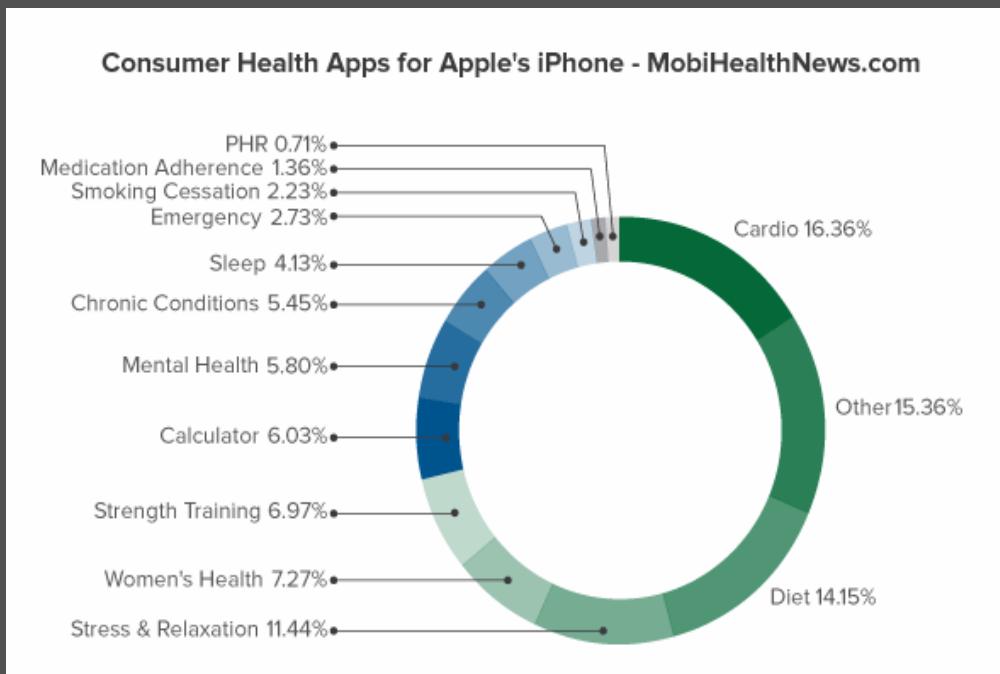


Learning from Online Health Communities

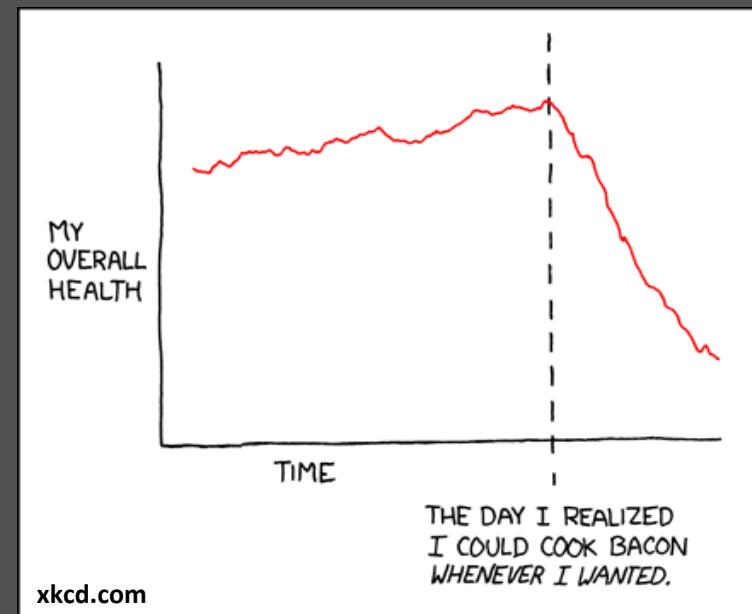
Noémie Elhadad
noemie@dbmi.columbia.edu

Apps/tools for health consumers & patients

iPhone “health apps”



A (not social) tracking tool



How Facebook Saved My Son's Life

My social network helped diagnose a rare disease initially missed.

By Deborah Kogan | Updated Wednesday, July 1



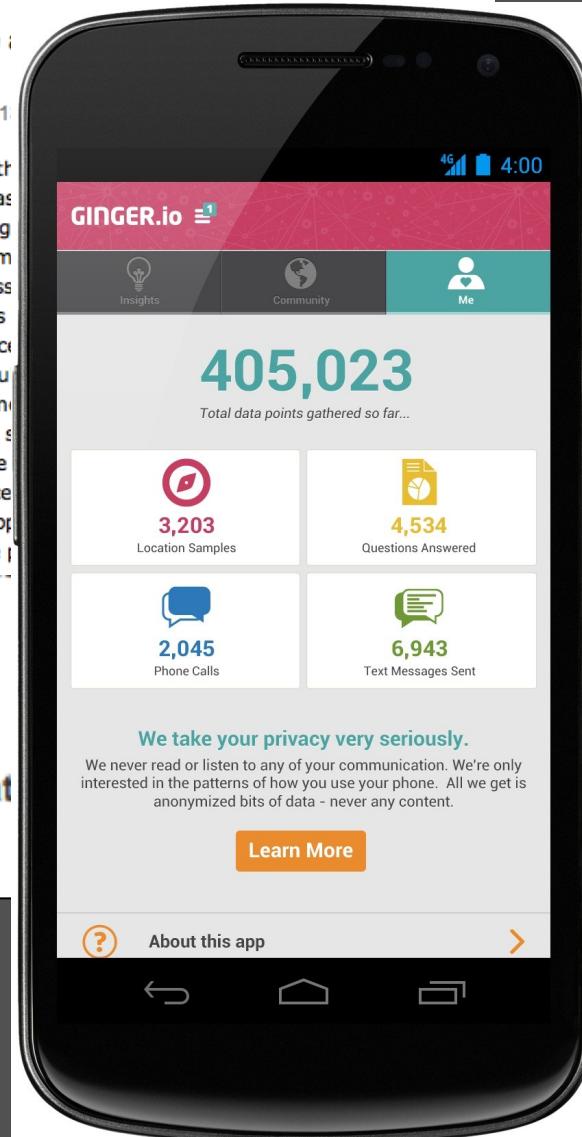
Self-portrait of the author and her son, Leo, on a stretcher in triage

