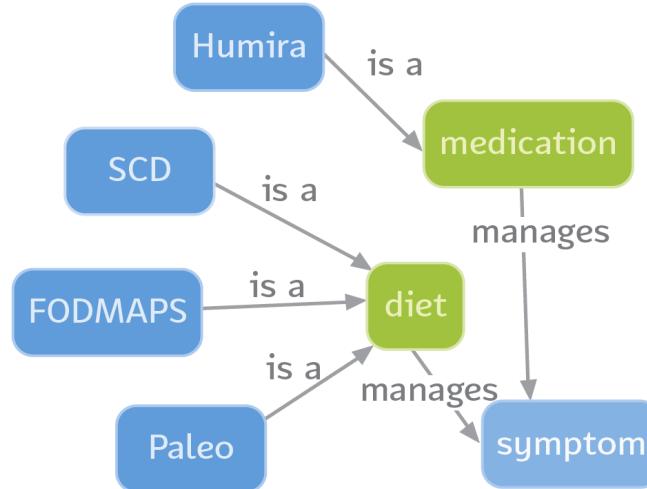
Phrases were extracted from forum text (i.e., from questions, descriptions, and comments). Those phrases with >2 appearances were used to create the initial visualizations.

This didn't turn out to be as informative as we'd hoped. The frequency of words and/or word phrases didn't successfully capture the 'aboutness' of the conversation on the CCFA forum.



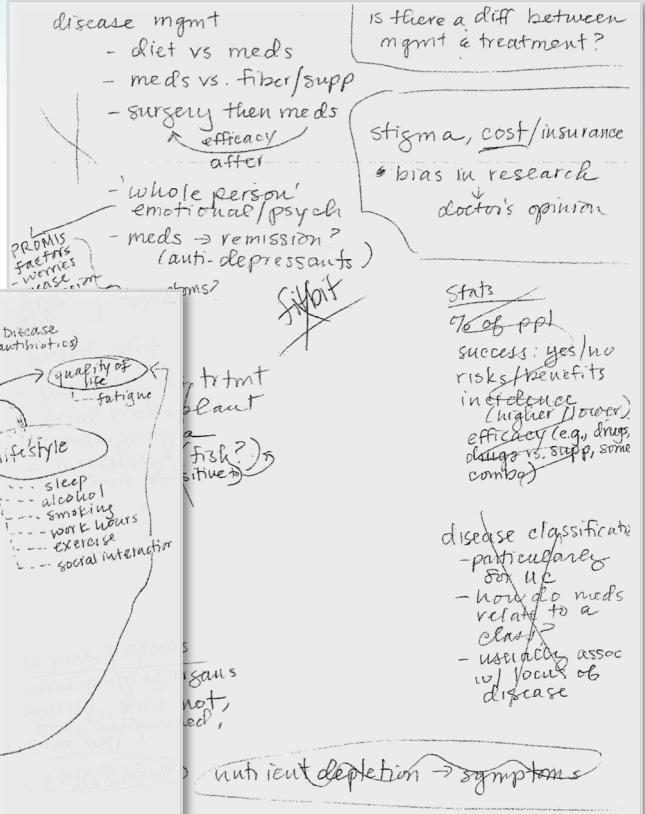
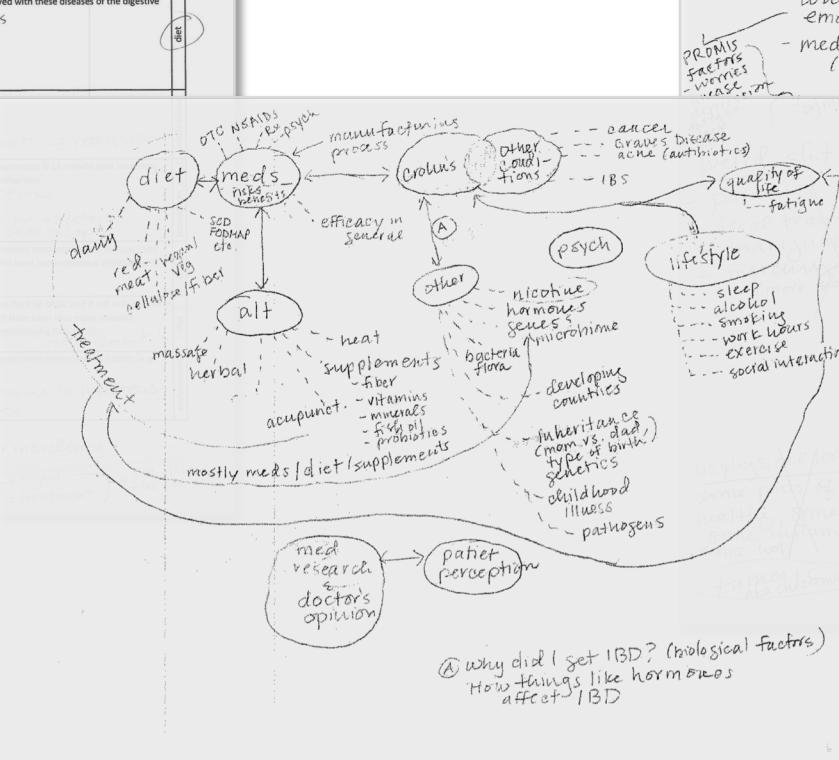
Ontology Creation

- **Ontology**
 - Controlled vocabulary
 - Represent knowledge about a domain of interest
 - Enable multiple types of relationships
 - “is a”
 - “treats”
 - Etc.



Content Analysis

	A recent study linked gut problems with food additives/emulsifiers such as polysorbate 80. Would anyone be interested in limiting their diet to prevent food additives and emulsifiers that are in processed foods to see if it affects disease progression?	Increases in IBD seem to follow economic development, processed foods. It would make sense that food is involved.
8	man a smot real research	processed foods → crohn adv. user
9	How many IBD patients take antidepressants to help manage their health? Does this help to fight off remission by controlling depression? treatment	Anything that prevents remission is important! emotional / psych depression / anti-depress
10	What are the best surveillance techniques after bowel resection surgery? When should medical treatment be initiated? How often should colonoscopies be performed? monitoring time	It looks like the current research only recommends a colonoscopy every 5 years. but there is very little information as to how to monitor post bowel rese
11	Treating IBD in Non-Hodgkin's Lymphoma Survivors cancer & IBD drugs may be part of treatment	- now - what to do - now to los
12	Research the validity of VSIBS probiotic in controlling flare ups or as a factor in remission. 05/11/2016 probiotic	While it may be a small subset of patients, the most common immunomodulators may be too risky for IBD patient's treatments need to be identified for this group.
13	We should determine why the prevalence of IBD in developing countries is so low, yet immigrants from those countries and their children are at increased risk of IBD. dev. countries	I tried this as a last resort 3 years ago during a very severe remission but I have not felt this healthy in over 9 year situations since being in remission and absolutely no symptoms
	developing	This question might help decipher the contribution of sunlight, the microbiome, exposure to antibiotics
		childhood lack of ex agents and paraex



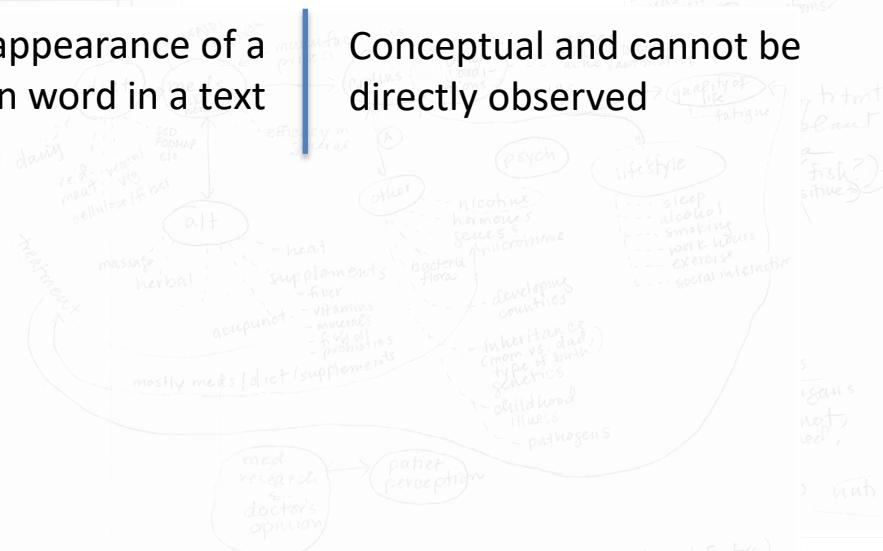
Content Analysis

	A recent study linked gut problems with total additives/emulsifiers such as polyesters in IBD. Would anyone be interested in limiting their diet to prohibit food additives and emulsifiers that are in processed foods to see if it affects disease management? <i>management</i> <i>real research</i>	increases in IBD seem to follow <u>gastrointestinal diseases</u> , when looking at the inclusion of non-processed foods; it would make sense that food is involved with these diseases of the digestive system <i>processed foods → crohn's</i> <i>adv. user</i>
8	How many IBD patients take corticosteroids to help manage their health? Does this help to fight off remission by controlling depression? <i>treatment</i>	Anything that prevents remission is <u>depressant</u> <u>emotional / physical</u> <u>depression / anti-depressants</u>
9	What are the best surveillance techniques after disease remission surgery? When should medical treatment be initiated? How often should colonoscopies be performed? <i>surveillance</i>	It looks like that current research only recommends a <u>colonoscopy every 1-2 years</u> , but there is very little information as to how to <u>monitor</u> IBD patients. <i>monitoring</i> <i>every 1-2 years</i> - what to look for - who to refer
10	Predicting IBD in Non-Hodgkin's Lymphoma survivors <i>Cancer & IBD</i> <i>drugs may be too harsh</i> <i>but we're still here</i>	While it may be a small subset of patients, the most common treatments for lymphoma may be too risky for IBD patient's. Treatments need to be identified for this group.
11	Research the validity of <u>self-rated pain</u> in controlling flare ups or as a factor in remission. <i>self rating</i> <i>not always accurate</i> <i>but useful</i>	I tried this as a last resort 3 years ago during a very severe remission but I have not felt this healthy in over 9 years since being in remission and absolutely no flare ups.
12	We should determine why the prevalence of IBD in developing countries is so low, yet immigrants from these countries and their children are at increased risk of IBD. <i>gov. countries</i>	This question might help decipher the contribution of (sunlight, the atmosphere, exposure to stimulants)
13	Developing <i>Crohn's</i> <i>low incidence</i> <i>IBD</i>	<i>childhood race of c. again and again</i> <i>highly</i> <i>3 diet can be</i>

