

Digital Ethnography – An Example

Note:
This research was self-funded

Entyvio/vedolizumab and what we can learn about...

Part 1: The Patient Experience

Part 2: Science Tweets

Part 3: Statistics and Influencers

Conclusions and Recommendations

October 2016

Entyvio (vedolizumab) is indicated for the treatment of
Ulcerative Colitis and Crohn's Disease

Part 1: The Patient Experience

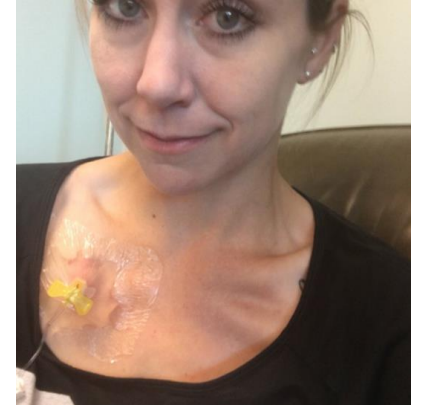


The most frequently posted visual content shows patients getting their infusion



Dutch patient receiving Entyvio infusion

Click above to play video



Source: YouTube Channel LonnekeFilmt



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Infusion day is both nerve wrecking and boring



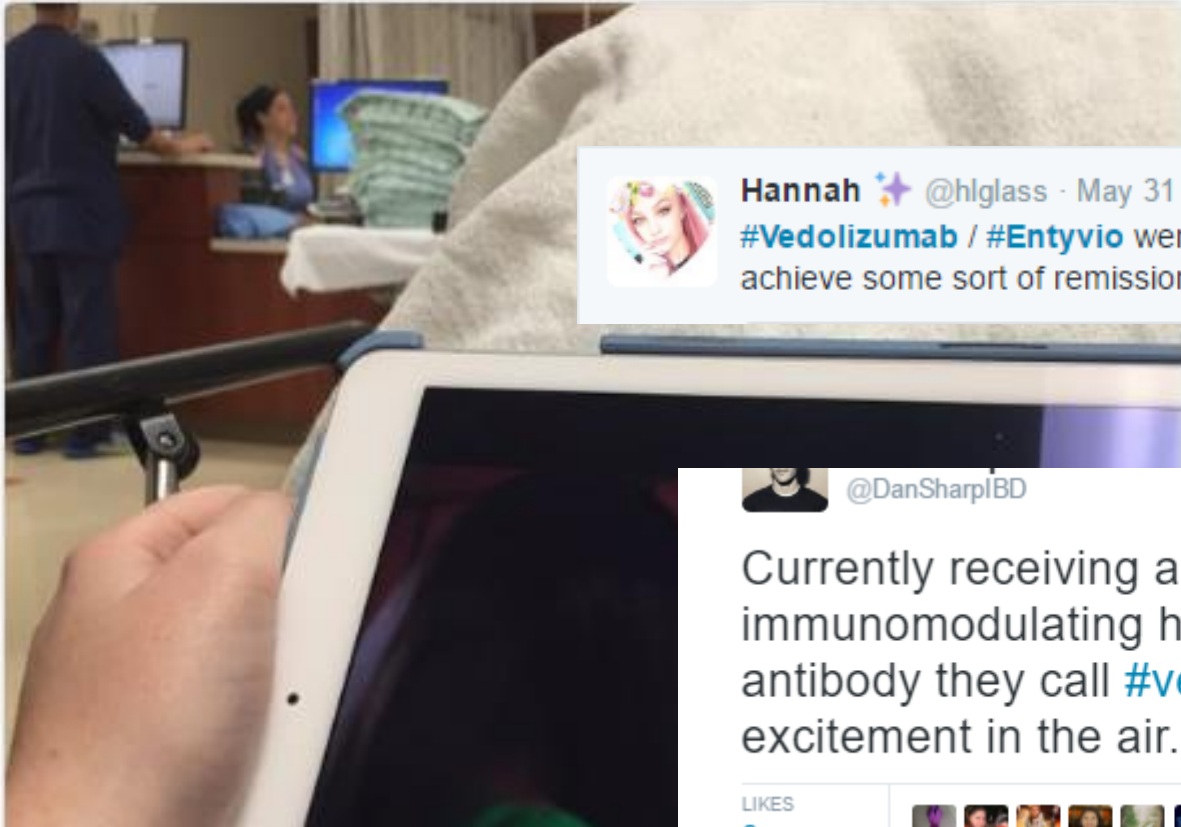
Missy @livingwcolitis · Jul 11

Geeking out and watching Star Wars Episode IV. A hard drive full of 300+ movies was my surgery gift from my brother! [#benefits](#)



Julie @SemiColonGirl · Apr 20

[#Entyvio](#) day! My iPad is a lifesaver [#themindyproject](#)



Hannah ✨ @hlglass · May 31

[#Vedolizumab](#) / [#Entyvio](#) went well 🍊 Fingers crossed this actually helps me achieve some sort of remission! [#crohns](#)



@DanSharpIBD

Currently receiving an infusion of the immunomodulating humanized monoclonal antibody they call [#vedolizumab](#). There's excitement in the air.

LIKES
8



[#entyvio](#) day! lucky to have these little red boots by my side. [#crohns](#) [#invisibleillness](#) [#fuckcrohns](#) [#uofm](#) [#MN](#) [#ccfa](#)



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Patients learn from each other

Throat ulcers

A: I need relief for little ulcers in my throat. They are very bothersome, any tips ?

B: I get them also in my mouth up2 30 a time very painfull. Haven't found anything that helps though sorry! Hope u get some relief

A: are you flaring? Often sign of active disease

B: yes been flaring a lot lately. Bit fed up 🤢

A: oh man! What meds you on?