Very good.

Irma M saw Felix Chu, DO

★★★★★ Recommendat

Very good, excellent



★★★★★ Walt Time

I explained my inquiry beforehand. As soon as I message and was very knowledgeable and helpful. He wasn't in a professional and helpful. I'd highly recommend him and smart. It was one of my best medical

★★★★★ Walt Time

foursquare

The studio is one of simplicity, allowing the students to practice the art of yoga in a peaceful, pressure-free environment. We offer 60 classes/wk including Vinyasa, Hatha, Prenatal, Mommy&Me, Privates, and workshops. The teaching staff at LIM are some of the most sought after instructors in NYC.

YOUR CHECK-INS 0 TOTAL PEOPLE 78 TOTAL CHECK-INS 366

Mayor Last 60 Days

Ashley H. 40 checkins

A screenshot of a Foursquare profile for a yoga studio. The profile includes a map showing the location on West 105th Street, a photo of a person, and statistics for check-ins, total people, and total check-ins. The mayor for the last 60 days is Ashley H. with 40 check-ins.

Breast Cancer Mailing List Archives

A wealth of information about breast cancer, from the experts.

 Search

Links

- ▶ [bclist.org](#)
- ▶ [Friends of BC List](#)
- ▶ [BC List Gathering](#)
- ▶ [Abbreviation list](#)
- ▶ [Rec Area](#)
- ▶ [Cancer Survivors Online](#)

Information

- ▶ [Donations: \\$75](#) in November 2012 (target = \$500); \$5090 overall for 2012
- ▶ [Click here to log into the chat room.](#)
- ▶ [Join the list \(you need an email address\)](#)
- ▶ [Post a message to the list](#) (list members only)

2012

January 2012	February 2012	March 2012	April 2012
May 2012	June 2012	July 2012	August 2012
September 2012	October 2012	November 2012	December 2012

2011

January 2011	February 2011	March 2011	April 2011
May 2011	June 2011	July 2011	August 2011

[Jump to Bottom](#)B
R

Topic: S

[Create a](#)[All Topics](#)[Active T](#)[Member](#)[Search](#)[Help](#)[Chat Ro](#)[We are 12
dis](#)

Posts 1 - 18 (18 total)

chainsawz

Tucson, AZ

Joined: Sep 2008

Posts: 1,423

12 hours ago

[+ Post a Reply](#)**chainsawz** wrote:

Wow wee Pee - great news!! I'm glad you found Reggie, but I hope you dump him soon for the cuter one...NED! Herceptin sure is great stuff....so is tykerb if I must add :>

Lisa -mets to lungs & brain - clear lymph nodes.....the weakest step toward the top of the hill, toward sunrise, toward hope, is stronger than the fiercest storm.

Diagnosis: 7/21/2008, IDC, 3cm, Stage IV, Grade 3, 0/2 nodes, mets, ER-/PR-, HER2+

jeanne46

CA

Joined: Nov 2006

Posts: 1,312

12 hours ago

[+ Post a Reply](#)**jeanne46** wrote:

Great news. Dance away with Reggie until you can meet up with Ned. Shrink, shrank, shrunk. Way to go!

Dx 12/05, Stage IV, Grade 3 ER+/PR- Her/2- YOU NEVER KNOW HOW STRONG YOU ARE UNTIL BEING STRONG IS THE ONLY OPTION YOU HAVE. -anonymous

justjudie

Simi valley, Ca

Joined: Apr 2010

Posts: 42

12 hours ago

[+ Post a Reply](#)**justjudie** wrote:

Congratulations to you & Reggie!! Happy news is definitely the BEST!! Good for you Pee.

Judie

RobinWendy

Long Island, NY

Joined: Mar 2007

Posts: 1,841

11 hours ago

[+ Post a Reply](#)**RobinWendy** wrote:

So wonderful to hear some good and great news. I'm so happy for you. I hope you and Reggie stay together until NED cuts in on the dance!!

dx Stage II primary BC in Jan. 2001;dx with DCIS on other breast in Jan. 2003; dx with mets to lungs in Jan. 2004 and in May 2007, mets spread to liver.