Manifest Content vs. Latent Content

The appearance of a given word in a text

Conceptual and cannot be directly observed



Content Analysis

8	A recent study linked gut problems with food additives/emulsifiers such as polyethylene BG. Would anyone be interested in limiting their diet to prohibit food additives and emulsifiers that are in processed foods to see if it affects disease progression?
9	What are the best surveillance techniques after ileal resection surgery? When should medical treatment be initiated? How often should colonoscopy be performed?
10	Treating IBD in Non-Hodgkin's Lymphoma survivors
11	Research the validity of IBSA problems in controlling flare ups or as a factor in remission.
12	We should determine why the prevalence of IBD in developing countries is so low, yet immigrants from those countries and their children are at increased risk of IBD.

Manifest Content vs. Latent Content

The appearance of a given word in a text

Conceptual and cannot be directly observed

E.g., "...the level of research anxiety present in user narratives about their experiences at the library."

- disease mgmt
- diet vs. med's
- med's vs. fiber/supp
- surgery then med's
 - efficacy
 - after
- whole person' emotional/psych
- med's → remission?
 - (anti-depressants)

is there a diff between mgmt & treatment?

stigma, cost/insurance
bias in research
doctor's opinion

stats
% of ppl
success yes/no
risks/benefits
intelligence
(higher Doctor)
efficacy (eg, drop, drugs vs. supp, some combos)

disease classification
- particularly
- how do meds relate to a class?
- usually assoc w/ focus of disease

Wildemuth BM. Applications of Social Research Methods to Questions in Information and Library Science. Westport, Conn: Libraries Unlimited; 2009.

Content Analysis

1 A recent study linked gut problems with food additives/emulsifiers such as polyethylene BG. Would anyone be interested in limiting their diet to prohibit food additives and emulsifiers that are in processed foods to see if it affects disease progression?	increases in IBD seem to follow economic development, which includes the availability of more processed foods. It would make sense that food is involved with these diseases of the digestive system. processed foods → crohn's
2 How many IBD patients take antidepressants to help manage their health? Does this help for fight off remission by controlling depression?	anything that prevents remission is important! emotional / psych depression / anti-depr
3 What are the best surveillance techniques after ileal resection surgery? When should medical treatment be initiated? How often should colonoscopy be performed?	it looks like the current research only recommends a monitoring post操行 but there is very little information as to how to do this
4 Treating IBD in Non-Hodgkin's Lymphoma survivors	CANCER & IBD drugs may be good at treating
5 Research the validity of IBD problems in controlling flare ups or as a factor in remission.	research validity controlling flare ups or as a factor in remission or as a factor in remission
6 We should determine why the prevalence of IBD in developing countries is so low, yet immigrants from those countries and their children are at increased risk of IBD.	developing countries low rate incidence

Manifest Content vs. Latent Content

The appearance of a given word in a text

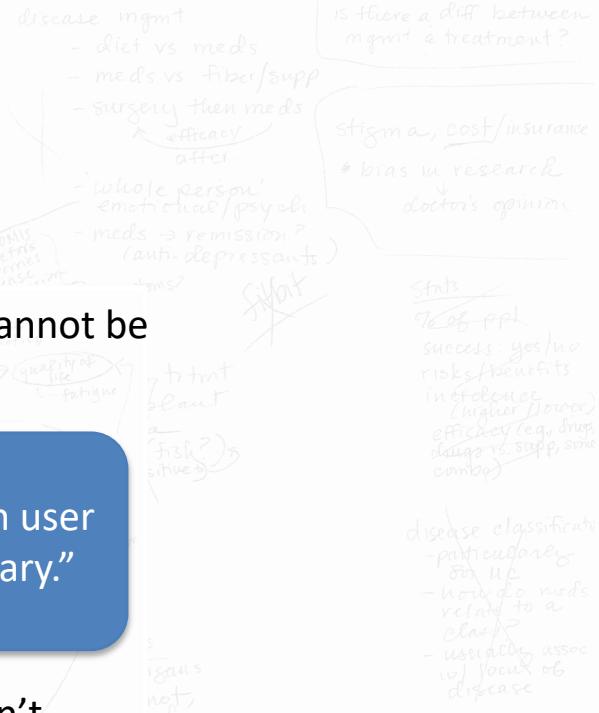
Conceptual and cannot be directly observed

E.g., "...the level of research anxiety present in user narratives about their experiences at the library."

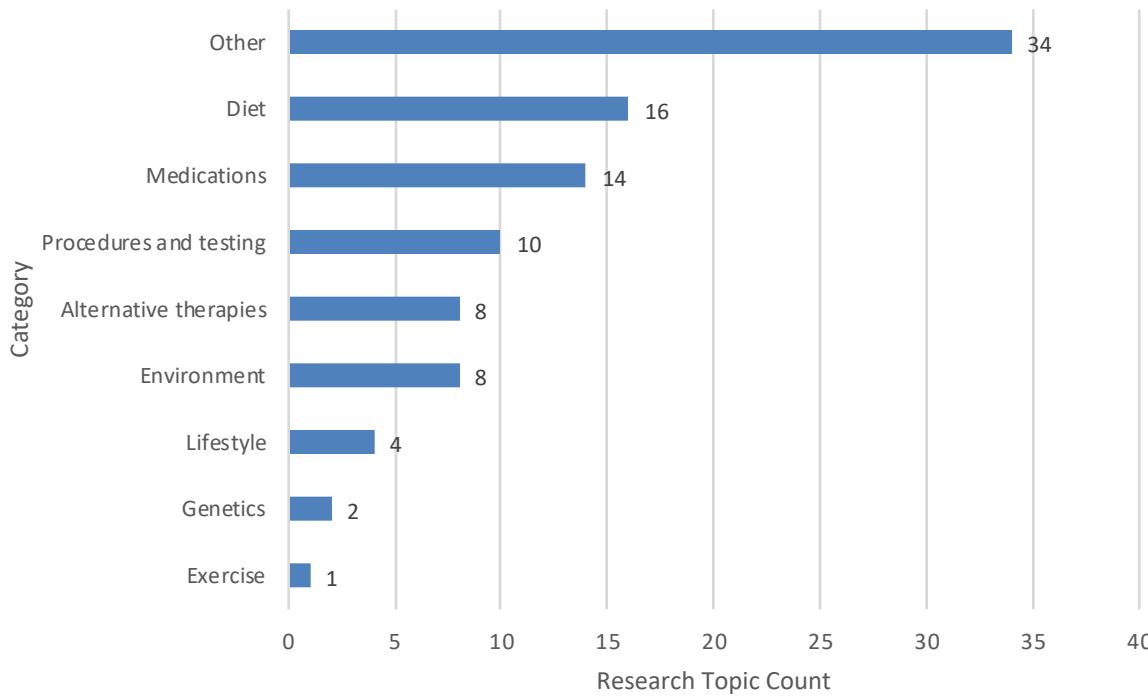
"I am so anxious"

"My heart won't stop beating"

"I wish I could relax"

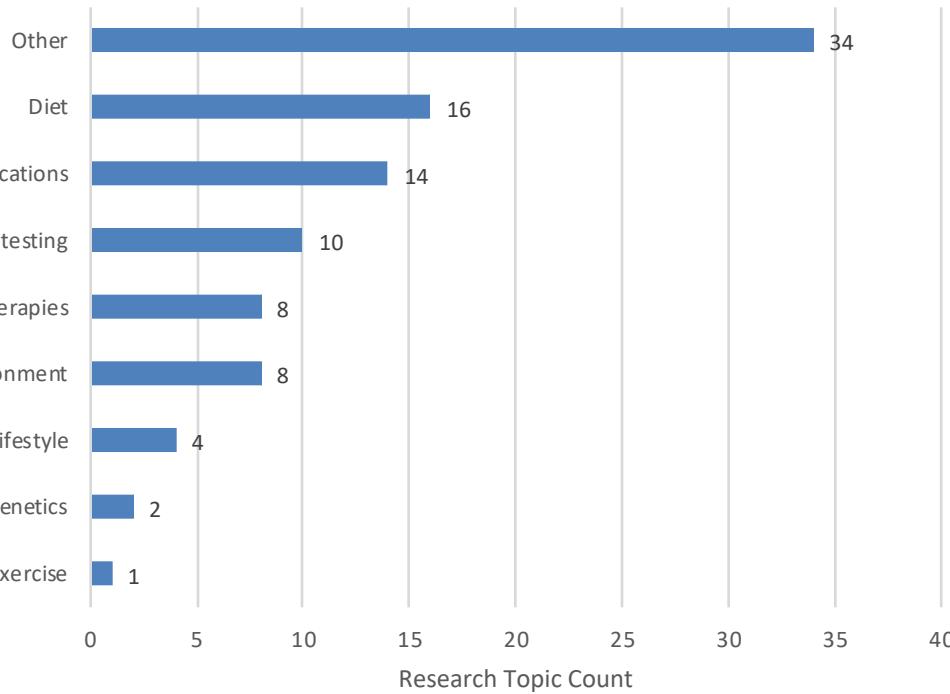


Content Analysis



Content Analysis

Category



"Sometimes there is no existing theory or research on your message populations; you may not know what the important variables are. The only way to discover them is to explore the content."