B: 6mp and monthly entyvio. Going through the Meds 2quickly as we running out of options. I'm just hoping no more surgery! U?

Fecal calprotectin

C: Hey #IBD peeps, Have you gotten your fecal calprotectin checked? How long did it take to get the results?

D: have mine checked every few months, takes around 10 days to get results.

E: why ur docs use it, whether it's 1st or last line of testing,whether U find it necessary 2 monitor ur health? Thank U!!

D: I'm currently stable-I have bloods&calpro checked every few months to see if numbers are still good or rising..

D: if bloods&calpro are going up meds can be increased/changed to try and prevent a bad flare. Worked well so far!

E: Have 2+yrs of entyvio under my belt and while it's been increased (dose& timing) I'm still having relief which is huge!

D: great that your GI got early access & that you're still getting relief! Humira has been good for me so far (1yr)

Joint pain

F: I can tell the day entyvio wears off. immediate start of a flare up, in my case with ileostomy.. severe joint pain.

G: Entyvio helps relieve your joint pain? It doesn't do much for me compared to the relief from when I was on Remicade

F: when my disease is more active I have fatigue / joint pain. less active after infusions, usually 2-3 weeks of no symptoms

H: Entyvio is gut specific and doesn't help with arthritis the way Remicade and Humira do! Spent a lot of time with rheum lately!



Misinformation is disseminated – and corrected



Elizabeth Scott @rigbyscott71 · Apr 21
@ibdjosh gotta out these quacks, dude 🙌



ibd josh
@ibdjosh



Follow

@Clarecool13 @rigbyscott71 yeah that annoyed me! The guy is starting vedolizumab today, asked how long it takes to work and got that reply! 😡



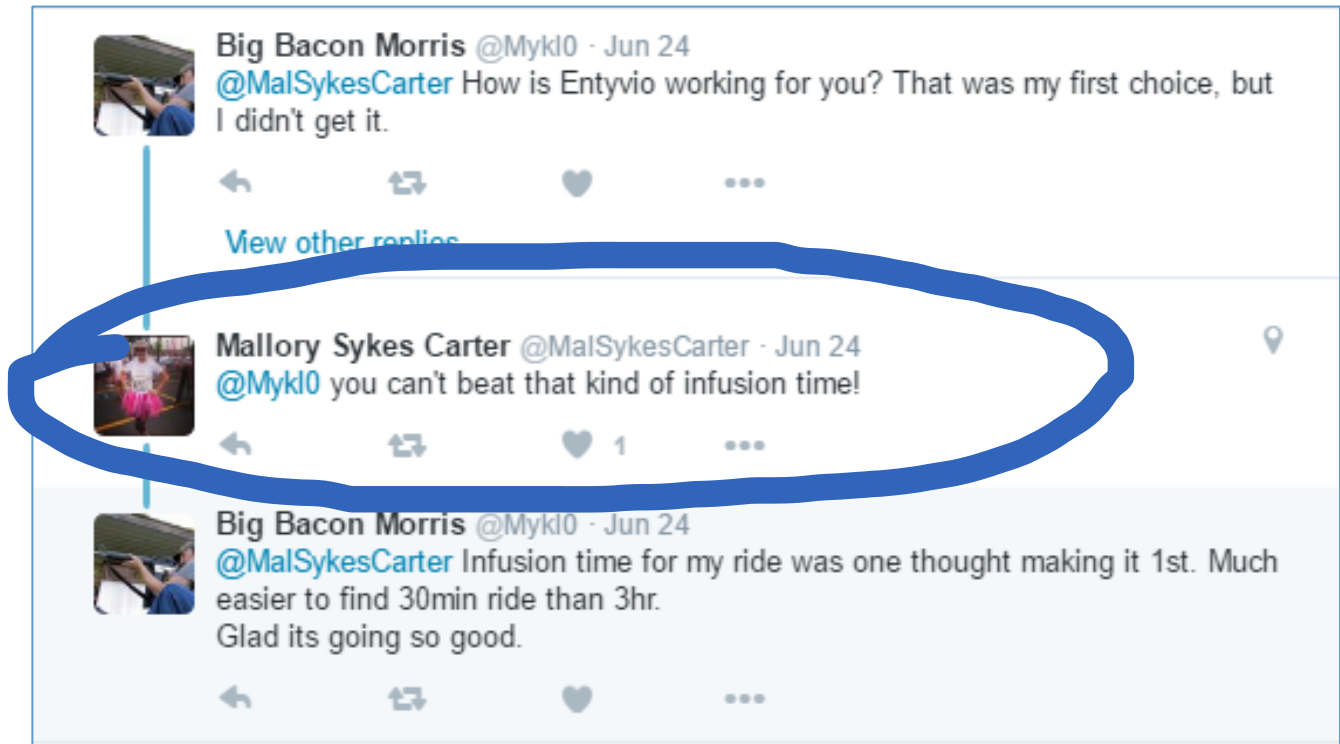
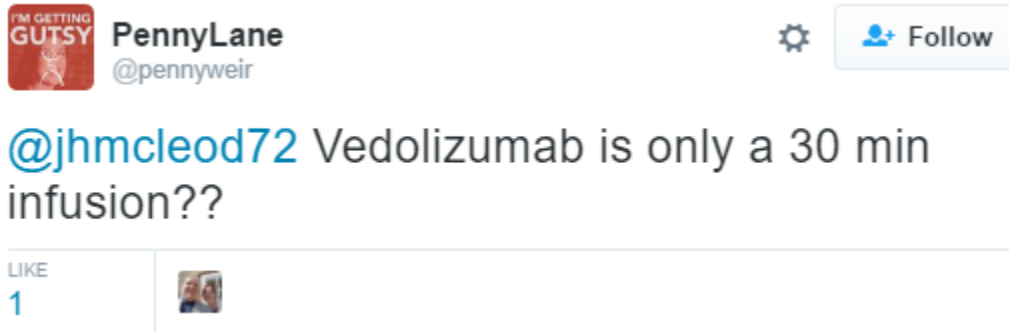
Clare (Clarecool) @Clarecool13 · Apr 21
@ibdjosh @rigbyscott71 he's fought hard to beat cancer, that doesn't make him an expert on everything #fact!!