Diagnosis: ER+/PR+, HER2-

lovinmomma

Spokane, WA

Joined: Oct 2008

Posts: 1,427

11 hours ago

[+ Post a Reply](#)**lovinmomma** wrote:

On Jan 2008, I...

PatientsLikeMe: ALS (Amyotrophic Lateral Sclerosis)



Find Patients Just Like You ➤

Patient Spotlight

tom



Male, 71 years, IA, United States



Quite work (retired) 9/99 Got a scooter 10/99 moved to condo (no steps) 12/99 ... [See Profile](#)

PatientsLikeMe Videos



Visit our ALS YouTube channel...

What is ALS?

ALS (amyotrophic lateral sclerosis) is a degenerative disorder affecting upper motor neurons in the brain and lower motor neurons in the brain stem and spinal cord. Symptoms include progressive weakness, atrophy, fasciculation, dysphagia, and eventual paralysis of respiratory function.

Amyotrophic Lateral Sclerosis (ALS) is a neurodegenerative disease caused by the degeneration of motor neurons. Around 3,000 to 5,000 new cases of ALS are diagnosed every year in the United States alone.

Why PatientsLikeMe?

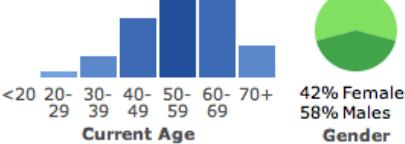
Imagine knowing what treatments work for people just like you — and having the ability to easily connect with those people. That's what makes PatientsLikeMe different. By sharing your symptoms, treatments and more, you can gain insight into what affects your condition while helping others learn from your experiences. Together, we can learn more. [Begin making a difference today!](#)

Who Will You Find?

4,772 Total patients

177 Profiles updated (last 7 days)

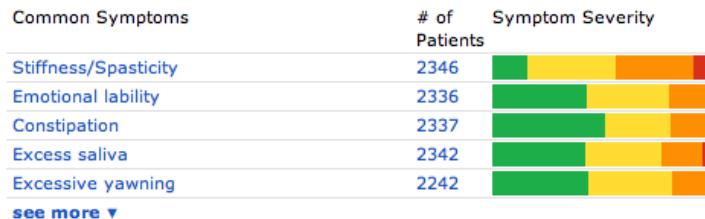
52 New patients (last 30 days)



Numbers based on subset of users who provided data.

What Are Patients Sharing?

Common Symptoms



[see more ▾](#)

Commonly Prescribed Treatments



PatientsLikeMe Blog: The Value of Openness

"A White Coat Affair": A Wonderful Evening Celebrating ALS TDI
November 4, 2011

[Moving Genetic Data Discovery Forward](#)

What Can You Learn?

Your Health Profile

By creating and sharing your health profile with the community, you can learn more about how your condition affects you and help others learn from your experience.

Patient Learning in Action

The first thing that I thought might be your problem is malnutrition. Man, you're losing weight crazy fast. I think you better consider getting peg tube if you desire. They are easy to care for and are literally a life saver. What are your thoughts on this?
— A PatientsLikeMe Member



PatientsLikeMe Research Updates

Take a minute to read recently published reports from the [PatientsLikeMe R&D team](#)

What are others saying about PatientsLikeMe?

Tune in to [Twitter](#)

Find us [In the News](#)

Read patient [Testimonials](#)

Newsletter Archive

Browse past editions of our [Newsletters](#)

[what is glu?](#)[faqs](#)[news](#)[login](#)

Glu is a type 1 diabetes network designed to accelerate research and amplify the collective voice of the type 1 diabetes community.



Parent



Injector



Traveler



Pumper



Newbie



Book Worm



Research Participant



Caregiver



Exercise Fanatic



Advocate



CGM User



Foodie

Choose up to **6 icons** above which best describe you and then click to register.

[click to register](#)

Online Health Communities

Individuals with chronic disease rely on disease-specific

- blogs
- mailing lists
- discussions forums

Research questions

- reach several fields (clinical discovery, epidemiology, health communication, HCI, data sciences)
- benefit different audiences (patients, health researchers)

Is it good or bad?

Are there health outcomes associated with participation in an online health community?

What about psycho-social outcomes?

Who are the members?

What are members' demographics and socio economic status?

What are their levels of health literacy?

Are there specific personalities which correlate with participation?

How much are members ready to disclose about their conditions?

What are the patterns of interaction amongst the participants?

Misinformation, trust

What is the prevalence of misinformation in a given forum?

How to characterize misinformation?

Are there mechanisms for members to identify/flag
misinformation?

Are there circles of trust?

What are the mechanisms for a member to identify them?

To which extent are the findings community/disease dependent?

What do members talk about?

What types of support do members get from each other?

What are topics of discussions?

What are the types of emotions expressed?

Are there evidence of collective sensemaking?

How much variation are there from one community to another
and if so, why is that?

Does it advance clinical discovery?

Can we discover side effects of drugs, co-morbidities, new symptoms from the contents of online health communities?

Can we recruit patients for clinical trials through an online health community?

Qualitative and data-driven methods

Qualitative methods

- Content analysis (select sample based on keywords reflective of research question at hand / establish a coding schema / manually code the samples)
- Surveys, focus groups

...

Data-driven

- Topic modeling
- Association studies
- Social network analysis

...