Wildemuth BM. Applications of Social Research Methods to Questions in Information and Library Science. Westport, Conn: Libraries Unlimited; 2009.

The Ontology

Protégé

The screenshot shows the Protégé interface with the following details:

- Class hierarchy:** microbiome
- Annotations:** microbiome (http://purl.obolibrary.org/obo/ibd.owl#microbiome)
- Definition:** The full collection of genes of all the microbes in a community; in other words, all of a human's microbes' genes.
- Definition source:** Learn.Genetics: Genetic Science Learning Center, the University of Utah (<http://learn.genetics.utah.edu/content/microbiome/>)
- Description:** microbiome
- Equivalent To:** physiological factor
- SubClass Of:** physiological factor
- General class axioms:** None listed.
- SubClass Of (Anonymous Ancestor):** None listed.
- Instances:** None listed.

Borrows some terms from pre-existing ontologies:
Ontology of Adverse Events, Disease Ontology

REPRESENTATIVE CLASSES	POSTS
comorbidity	11
diagnosis/monitoring method	7
IBD course	39
pre-diagnosis time period	1
diagnosis event	5
post-diagnosis time period	31
quality of life	8
risk factor	58
demographic factor	7
environmental factor	18
lifestyle factor	20
physiological factor	28
psychological factor	5
symptom	36
gastrointestinal manifestation	12
extra-gastrointestinal manifestation	3
treatment method	50
alternative therapy	7
holistic treatment	12
medication	28
surgery	13

The Ontology

Protégé

The screenshot shows the Protégé interface with the 'microbiome' class selected. The left sidebar displays a tree view of the class hierarchy under 'cwl:Thing'. The main panel shows the 'Annotations' tab for the 'microbiome' class, which includes:

- Annotations:** rdf:label microbiome, definition: 'The full collection of genes of all the microbes in a community; in other words, all of a human's microbes' genes.', definition source: Learn.Genetics: Genetic Science Learning Center, the University of Utah (<http://learn.genetics.utah.edu/content/microbiome/>)
- Description:** microbiome
- Equivalent To:** 'physiological factor'
- SubClass Of:** 'physiological factor'
- General class axioms:** SubClass Of (Anonymous Ancestor)
- Instances:** (list of instances)

At the bottom, there is a note: 'No Reasoner set. Select a reasoner from the Reasoner menu.' and a checkbox for 'Show Inferences'.

Borrows some terms from pre-existing ontologies:
Ontology of Adverse Events, Disease Ontology

337 classes
7 top-level classes

OWL → ROBOT → OBO Graph (JSON)

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surgery	13

The Ontology

Protégé

The screenshot shows the Protégé interface with the 'ibd' ontology loaded. The left sidebar displays the class hierarchy under 'microbiome'. A central panel shows the 'microbiome' class definition, including its annotations (rdfs:label, definition, source), description ('The full collection of genes of all the microbes in a community; in other words, all of a human's microbes' genes'), and sub-classes ('physiological factor'). Below this is the 'Description' tab for 'microbiome', which lists 'Equivalent To', 'SubClass Of' (including 'physiological factor'), 'General class axioms', 'SubClass Of (Anonymous Ancestor)', and 'Instances'.

Borrows some terms from pre-existing ontologies:

Ontology of Adverse Events, Disease Ontology

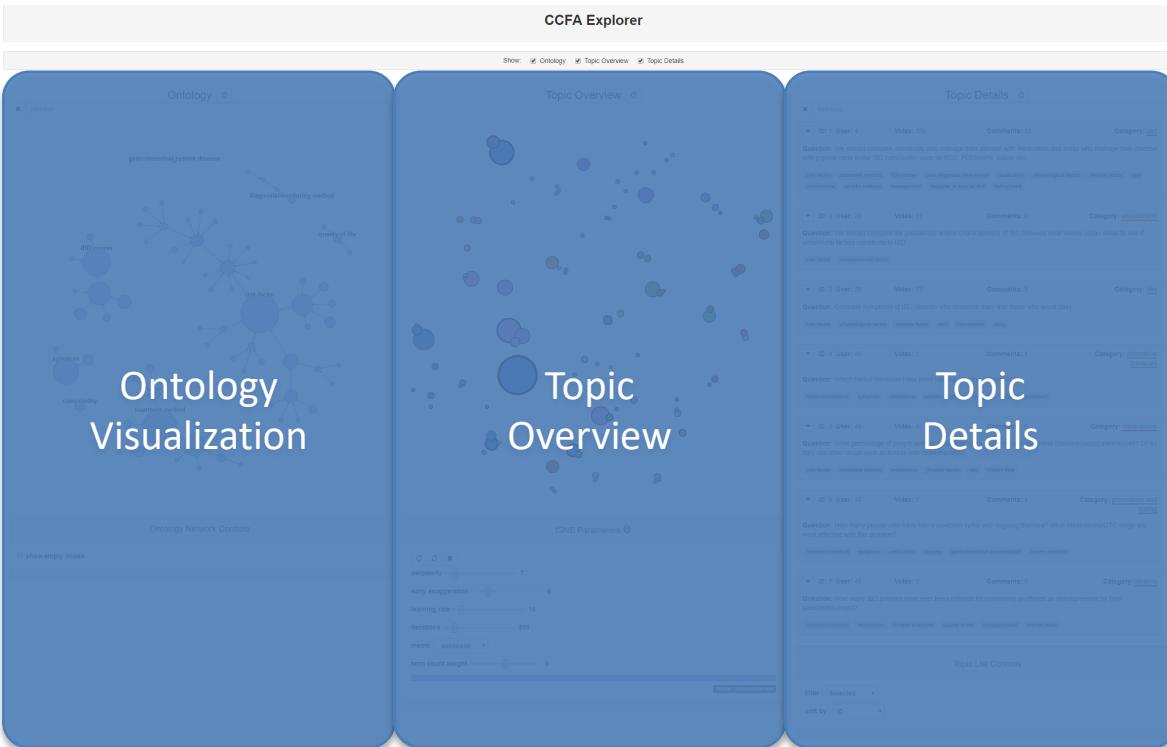
337 classes
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OWL → ROBOT → OBO Graph (JSON)

Research Topics ↔ Ontology Terms (Classes)

REPRESENTATIVE CLASSES	POSTS
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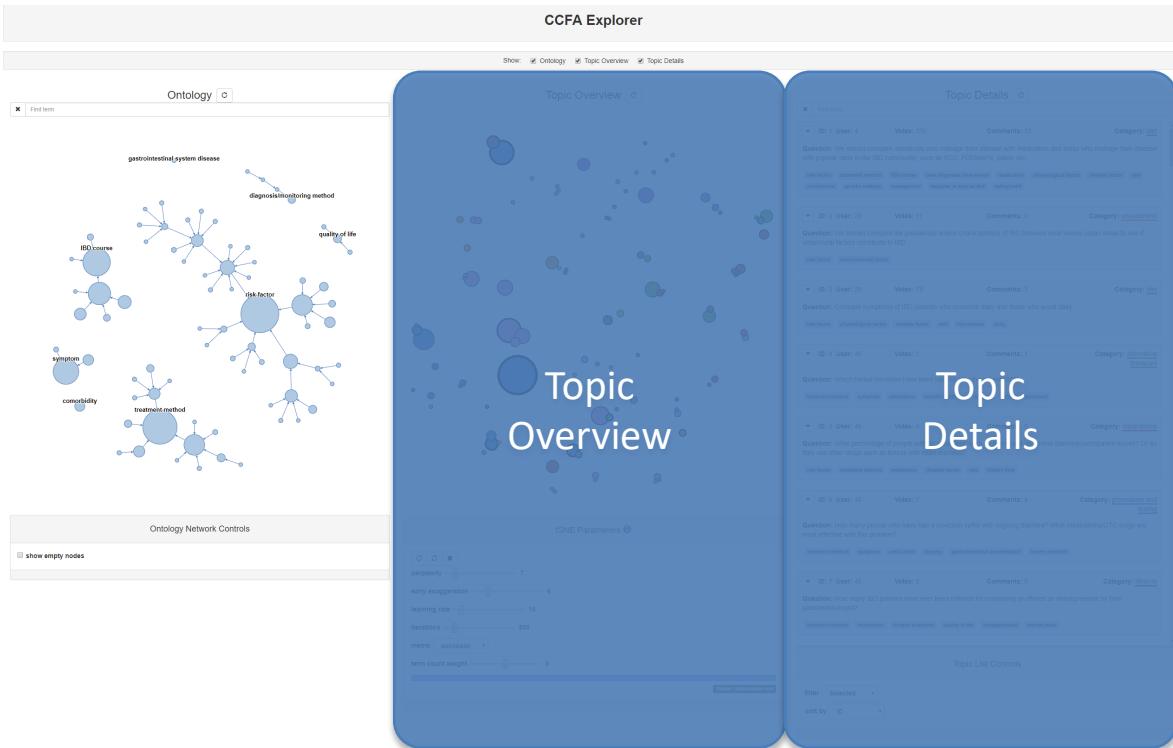
CCFA Explorer