ibd josh @ibdjosh · Apr 21
@Clarecool13 @rigbyscott71 he should use his position to raise awareness, rather than giving out dangerous and misleading medical advice!



Patients are delighted to hear that Entyvio is only a 30-minute infusion



Patients educate each other on Entyvio expected onset of action, thus encouraging adherence



Busta Coogie
@BustaCoogie



Follow

Well, got my first Entyvio infusion today 3 hours of just sitting LOL I guess I can handle that Next one in two weeks ;-)<3



chiviolet @blitin · Jul 14
@BustaCoogie Fingers crossed that it helps :)



1



Busta Coogie @BustaCoogie · Jul 14
@blitin I won't know for a few months yet Thanks for the entangled digits LOL Have a great night :-)<3



Shawnee Ryan @shawneeinva · Jun 22
@amy4tink How is this working for you?



Amy Emling @amy4tink · Jun 23
@shawneeinva I've only had 2 treatments and my GI told me after 4 or 5 I "should" see a difference. Nothing yet, unfortunately 💜💜



1



Source: YouTube Channel Emily Ellen | Purple Music



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Trials and tribulations that patients experience

Chronic fatigue

Click below to play audio



Source: www.colitisandme.blogspot.com



Hannah ✨ @hlglass · Jul 22

Super exhausted today but we're off to J's parents for lunch. They haven't seen me since this relapse and it's making me anxious.



1



Hannah ✨ @hlglass · Jul 31

It would be easier for me to maintain weight and have a decent body shape if I could exercise more but chronic fatigue is a thing



3



Don't like the way I look



Hannah ✨ @hlglass · Jul 30

I want to go on a night out so badly. I want to dress up and dance and not hate the way I look for once



1



Hannah ✨ @hlglass · Jul 20

I can't wait for the moon face and steroid weight to go so I can start maintaining my weight instead of gaining



Trials and tribulations that patients experience

Bathroom troubles

For people living with Inflammatory Bowel Disease (IBD), finding a restroom while in public can be a nerve-wracking experience ...



Source: www.dansharpibd.org

Stomach and food issues



Hannah ✨ @hlglass · Aug 3

What's it like to be not bloated??? That must be nice



Hannah ✨ @hlglass · Aug 2

I'm never hungry for breakfast anymore, I just force myself food.

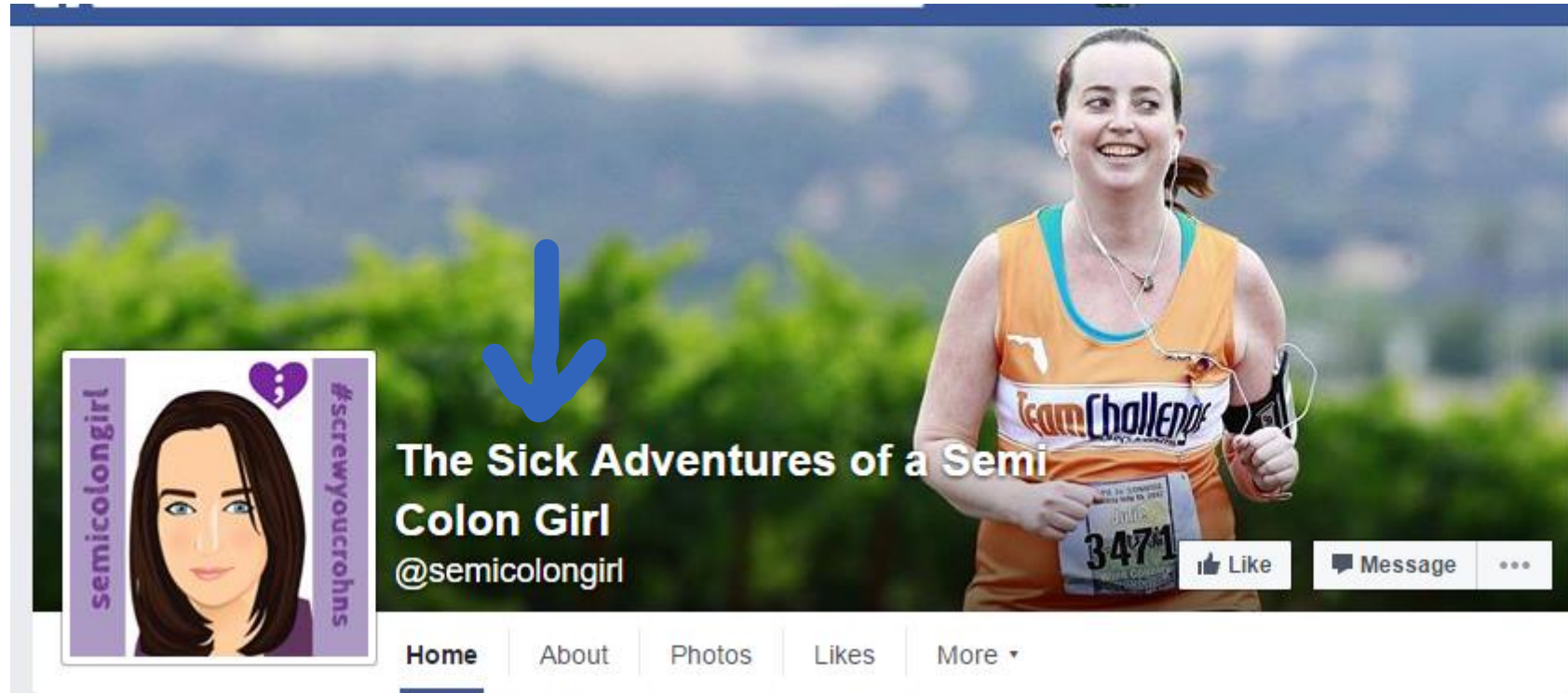
I have been trying to make some diet alterations based on how my stomach has been feeling. I have also needed to pay extra attention to my ostomy since my skin has been a wreck due to my stomach always being distended. ... I have figured out somewhat of a way to keep things at bay (I think) and that is to do a pretty much 80/20 liquid diet. I count gummies as liquid since they have always been good for my stomach and still continue to be. I am sure some of you will think that is odd, but what can I say?:) I have been having a lot of soups and trying to be sure I have at least one smoothie/shake a day.