Predicting cancer stage of members in a breast cancer online community (Jha & Elhadad, 2010)

Only 10% of members in a breast cancer forum give their clinical profile

Can we infer the stage of a member based on their discourse

- what they talk about
- who they talk to

(and why do we want to do so?)

I've managed to keep a pretty sunny outlook through all of this (until lately) and now that the hard stuff is over, I can't bring myself to do the easiest thing of all....take one pill a day. Is anyone else facing this?? HELP!!

SAN :-\

Mastectomy ~ 9/23/11, chemo (TAC x 6) ~ 11/4/11, radiation x 36 (28 to two fields & 8 boosts to incision) ~ 3/24/12

Dx 8/5/2011, IDC, 5cm, Stage IIb, Grade 3, 0/6 nodes, ER+/PR+, HER2-

Dataset

Users with entered profile information

Stage I	2,226
Stage II	2,406
Stage III	1,031
Stage IV	749
Total	6,412

Active users with entered profile information (post > 50 words)

Stage I	1,317
Stage II	1,400
Stage III	580
Stage IV	448
Total	3,745

Overall forum usage

(as of March 2010; compare to 119,000 members as of September 2012)

Nb. of participants	62,000
Nb. of threads	26,160
Nb. of posts	524,247
Nb. of threads with < 20 posts	22,334

Cancer stage prediction

What participants say

- text-based prediction

Who the participants interact with

- network-based prediction

Machine learning, supervised framework

- Active participants with cancer stage information
- 5-fold stratified cross validation

Text-based classification

Full post history, concatenated

Signatures removed

Stages	Min nb. words	Max nb. words	Average nb. words	Median nb. words
I	4	609,608	8,429	3,123
II	2	353,731	8,142	3,112
III	8	211,655	9,297	3,189
IV	10	893,326	17,083	326

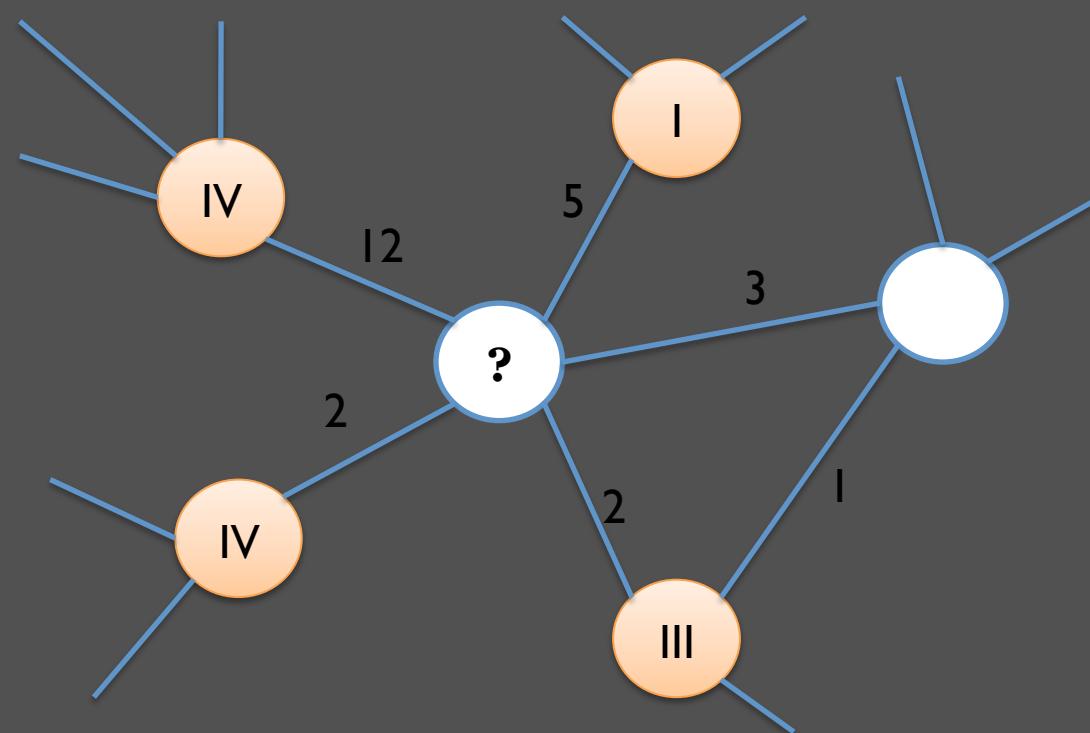
Lexical features only (unigram, bigrams, trigrams)

Network-based classification

Build network of interactions

- Nodes = forum participants
- Edges = level of interaction among participants

Propagate labels



Network-based classification

Represents presence of interaction between two participants

Participants post in the same threads, within 5 posts of each other

One participant explicitly mentions the other

- Extract real names and aliases

Results

Baseline

Stage	P	R	F
I	76.2	26.4	39.3
II	79.4	18.7	30.3
III	76.6	35.0	48.0
IV	76.4	50.7	60.9

Text-based

Stage	P	R	F
I	54.9	63.9	59.1
II	51.6	55.0	53.2
III	52.7	30.3	38.5
IV	82.5	71.2	76.4

Network-based

Stage	P	R	F
I	50.4	56.7	53.4
II	49.6	49.1	49.3
III	65.7	27.7	39.0
IV	59.3	83.7	69.4

Combined

Stage	P	R	F
I	57.1	65.4	61.0
II	56.6	53.5	55.0
III	56.1	48.3	51.9
IV	84.7	81.3	83.0

Detecting salient concepts of discussion in ASD forums (ongoing work)

Autism spectrum disorder forums
caregivers and parents of patients

Can we identify salient concepts of discussion, where

- Concept = semantic concept determined by a set of lexical variants (e.g., heart attack, myocardial infarct, heart attacks)
- Salient = significantly more discussed in ASD forum than in a control, non-ASD forum

(and why we want to do so?)