3 linked
views

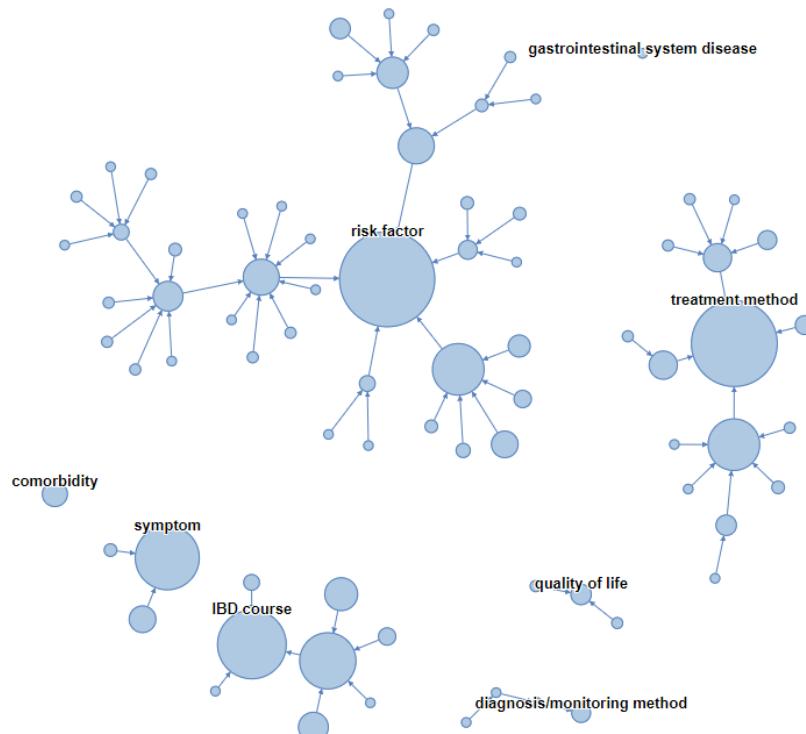
D3
React/Flux
Bootstrap

Ontology Visualization

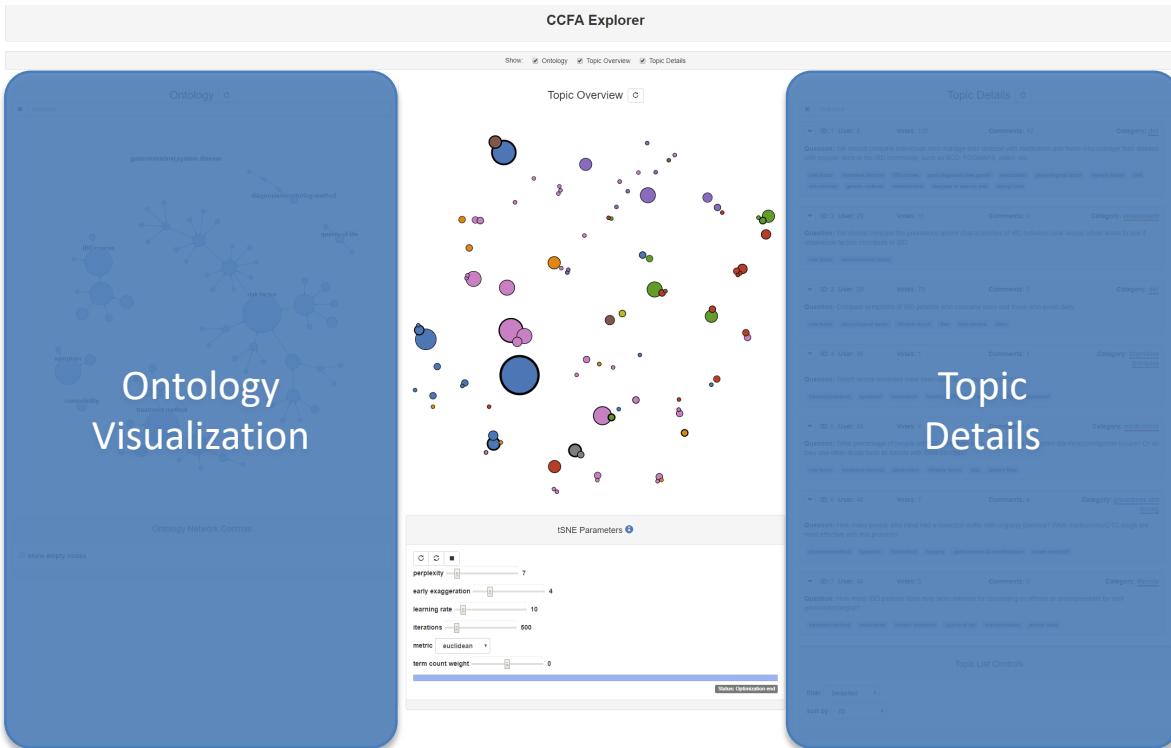


Ontology Visualization

- Force-directed network
 - Node size
 - Number of topics labeled with term
 - Labeled with child implies labeled with parent
 - Links
 - Class relationships
 - Currently only “is a”

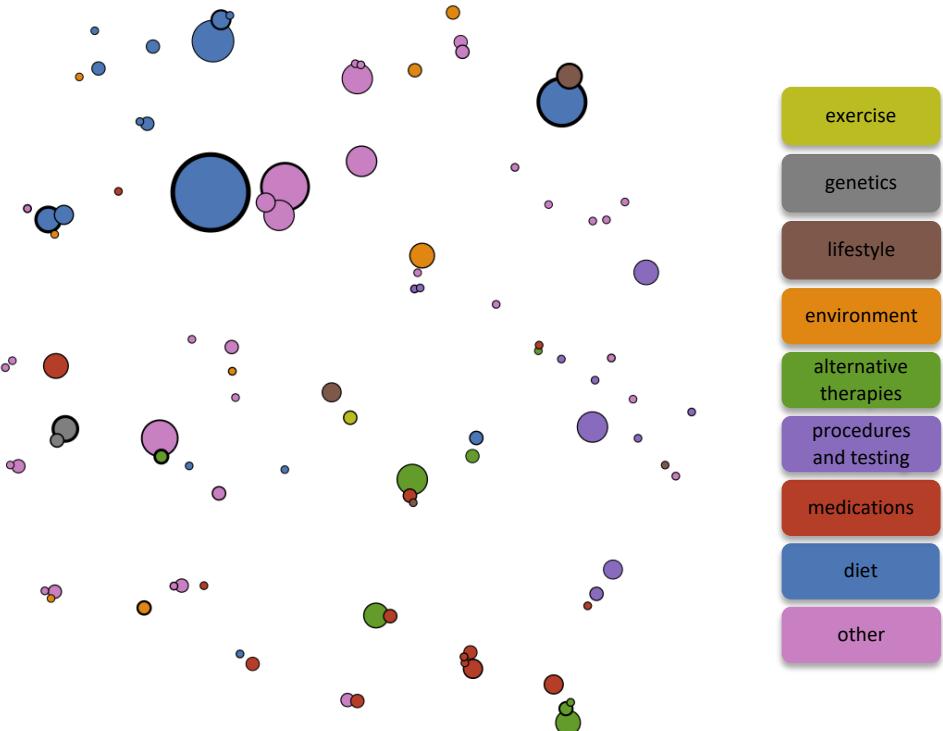


Topic Overview



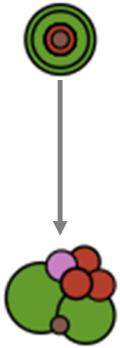
Topic Overview

- **t-SNE Layout**
 - Based on labeled ontology terms
 - Clusters of topics with similar ontology terms
- **Glyph**
 - Size
 - Number of comments
 - Border width
 - Number of votes
 - Color
 - Category



t-SNE Modifications

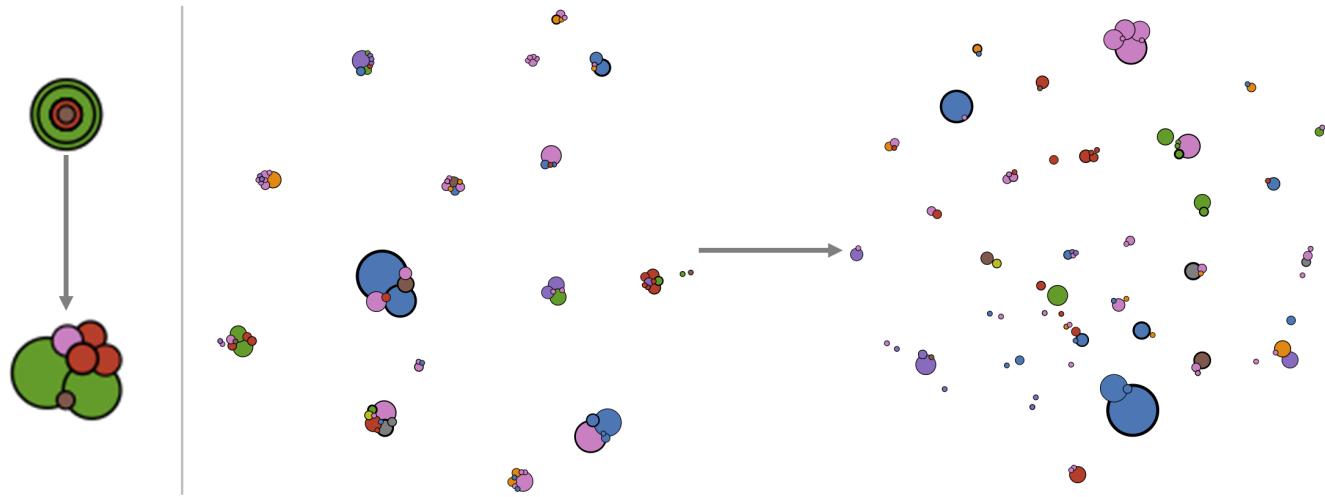
van der Maaten LJP, Hinton GE.
Visualizing High-Dimensional Data Using
t-SNE. Journal of Machine Learning
Research. 2008;9:2579–2605.