Source: www.journalingibd.org



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UC and Crohn's are real, serious diseases



semi colon?



UC and Crohn's are real, serious diseases


🏠 dansharpibd.org/about-me/

Dan Sharp
Inflammatory Bowel Disease patient and advocate.

🐦 📺 f 📺

Blog Resources **About Me** Contact Me Events

About Me

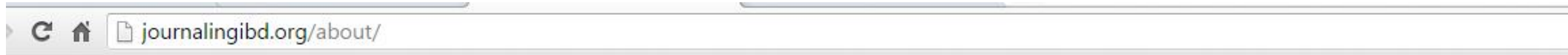


My name is Dan Sharp, and I have Crohn's disease. I was diagnosed 20 years ago, at age 12, although I first started having symptoms of Crohn's at 18 months of age. It was a very difficult and painful journey to my eventual diagnosis, with many tests, procedures, late-night ER trips, and theories from various specialists, before discovering the true cause of my suffering.

Life as a pediatric Crohn's patient ranged from difficult to nightmarish. One of my greatest goals as an adult is to help children that are living with Inflammatory Bowel Disease (Crohn's disease and ulcerative colitis). As an IBD advocate, I feel I'm doing the most good when I'm helping the next generation of patients and advocates. I am going into my fourth year as a volunteer counselor and coordinator at two summer camps for kids with IBD, and it continues to be a life-changing and life-defining experience for me.

nightmare

UC and Crohn's are real, serious diseases



I am a 28 year old girl who was diagnosed with ulcerative colitis at the age of 13, and since then I have had 14 major operations. I have been in and out of the hospital due to many complications, blockages and usual UC symptoms.

14?



Until about two years ago, I kept everything inside. My parents were the only ones who knew what I had been through and have/had to deal with each day.

Thanks to some wonderful friends, I have been able to finally open up and share who I am with the world. I see how important it is, if not necessary, to go through this journey with a support system. I understand how difficult it is to open up, but also in hindsight now see how truly devastating it was/is for me to have kept it all inside for 12 years. I want to help those who are suffering, and let people know that they are not alone.

I am very open to making this blog interactive so please feel free to email me at



Lack of support and understanding

I think it's fair to say that people with invisible illnesses **spend a great deal of time trying to convince the medical professions that they are genuinely sick** and are in desperate need of the extra support ... [] ...

I can't express **how frustrating it is when people compare individuals with chronic illness** or how judgemental people can be to those with invisible illnesses. "My friends cousin has that illness and he gets on with things just fine" ... [] ...

I believe that these things aren't said out of malice and friends/family feel like they're trying to encourage us, when **in reality they're just making me feel worthless**. Don't you think that I am doing the utmost to tackle my own journey with an invisible illness? **Do you feel that I'm simply not trying hard enough?**

Source: www.colitisandme.blogspot.com

Overwhelmed by other patients looking for help

Click on the right to play audio

Source: www.colitisandme.blogspot.com



What not to say to an IBD patient



Source: YouTube Channel Emily Ellen | Purple Music



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Sometimes patients interact with the medical community online and ask questions



The Bottom Line @bottomline_ibd · Jun 22

@IBDPassport @TakedaPharma How do these safety stats stack up against infliximab?

← ↻ 1 ...



IBD Nurse Kay @IBDPassport · Jun 22

@bottomline_ibd Vedo is gut specific & not a TNF.less infusion reactions, skin issues & lymphoma risk. inflix has almost 20yrs safety data

← ↻ 1 2 ...



Peter Higgins @ibddoctor · Jun 22

@IBDPassport @TakedaPharma We just watch out for C diff. #gutSpecific #IBD

← ↻ 1 ...



The Bottom Line @bottomline_ibd · Jun 22

@IBDPassport @TakedaPharma Also, is it true some cardiac events possibly linked to Vedo?



@elevensrh · Jun 26

@jhmcleod72 Can you tell me if Vedolizumab works? pls

← ↻ ❤️ ...

[View other replies](#)



Johnny Mac @jhmcleod72 · Jun 26

@elevensrh your consultant will surely do what they see as being best for you. I hope this helps even though I didn't answer the question.

← ↻ ❤️ 1 ...



Alistair Kennedy

@climbthatill



[Follow](#)

@ibdpassport @ibdnurse Do you think Entyvio (Vedolizumab) will become a more common 2nd line treatment for #IBD? Or just too expensive?