Build a lexicon of concepts

Start with a known health dictionary (UMLS), but...

it's technical,

it's noisy,

it might not have good coverage of ASD concepts

Add spelling variants of UMLS concepts

Double Metaphone algorithm (phonetic encoding)

e.g., risperdal: 'rhisperadol', 'respirdol', 'risperdall', 'rispardal'

Add frequent bigrams from texts we know are relevant to ASD

PubMed articles on ASD

Identify salient concepts

Control forum: general parenting forum

Association study

Is concept "Aggressive Behaviors" Salient in Autism Forum ?			
	Observed (O)	Expected (E)	$(O - E)^2/E$
Autism	281	101.97	314.33
Control	75	257.03	126.73

$\chi^2 = ?$ p-value = ?

Multiple hypothesis testing, false discovery rate

Identify salient concepts

Raw frequency is not a valid measurement of prevalence of a concept in a forum!

VACCINE

Raw freq: 9939

Post support: 4134

Member support: 850

SOCIAL SKILLS

Raw freq: 6794

Post support: 5227

Member support: 1006

EARLY INTERVENTION

Raw freq: 4345

Post support: 3632

Member support: 1063

SPEECH THERAPY

Raw freq: 3712

Post support: 3245

Member support: 1048

Dataset

Autism: 47M words, vocabulary 165K

	Autism	Control
Years active	2005-2011	2003-2011
Nb. members	8,856	21,427
Nb. posts	387,327	201,895
Nb. sentences	979,278	1,037,837

Results

Lexicon

Semantic grouping	Nb. Terms
Activities & Behaviors (ACTI)	4,074 (1.28%)
Anatomy (ANAT)	11,576 (3.64%)
Chemicals & Drugs (CHEM)	92,232 (29.02%)
Concepts & Ideas (CONC)	14,184 (4.46%)
Devices (DEVI)	3,113 (0.98%)
Disorders (DISO)	55,418 (17.43%)
Genes & Molecular Seq. (GENE)	20,190 (6.35%)
Geographic Areas (GEOG)	2,517 (0.79%)
Living Beings (LIVE)	17,111 (5.38%)
Objects (OBJC)	6,667 (2.10%)
Occupations (OCCU)	1,816 (0.57%)
Organizations (ORGA)	1,516 (0.48%)
Phenomena (PHEN)	2,482 (0.78%)
Physiology (PHYS)	6,991 (2.20%)
Procedures (PROC)	20,668 (6.50%)
From PubMed (PUBMED)	57,300 (18.03%)
Total	317,855

Results

Salient concepts

8K concepts frequent enough for hypothesis testing,
79% are significant for ASD; 3% are significant for Control

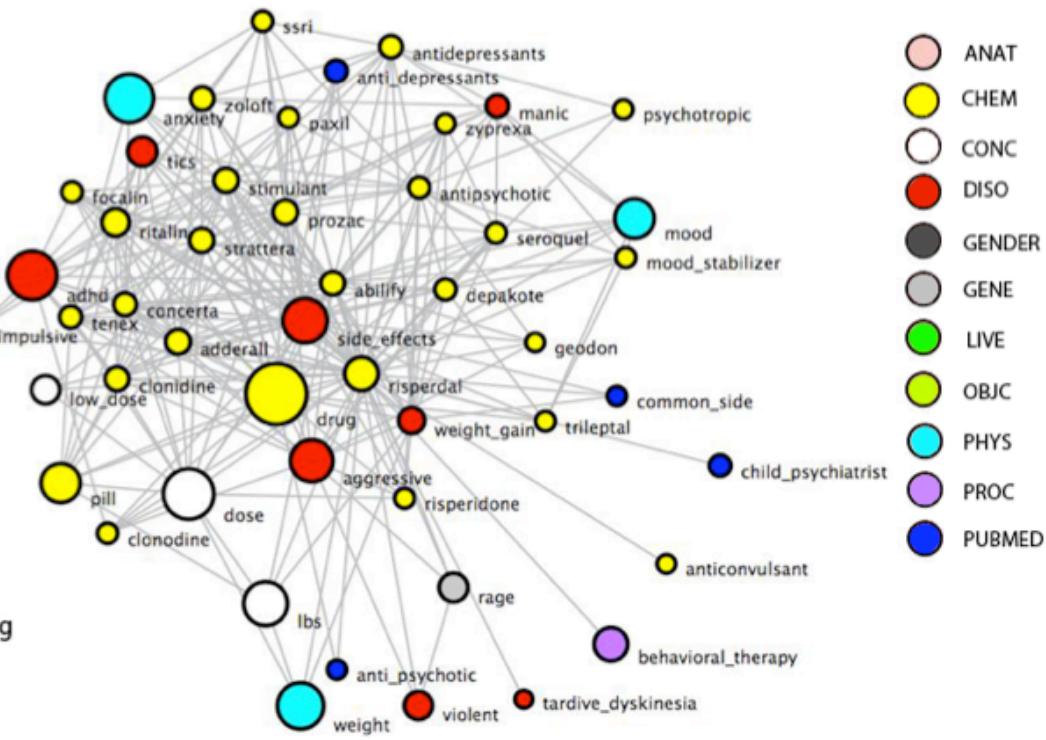
Autism concept	members		Control concept	members
eye contact	1,540	Activities & Behaviors	sex	1,896
hand flapping	311	Anatomy	pubic hair	101
gluten	746	Chemicals & Drugs	cigarette	267
language	1,421	Concepts & Ideas	lying	358
tympanostomy tube	520	Devices	tampons	178
speech	2,779	Disorders	tattoo	255
speech therapist	592	Living Beings	boyfriend	1,416
supplement	1,345	Objects	high school	1,682
neurology	127	Occupations	gyn	100
sounds	1,584	Phenomena	room clean	170
movements	516	Physiology	sexual orientation	242
early intervention	1,004	Procedures	abortion	242
behavior stimming	1,177	PubMed	Harry potter	241