1. Force-directed layout
of overlapping glyphs

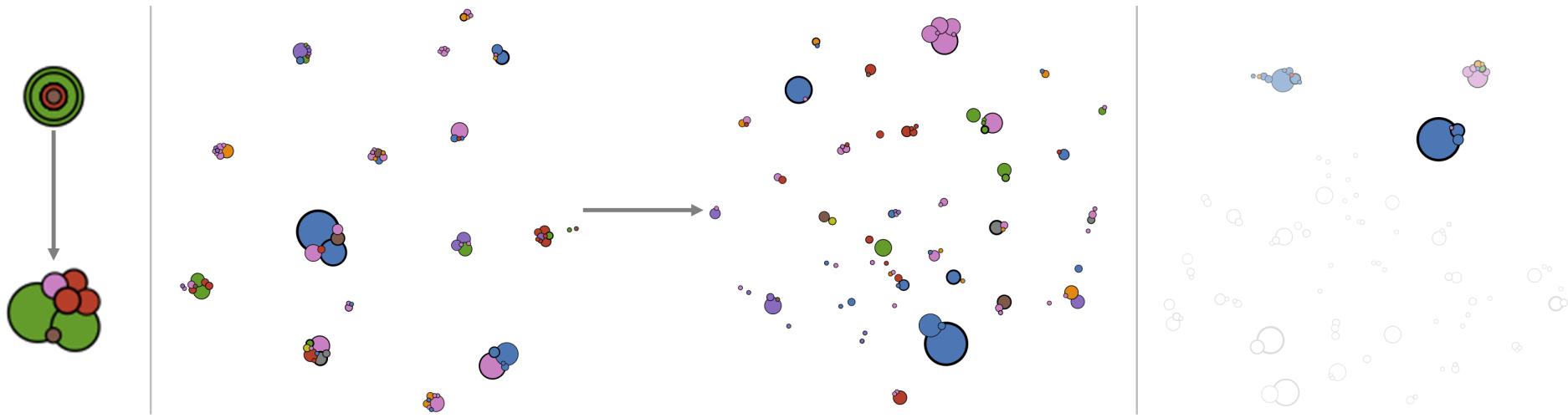
t-SNE Modifications

van der Maaten LJP, Hinton GE.
Visualizing High-Dimensional Data Using
t-SNE. Journal of Machine Learning
Research. 2008;9:2579–2605.



2. Differential weighting of higher-level (left) vs. lower level (right) ontology terms

t-SNE Modifications



3. Emphasizing selected ontology terms for layout

Topic Details

CCFA Explorer

Show: Ontology Topic Overview Topic Details

Ontology

ontology

IBD symptom

IBD disease

IBD treatment

symptom

comorbidity

treatment method

diagnosis/monitoring method

quality of life

Topic Overview

Topic Details

Topic List Controls

filter: Selected

sort by: ID

Topic Overview

DNE Parameters

perspective

early exaggeration

learning rate

iterations

metrics

term count weight

Topic Details

ID	User	Votes	Comments	Category
1	User: 4	130	12	diet
2	User: 29	11	0	environment
3	User: 29	79	3	diet
4	User: 45	1	1	alternative therapies
5	User: 40	4	0	medications
6	User: 48	7	4	procedures and testing
7	User: 40	0	0	sterile

Question: We should compare individuals who manage their disease with medication and those who manage their disease with popular diets in the IBD community, such as SCD, FOAMAPS, paleo, etc.

Question: We should compare the prevalence and/or characteristics of IBD between rural versus urban areas to see if environmental factors contribute to IBD.

Question: Compare symptoms of IBD patients who consume dairy and those who avoid dairy.

Question: Which herbal remedies have been used to effectively treat IBD?

Question: What percentage of people with IBD use fiber, such as metamucil, to control diarrhea/constipation issues? Or do they use other drugs such as lomotil with more success?

Question: How many people who have had a resection suffer with ongoing diarrhea? What medications/OTC drugs are most effective with this problem?

Question: How many IBD patients have ever been referred for counseling or offered an antidepressant by their gastroenterologist?

Topic List Controls

filter: Selected

sort by: ID

Topic Details

ID: 83 **User:** 2560 **Votes:** 3 **Comments:** 3 **Category:** procedures and testing

Question: Creation of a test to verify or deny IBD in persons struggling with symptoms

treatment method IBD course symptom surgery diagnosis/monitoring method diagnosis event pre-diagnosis time period

Topic Details

 ID: 83 User: 2560	Votes: 3	Comments: 3	Category: procedures and testing
<p>Question: Creation of a test to verify or deny IBD in persons struggling with symptoms</p> <p>Description: It took 16 years to verify my Cohn's, from age 13-29 years. Had all sorts of tests and was treated like I was crazy. Spent a month in treatment due to anorexia because eating was so painful. Diagnosed by having exploratory surgery. Because of that I had malnutrition, lost all my teeth and suffered way too long.</p> <p>treatment method IBD course symptom surgery diagnosis/monitoring method diagnosis event pre-diagnosis time period</p>			

Topic Details

-	ID: 83 User: 2560	Votes: 3	Comments: 3	Category: procedures and testing
<p>Question: Creation of a test to verify or deny IBD in persons struggling with symptoms</p> <p>Description: It took 16 years to verify my Cohn's, from age 13-29 years. Had all sorts of tests and was treated like I was crazy. Spent a month in treatment due to anorexia because eating was so painful. Diagnosed by having exploratory surgery. Because of that I had malnutrition, lost all my teeth and suffered way too long.</p> <p>Comments</p> <p>1. User: 2777 There is a blood test for this.</p> <p>2. User: 2777 There is a blood test for this. It was only developed a few years ago.</p> <p>3. User: 727 Do you know the name of the test?</p> <p>treatment method IBD course symptom surgery diagnosis/monitoring method diagnosis event pre-diagnosis time period</p>				

Topic Details

- List
 - Sort
 - Topic ID
 - User ID
 - Votes
 - Comments
 - Category
 - Filter
 - Selected topics
 - Selected ontology terms
 - Highlight
 - Text from search box in red

The screenshot shows a search interface with a search bar containing the word "genetic". Below the search bar are three search results, each represented by a card:

- Result 1:** ID: 15 User: 144 Votes: 58 Comments: 7 Category: other
Question: What is the effect of hormones, particularly increased estrogen, on Crohn's disease.
Tags: risk factor, IBD course, post-diagnosis time period, physiological factor, remission, hormonal state
- Result 2:** ID: 16 User: 168 Votes: 19 Comments: 1 Category: genetics
Question: Are there sub-types of UC? IBD has been broken into UC and Crohn's which helped with treatment. What other sub-categories are there? Could explain why certain meds work for some and not others, and shed light on question of genetics?
Description: I have UC and so far no treatment works. My mother had the same problem until she had a colectomy. Perhaps if we understood why our disease is different than some other folks' UC, we could devise a better treatment plan.
Comments:
 - 1. User: 1001 | Response from the CCFA Partners Research Team: There are different "sub-types" of UC that have to do with the area of involvement. People can have "proctitis" which involves only the rectum, "proctosigmoiditis" which involves the left side of the colon, and "extensive" disease which involves most or all of the colon. Knowing these areas of involvement is important, as there are medications (such as enemas or suppositories) that work very well in the end part of the colon. In fact, studies have shown that combination therapy with rectal and oral mesalamine preparations is more effective than either alone for inducing remission in patients with left sided ulcerative colitis. At this point, we do not have information that **genetic** aspects guide therapeutic efficacy of medications. We do have ongoing studies looking at the **genetics** of IBD, including ones by Dr. Balfour Sartor, Dr. Judy Cho, Dr. Ramnik Xavier, and Dr. Steve Brant, which are designed to increase our understanding of the role of **genetics** in IBD. If you are interested in learning more about either study, please see our affiliated studies page here.Tags: risk factor, treatment method, medication, physiological factor, genetic makeup, family genetic history
- Result 3:** ID: 17 User: 212 Votes: 75 Comments: 3 Category: genetics
Question: I propose a **genetics**-based investigation that explores why some drugs work for some people but not others.
Description: Many IBD patients go through years of pain and suffering because they haven't found "their drug" yet. This immense suffering could be reduced if we could determine which individuals respond to which drugs and WHY, as determined by their environment and DNA.
Comments:
 - 1. User: 168 | I posted a similar question - but I'd like to see more than just **genetics**. I'd like to see more categorizations of IBD, beyond just UC and Crohn's.
 - 2. User: 480 | I think the study being conducted through 23andMe is going to address this question! If you're in the US, you can participate (and also get a free 23andMe test if you qualify) here: <https://www.23andme.com/ibd/> If you already have a 23andMe profile, you can still participate in the research here: https://www.23andme.com/you/survey/take/ibd_main/ibd_background/
 - 3. User: 1001 | From the CCFA Partners Research Team: This is the wave of the future in IBD therapy: "personalized medicine." Studies are currently under way to investigate the role of **genetics** in disease course and therapeutics. While we do not study this directly within CCFA Partners, external researchers are studying the **genetics** of IBD and are recruitingTags: risk factor, treatment method, medication, physiological factor, genetic makeup, family genetic history

Interactive Selection and Highlighting

- Selection
 - Ontology terms
 - Research topics
 - Selection in any view updates all views

Interactive Selection and Highlighting

- **Selection**
 - Ontology terms
 - Research topics
 - Selection in any view updates all views
- **Relationships**
 - Co-occurrence
 - Between *ontology terms*
 - Number of topics in common
 - Union for multiple
 - Association
 - Between *research topics*
 - Number of terms in common
 - Union for multiple
 - Connection
 - Between *terms and topics*
 - Topic labeled with term or not
 - Sum for multiple