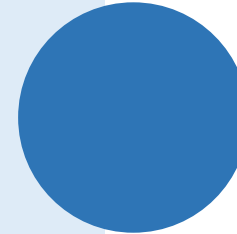


Part 2: Science Tweets

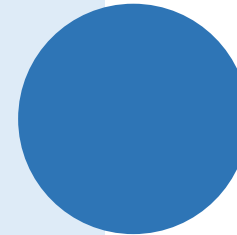


Three main types of science tweets

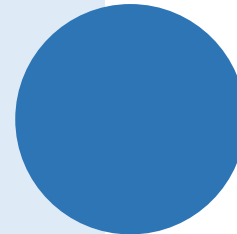
Physicians tweeting live from scientific meetings



Physicians exchanging opinions and experiences



Breaking news, mostly regarding new evidence



Physicians tweeting live from scientific meetings

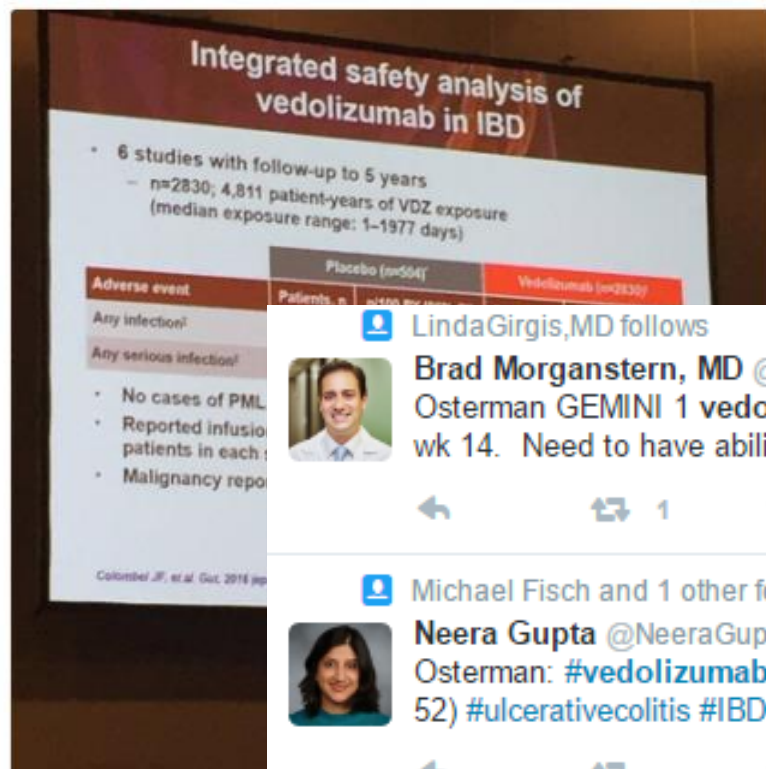


IBD Nurse Kay
@IBDPassport



Follow

Irving: 5 yr safety data of [#vedolizumab](#) in IBD is reassuring [#BSG2016](#) [@TakedaPharma](#) [#symposium](#)



RETWEETS 6
LIKES 12

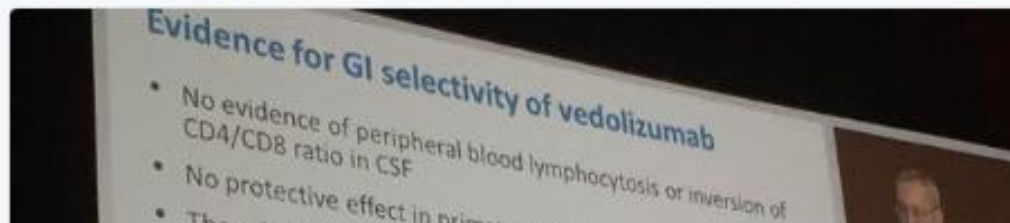


LindaGirgis,MD and 3 others follow



Peter Higgins @ibddoctor · Apr 29

[#Falk202](#) Sands - illustration of gut selectivity of Vedolizumab by systemic vs. oral immunization



Paulo G. Kotze @pakotze · Jun 4

Live from Brazil [@fgomollon](#) describing the mechanism of action of [#vedolizumab](#) [#IBD](#)



LindaGirgis,MD follows



Brad Morganstern, MD @bradmorganstern · May 23

Osterman GEMINI 1 vedolizumab levels at Wk 6 levels correlate w/remission at wk 14. Need to have ability to check levels soon! [#DDW16](#)



1



1



Michael Fisch and 1 other follow



Neera Gupta @NeeraGuptaMD · May 23

Osterman: [#vedolizumab](#) PK at week 6 may predict later outcomes (week 14 & 52) [#ulcerativecolitis](#) [#IBD](#) [#DDW16](#)



2



Physicians exchanging opinions and experiences



Alan Coss

@alcoss



Follow

Vedolizumab - "starving the fire, rather than putting out the fire" of IBD. A very useful new tool. Sandborn [#agapc](#) [#DDW16](#)

RETWEET

1

LIKE

1



1:22 PM - 21 May 2016

San Diego, CA



1

1



Anthony O'Connor @Antcon7062 · May 21

[@alcoss](#) we've had much better than expected outcomes for crohns tnf failures



1



Alan Coss @alcoss · May 21

[@Antcon7062](#) Great to hear. I've a few patients who might benefit, but still struggling to get my hands on it...