Concept-concept associations

started my 8 year old DD on Risperdal...It hasn't really helped with her anxiety, but it did decrease her tantrums and made her interact more... At the low dose I didn't notice any side effects. But as we increased the dosage she gained weight and became tired all the time.

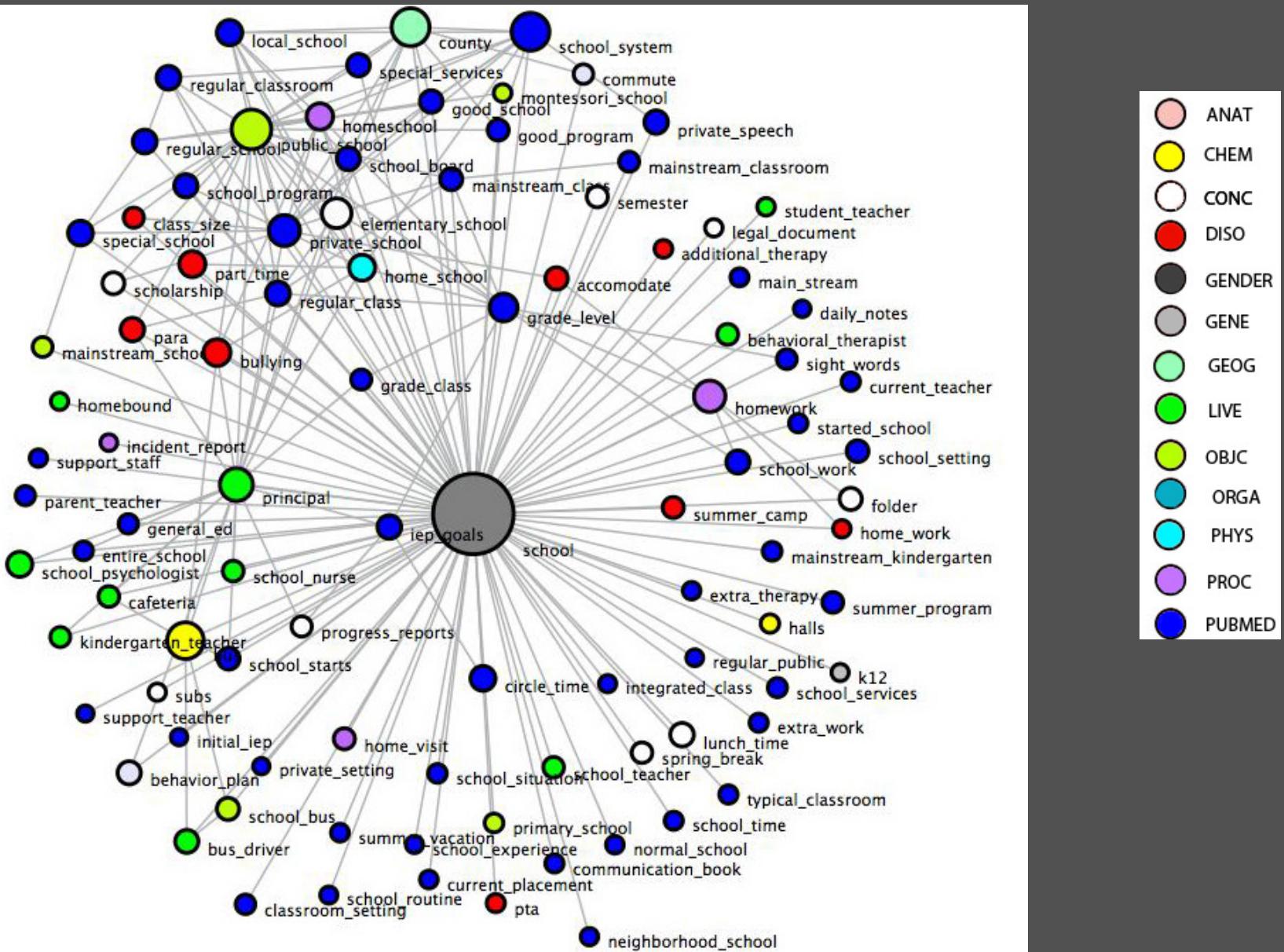
risperdal...has helped take the edge off and decrease aggressive behaviors but overall he did not have a huge change. He also gained about 15 pounds on that dose.