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Topic 1
Term 1, Term 2, Term 3

Topic 2
Term 1

Topic 3
Term 2, Term 3, Term 4

Interactive Selection and Highlighting

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Select *Term 3* and *Term 4*

Topic 1

Term 1, Term 2, **Term 3**

Topic 2

Term 1

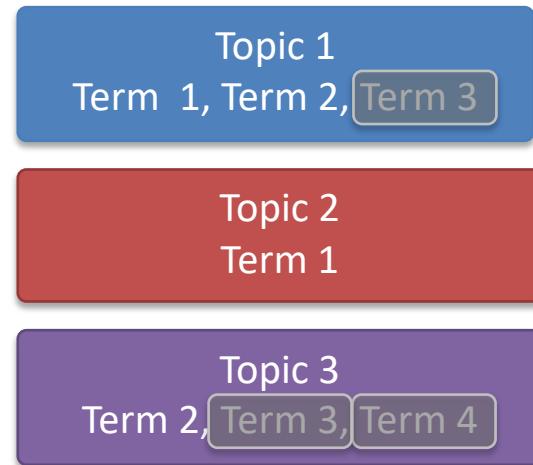
Topic 3

Term 2, **Term 3**, **Term 4**

Interactive Selection and Highlighting

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 - Ontology terms
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Select *Term 3* and *Term 4*



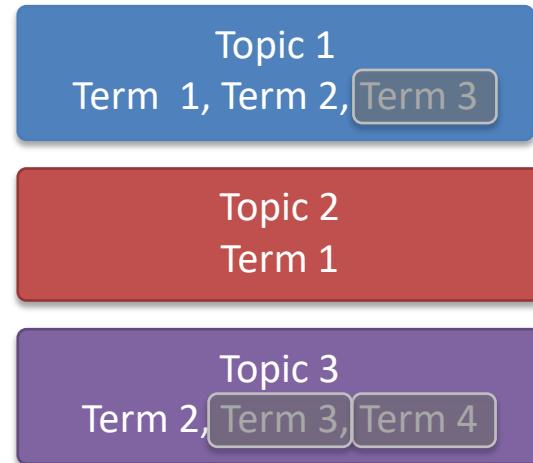
Co-occurrence:

Term 1: 1
Term 2: 2
Term 3: 2
Term 4: 1

Interactive Selection and Highlighting

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 - Ontology terms
 - Research topics
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 - Union for multiple
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 - Between *terms and topics*
 - Topic labeled with term or not
 - Sum for multiple

Select *Term 3* and *Term 4*



Co-occurrence:

Term 1: 1
Term 2: 2
Term 3: 2
Term 4: 1

Connection:

Topic 1: 1
Topic 2: 0
Topic 3: 2

Interactive Selection and Highlighting

- **Selection**
 - Ontology terms
 - Research topics
 - Selection in any view updates all views
- **Relationships**
 - Co-occurrence
 - Between *ontology terms*
 - Number of topics in common
 - Union for multiple
 - Association
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 - Number of terms in common
 - Union for multiple
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 - Topic labeled with term or not
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Select *Topic 2* and *Topic 3*

Topic 1

Term 1, Term 2, Term 3

Topic 2

Term 1

Topic 3

Term 2, Term 3, Term 4

Interactive Selection and Highlighting

- **Selection**
 - Ontology terms
 - Research topics
 - Selection in any view updates all views
- **Relationships**
 - Co-occurrence
 - Between *ontology terms*
 - Number of topics in common
 - Union for multiple
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 - Number of terms in common
 - Union for multiple
 - Connection
 - Between *terms and topics*
 - Topic labeled with term or not
 - Sum for multiple

Select *Topic 2* and *Topic 3*

Topic 1
Term 1, Term 2, Term 3

Topic 2
Term 1

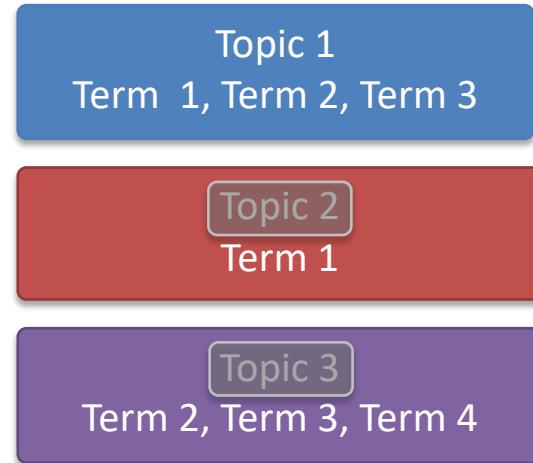
Topic 3
Term 2, Term 3, Term 4

Association:
Topic 1: 3
Topic 2: 1
Topic 3: 3

Interactive Selection and Highlighting

- **Selection**
 - Ontology terms
 - Research topics
 - Selection in any view updates all views
- **Relationships**
 - Co-occurrence
 - Between *ontology terms*
 - Number of topics in common
 - Union for multiple
 - Association
 - Between *research topics*
 - Number of terms in common
 - Union for multiple
 - Connection
 - Between *terms and topics*
 - Topic labeled with term or not
 - Sum for multiple

Select *Topic 2* and *Topic 3*



Association:

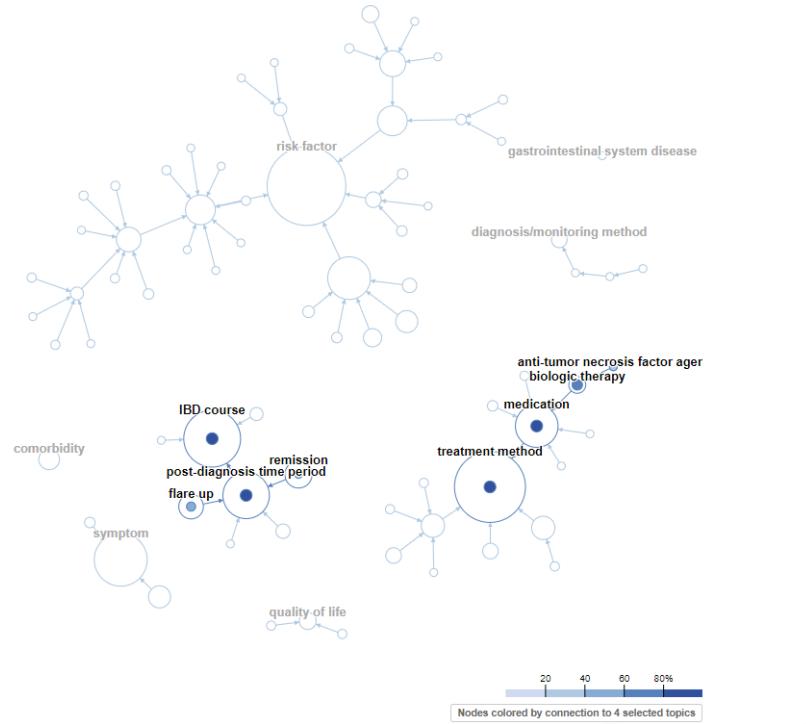
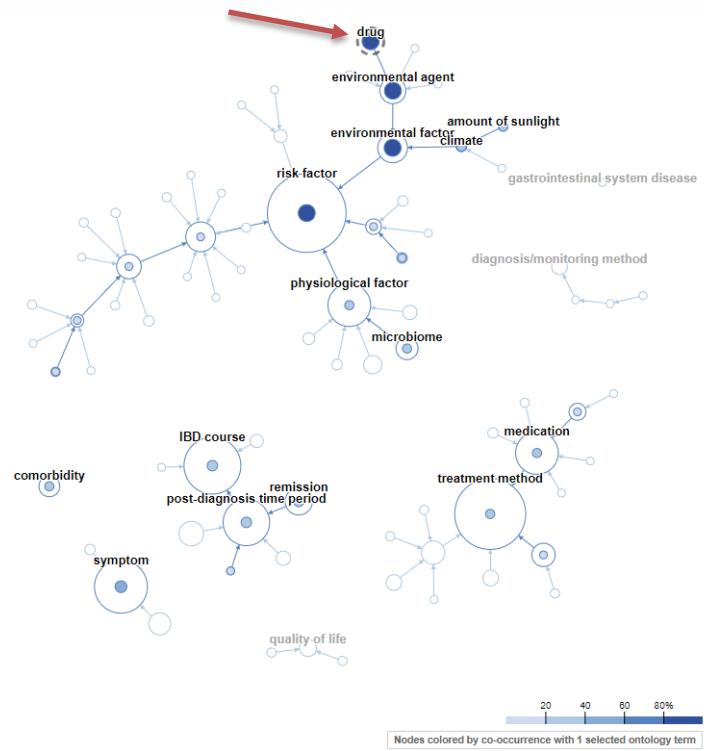
Topic 1: 3
Topic 2: 1
Topic 3: 3

Connection:

Term 1: 1
Term 2: 1
Term 3: 1
Term 4: 1

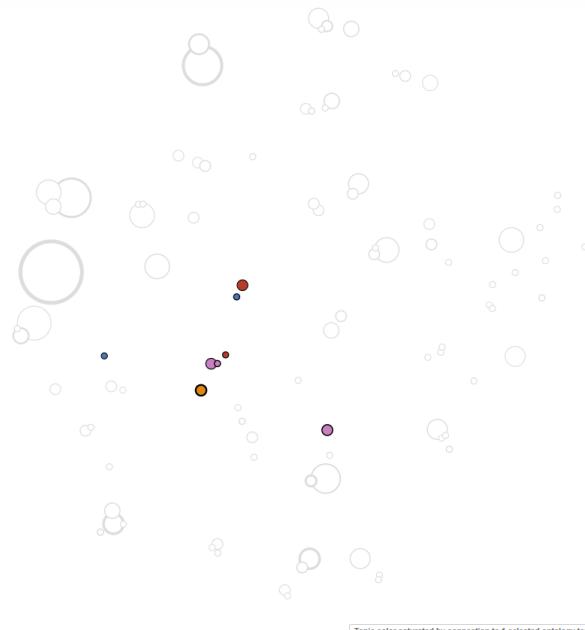
Ontology Highlighting

Node interior size and color proportional to co-occurrence/connection
Labels shown if > 25%