KT Park @KTPark6 · May 21

Dr Abreu: Noting optimizing vedolizumab effectiveness by using bridging steroids during induction period [#DDW16](#)



10

16



Fernando Gomollón @fgomollon · May 21

[@KTPark6](#) there are clinicians who in very severe cases start tacrolimus and vedo to further maintenance with vedo after remission [#DDW16](#)



1

3



KT Park
@KTPark6



Follow

[@fgomollon](#) Yes! That is actually what I do. Tacrolimus as my preferred bridge during vedolizumab induction, esp in severe colitis. [#DDW16](#)



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Part 3: Statistics and Influencers



Twitter Stats for Entyvio/vedolizumab

(April 18 – July 18, 2016)

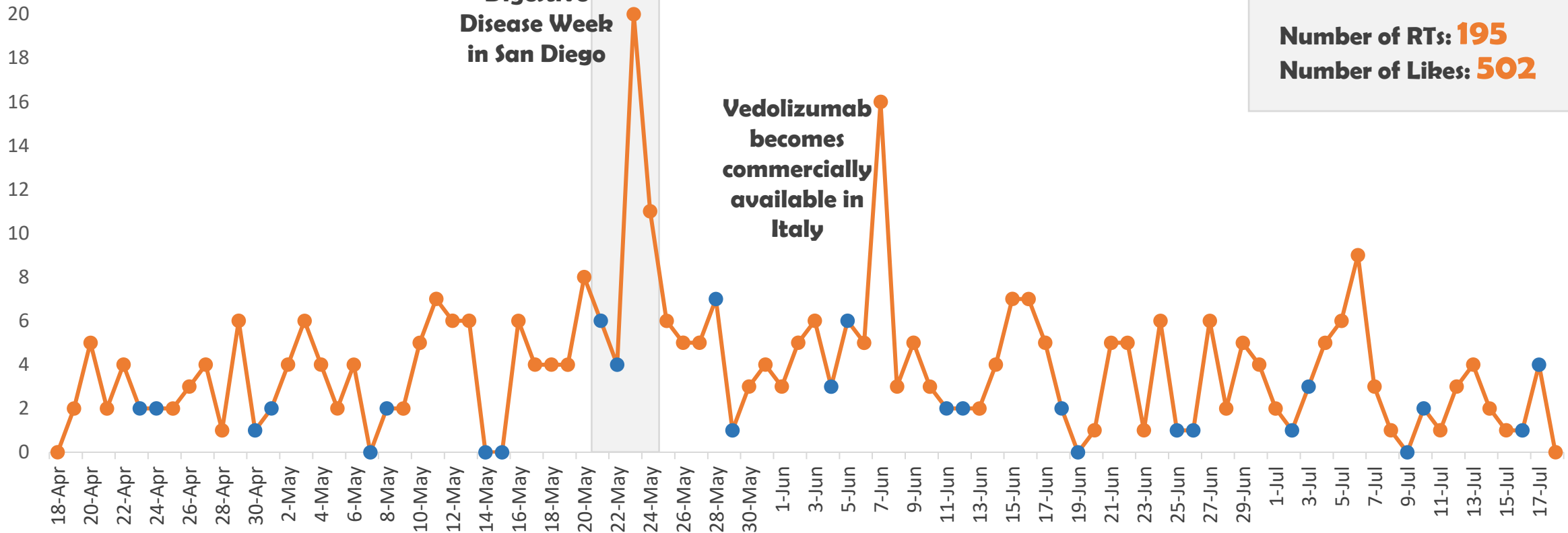
Total Tweets for Entyvio/
vedolizumab over the three
months time period: **353**

Audience engagement (RT
and/or like) on **161** Tweets

Number of RTs: **195**

Number of Likes: **502**

Number of
Tweets



Blue dots indicate Sat & Sun



What is influence?

- **Social influence on online media is measured via reach, relevance and resonance**
 - How many followers does an individual have
 - How relevant is the content that they post to your brand
 - How much engagement does their content garner

In the following pages, we'll look at...

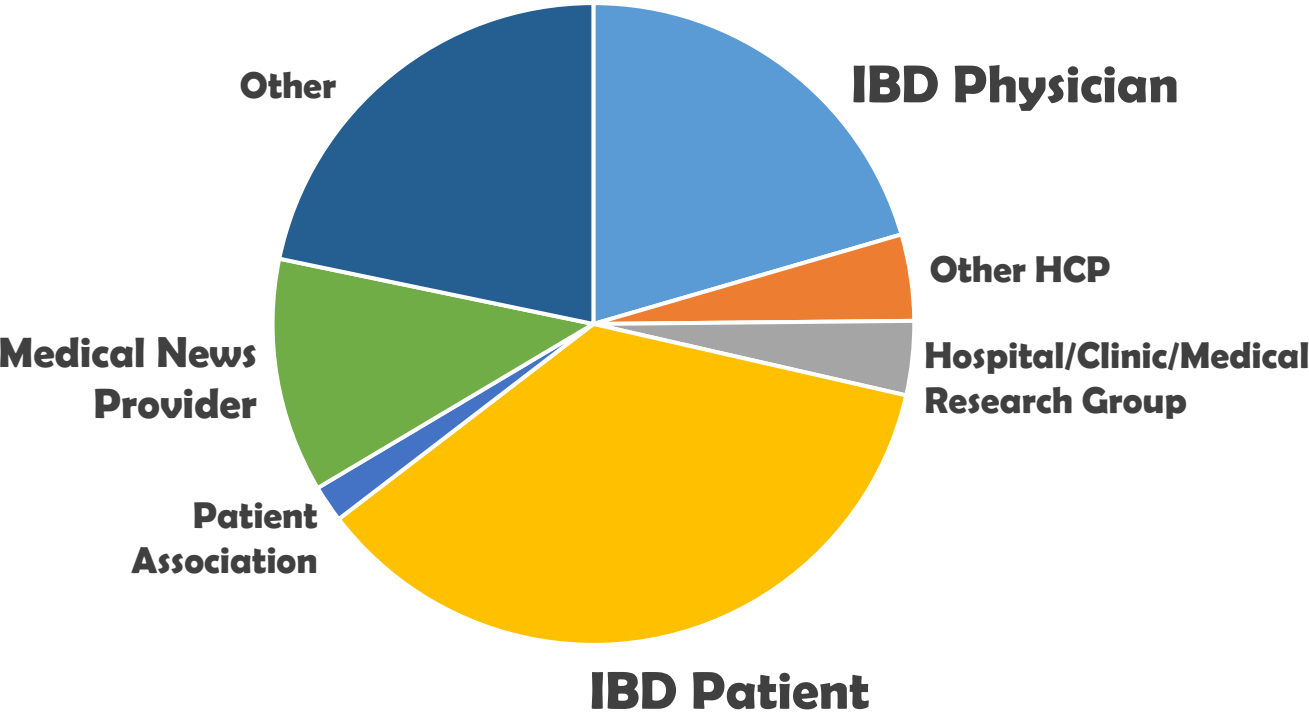
- **Resonance**
 - What types of accounts did create any engagement for Entyvio/vedolizumab (any retweets and/or likes)?
 - Which accounts created the most engagement (highest # of retweets)?
- **Reach**
 - Which accounts reached the largest audience, through own followers and through followers of accounts that retweeted their content?
- **Relevance**
 - Two examples of how reach and resonance may or may not be relevant to the brand