... My son was so violent and aggressive ... We were willing to try anything. He was off of it for 1 week last spring-his anxiety went thru the roof and had a couple of raging episodes (throwing chairs, tipping over the huge oak dining table, etc)-Raging for him when not on risperdal was horrible...-trying to kill his younger sister, choking me in the van while I'm driving, etc.



Example excerpts taken from ASD forum posts containing concepts found through exploration of all neighbors 1 & 2 edges from Risperdal. Relative size of node depicts relative member mention of concept. Color of node depicts semantic group.

Concept “school”, in ASD forum



Concept “school”, in ASD forum

When my dd was really having a hard time a few years ago (about age 5), we were able to have the behavioral therapist from the school do an eval and help us with a game plan of how to redirect the behavior.

The autism school is run through the scholarship which is taken from the school district's funds they would get for having our ryan.

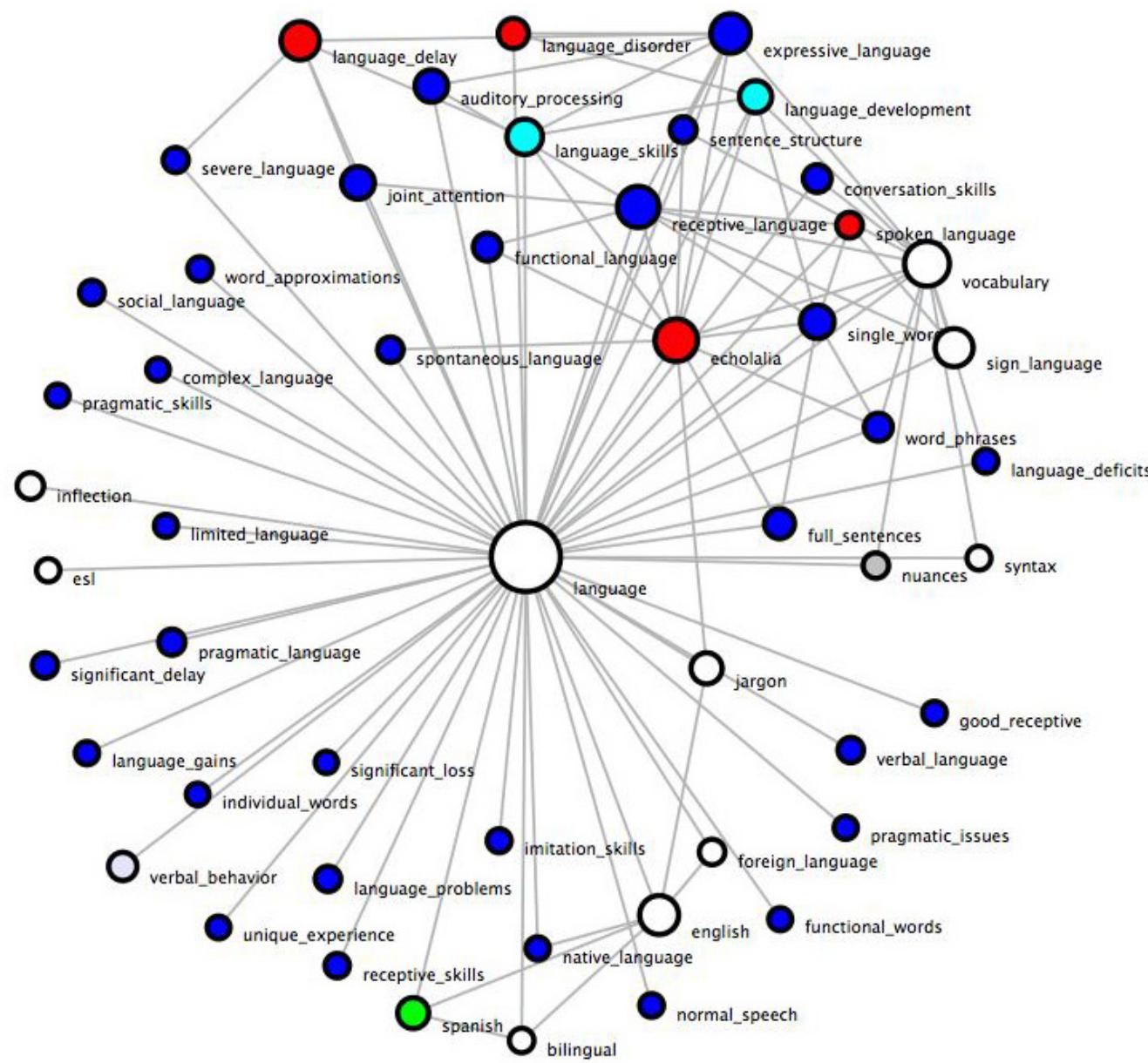
If you chose to home school will you be able to do any private speech or ot services?

The behavioral therapist has done wonders with her, gave us tips and i have used those at home-taylor was totally unruly when she started school 5 years ago.