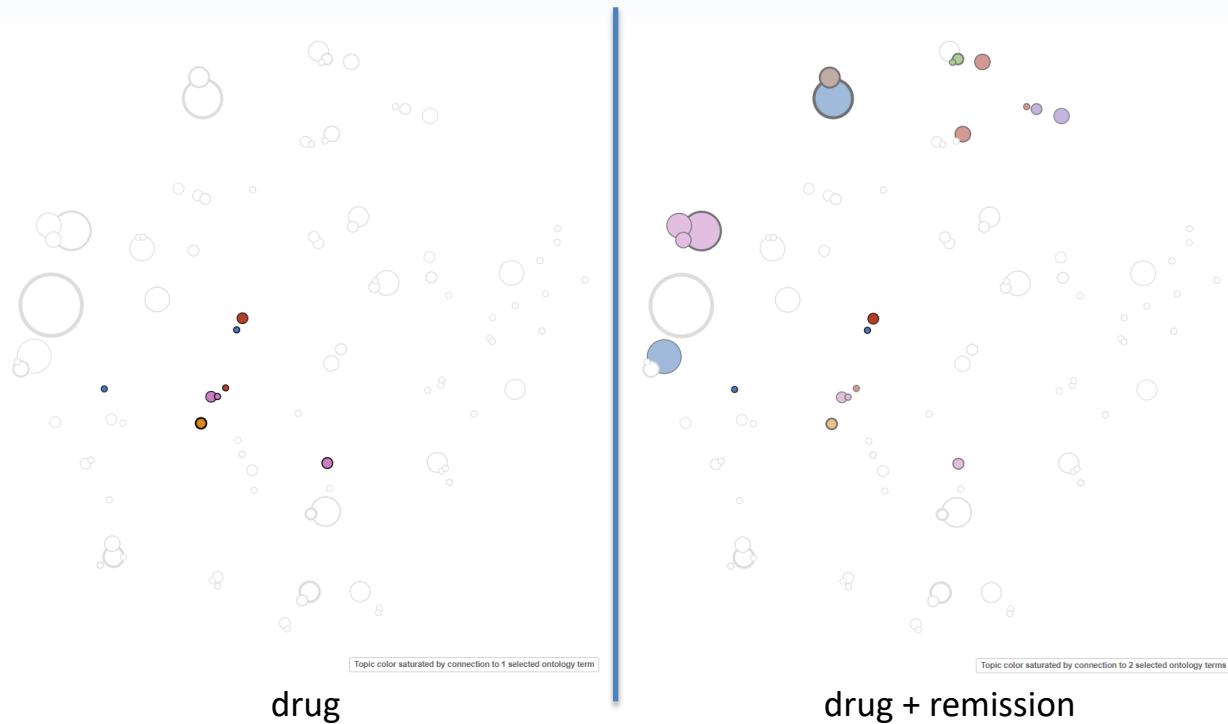
Glyph saturation proportional to
association/connection

Topic Overview Highlighting



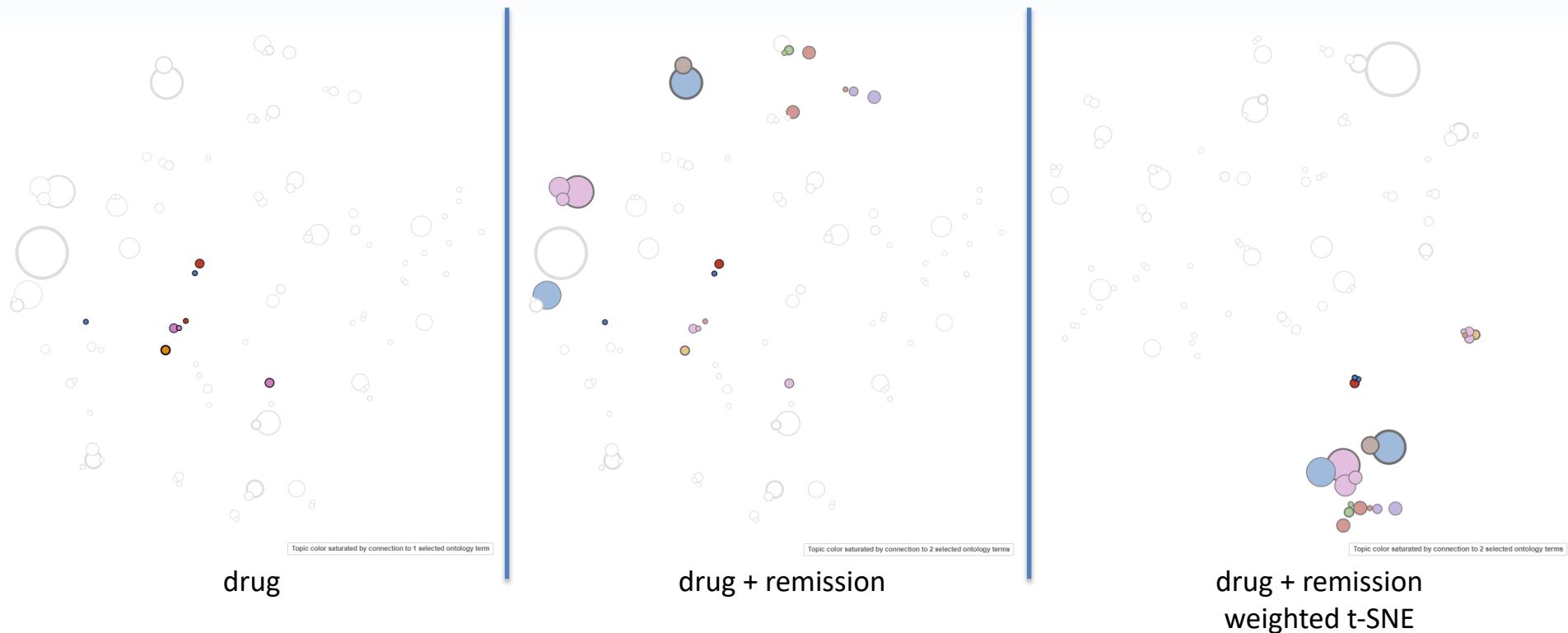
Glyph saturation proportional to
association/connection

Topic Overview Highlighting



Glyph saturation proportional to
association/connection

Topic Overview Highlighting



Topic Details Highlighting

Ontology terms colored as in ontology network visualization

ID: 7 User: 48 Votes: 5 Comments: 0 Category: lifestyle

Question: How many IBD patients have ever been referred for counseling or offered an antidepressant by their gastroenterologist?

Description: Depression and anxiety levels are very high in this population. Extending care to the whole person would make sense in managing disease and quality of life.

treatment method medication holistic treatment antidepressant quality of life mental state

ID: 18 User: 213 Votes: 12 Comments: 4 Category: alternative therapies

Question: What is the comparative safety and efficacy of natural supplements (vitamin D, fish oil, turmeric) commonly used in IBD versus prescription medications?

Description: Many of us try natural supplements instead of or in addition to prescription medications in the management of IBD. Are natural supplement products more safe or effective when compared to prescription medications? Is combining natural supplements with prescription treatments more effective?

treatment method medication holistic treatment

ID: 24 User: 213 Votes: 15 Comments: 1 Category: medications

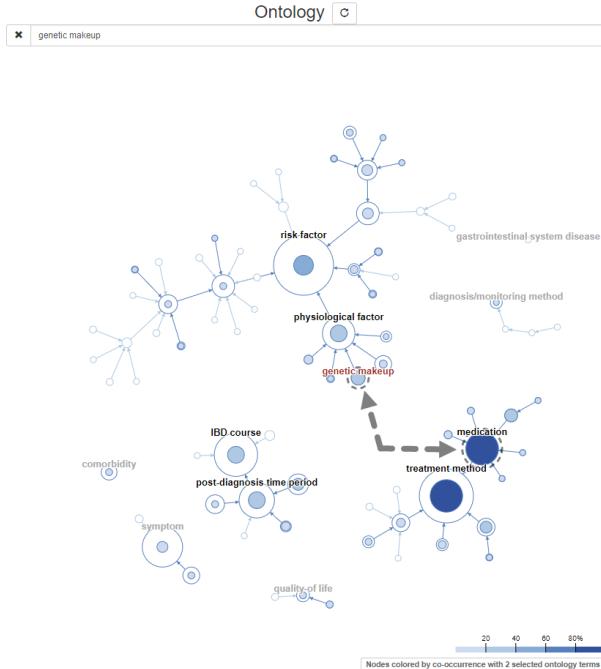
Question: What pain treatment options (pharmacologic or otherwise) do IBD patients find most effective, and what are the risks associated with these treatments.