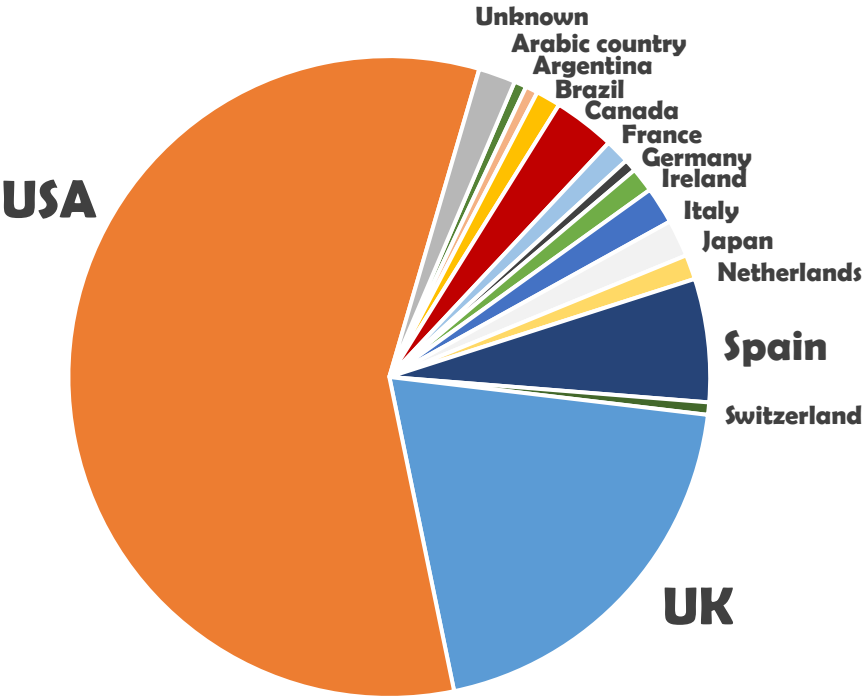
Stats on Tweets with Audience Engagement for
Entyvio/vedolizumab

(April 18 – July 18, 2016)