...great dvd for our kids starting school and modeling what is expected ... "time for school" it is loaded with real kids and step by step the rules of school like " sitting and looking at teacher" and "standing in line", "sitting in circle time" , "listening to a story" and peer social rules and many more...

You should be getting progress notes on the iep goals at least as frequently as the rest of the school gets report cards or progress reports.

Concept “Language”, in ASD forum



Concept “Language”, in ASD forum

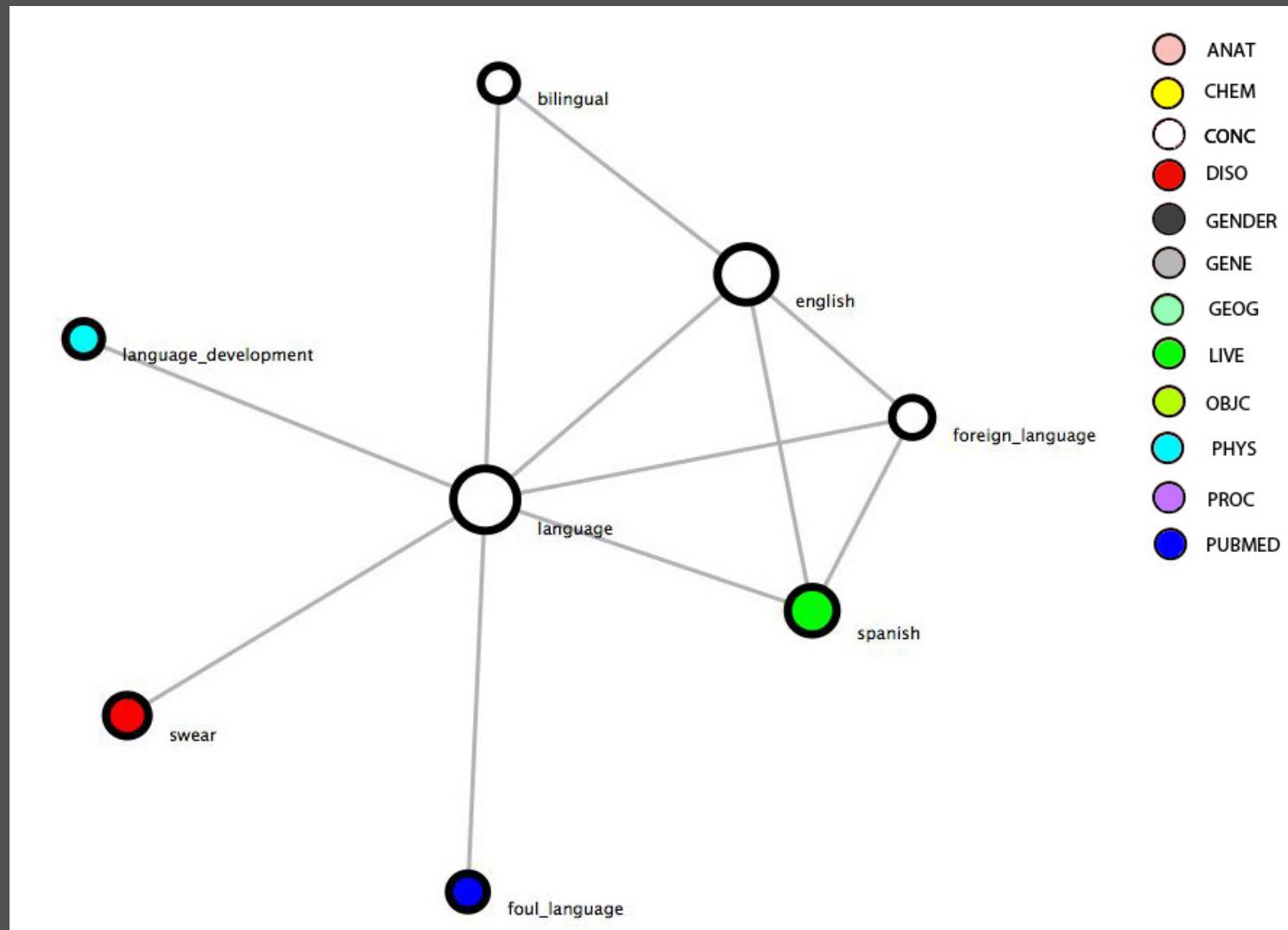
“...it's called 'jargoning' and is a milestone along the way towards language development.”

“X never had an echolalia phase, at least that i noticed. it is definitely a pre-cursor to functional language, and i think that you have reason to be encouraged, given Y's young age.”

“He recently started teaching himself sign language, he speaks and is conversational, but he is really interested in sign language.”

“...their language tests in the normal range now (using the same test that they were given at three), though the test doesn't account for pragmatics issues and social use of language and conversation skills, both of which are still significantly delayed – their talent in rote memorization raises their score on these tests (the test way above age-level in things such as picture recognition and vocabulary)...”

Concept “Language”, in General parenting forum



Final thoughts

Methodology

- social network – real interactions are more meaningful than naïve ones
- prevalence of a concept – raw frequency is not as meaningful as member support (and member support is a stringent metric)

Research

- beyond analysis, what interventions/tools can be built?