Description: Many pain medications are addictive and/or harmful, particularly in IBD patients. Pain is a common symptom of IBD. I would like to explore patient experiences of the efficacy of pain treatments including: acupuncture, message therapy, heat therapy, NSAIDs, acetaminophen, SNRI antidepressants, tramadol, opiate pain medications. Either through literature review or additional research, it would be valuable to see a comprehensive review of risks and benefits of common pain treatments specific to use in IBD patients.

treatment method medication holistic treatment antidepressant pain medication

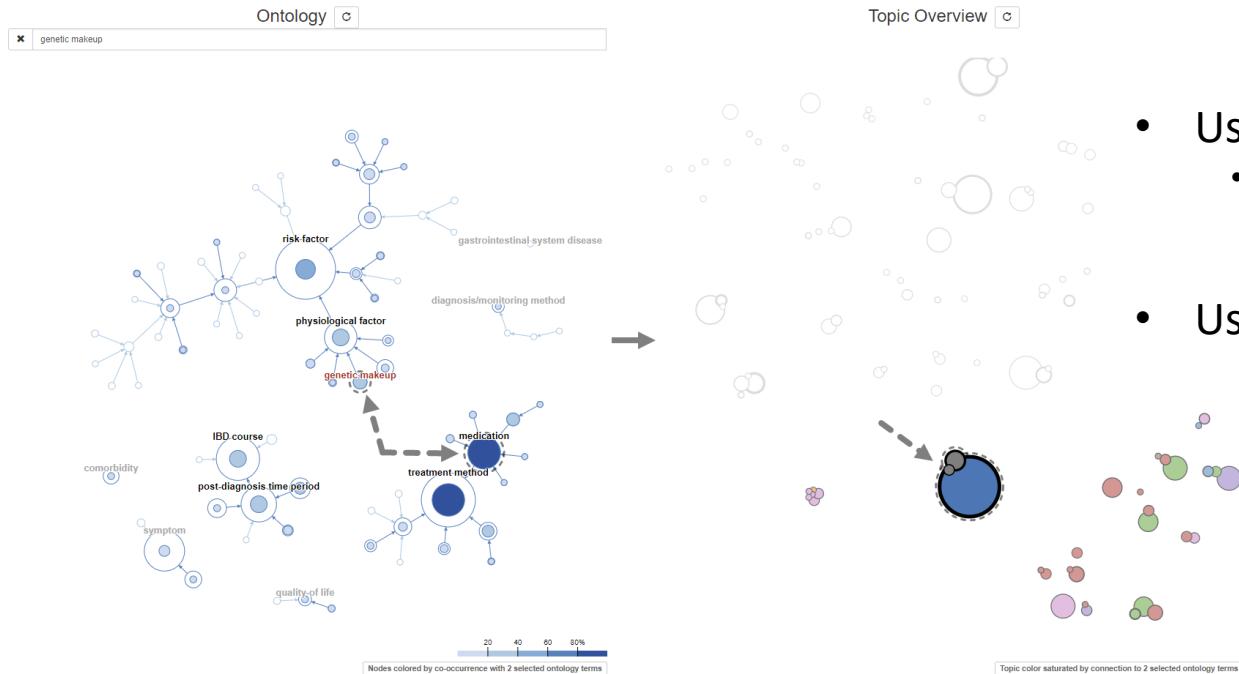
Filtered by selected topics

Example Scenario



- User searches for *genetic makeup*
 - Highlighted in red
- User selects *genetic makeup*
 - Notices *medication* co-occurs with *genetic makeup*
- User select *medication* also

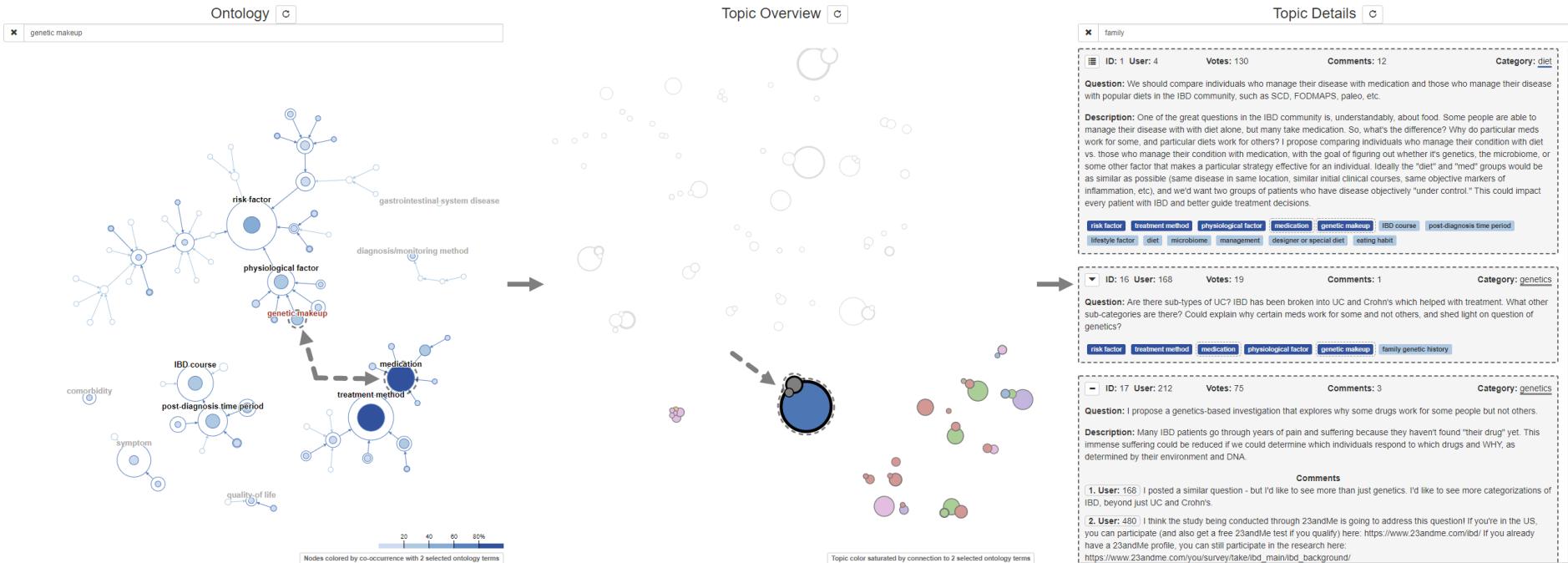
Example Scenario



- User re-runs t-SNE
 - Notices cluster of three topics, including one very large glyph
- User selects these three topics

Example Scenario

- User filters topic details to show only these topics for in-depth inspection/comparison



Feedback and Future Work

- Demonstration to IBD Partners
 - Generally positive feedback
 - Useful way to explore the forum data
 - Quickly identify major themes and popular research topics
 - Some features may be too complex for more naïve users
 - Two particular themes identified
 - Patient-facing interface
 - Find similar patients
 - More easily identify research topics relevant to them
 - Researcher-facing interface
 - Quickly identify relevant information in their research area
 - Quickly generate summaries of relevant information
 - Easily presented to stakeholders

Feedback and Future Work

- **Interface**
 - Redesign ontology visualization
 - Improve navigation
 - Explore automatic text summarization
 - Include in summary panel for selected terms/topics

Feedback and Future Work

- **Interface**
 - Redesign ontology visualization
 - Improve navigation
 - Explore automatic text summarization
 - Include in summary panel for selected terms/topics
- **Data processing**
 - Explore ways to automate/semi-automate topic classification
 - Enable ontology editing/expansion

The screenshot shows the homepage of the IBD Partners website. At the top, there is a navigation bar with links for Home, Research Ideas, My Health Data, My Contributions, Members, and Blog. A 'Sign In' button is also present. Below the navigation, a banner features two people working together with a video camera, with the text 'An IBD Patient-Powered Research Network'. A call-to-action button 'Join' is visible. The main content area has a purple background with text about patient and researcher collaboration. On the right, there is a box for 'Our Community' showing statistics: 15,680 patients and over 300 researchers. Below this, a 'How It Works' section details the process of proposing research ideas, comparing it to popular diets in IBD.

An IBD Patient-Powered Research Network

IBD Partners (formerly known as CCFAPartners) is an online research network brought to you by the Crohn's and Colitis Foundation and the University of North Carolina School of Medicine. We bring together inflammatory bowel disease (IBD) patients and researchers in a revolutionary partnership aimed at optimizing treatment of IBD.

Want to learn more? [View infographic.](#)

Join IBD Partners to start collaborating with researchers today.

Join

We believe that when patients and researchers work together we learn so much more about how to better treat inflammatory bowel diseases (IBD).

Patients understand their own body and disease best and have valuable information to share. We provide a way for researchers to listen to patients about their experiences with IBD. By working together, we can answer the questions that are most important to patients.

Our Community

We are one of the largest IBD research networks in the world.

[See Our Community](#)

15,680 We are now 15,680 patients strong.

300+ There are over 300 IBD researchers involved in our network.

How It Works

Patients Propose Research Ideas

Patients come up with insightful research ideas. We invite you to propose, vote, and discuss research ideas. IBD researchers will review these ideas. Your idea may even lead to a study!

Popular Research Ideas

We should compare individuals who manage their disease with medication and those who manage their disease with popular diets in the IBD

15,680 > 400

Feedback and Future Work

- ## Interface

- Redesign ontology visualization
 - Improve navigation
- Explore automatic text summarization
 - Include in summary panel for selected terms/topics

- ## Data processing

- Explore ways to automate/semi-automate topic classification
- Enable ontology editing/expansion

- ## User evaluations

The screenshot shows the top navigation bar of the IBD Partners website. It includes the logo 'IBD PARTNERS' with a stylized blue and green icon, followed by links for 'About', 'Resources', 'For Researchers', 'For Kids & Teens', 'Help', and 'Sign In'. Below the main navigation, there is a secondary navigation bar with links for 'Home', 'Research Ideas', 'My Health Data', 'My Contributions', 'Members', and 'Blog'.

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15,680 > 400

Thanks to IBD Partners for their help with this work!

Questions?