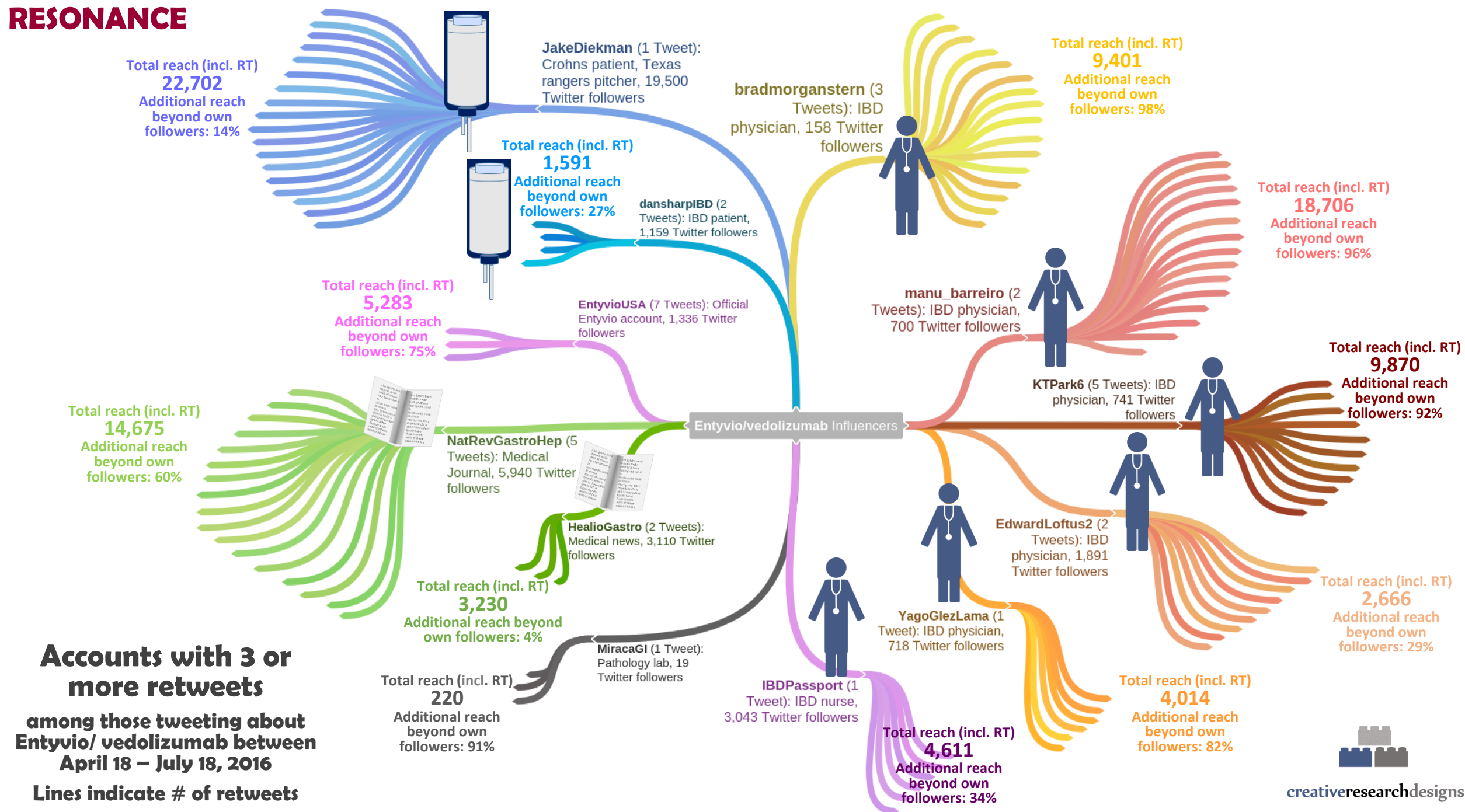
Type of account



Country



RESONANCE



Top 10 accounts with largest reach
(who tweeted about Entyvio/vedolizumab April 18 – July 18, 2016)

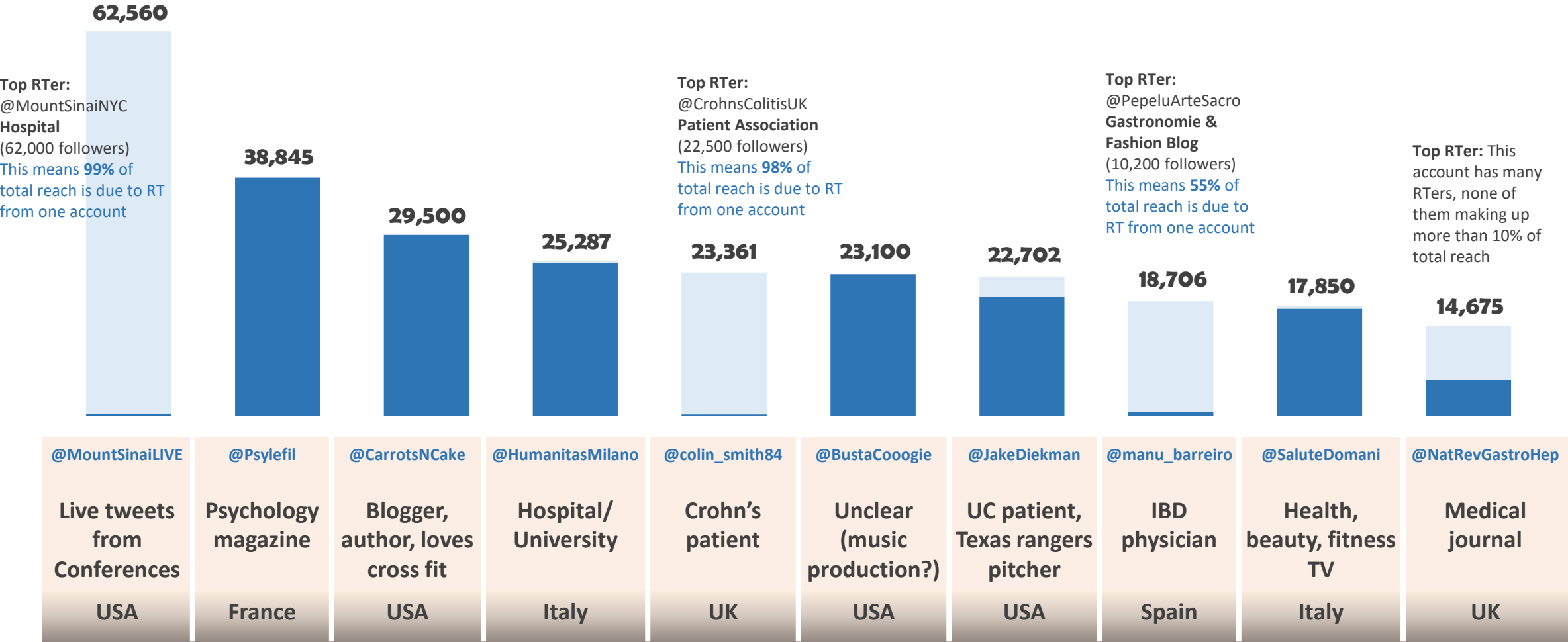
LEGEND

means: Total reach, composed of...

Retweet audience

Account followers

Note: Some achieve most of their reach through a single retweet by a large account



Top 11-20 accounts with largest reach
(who tweeted about Entyvio/vedolizumab April 18 – July 18, 2016)

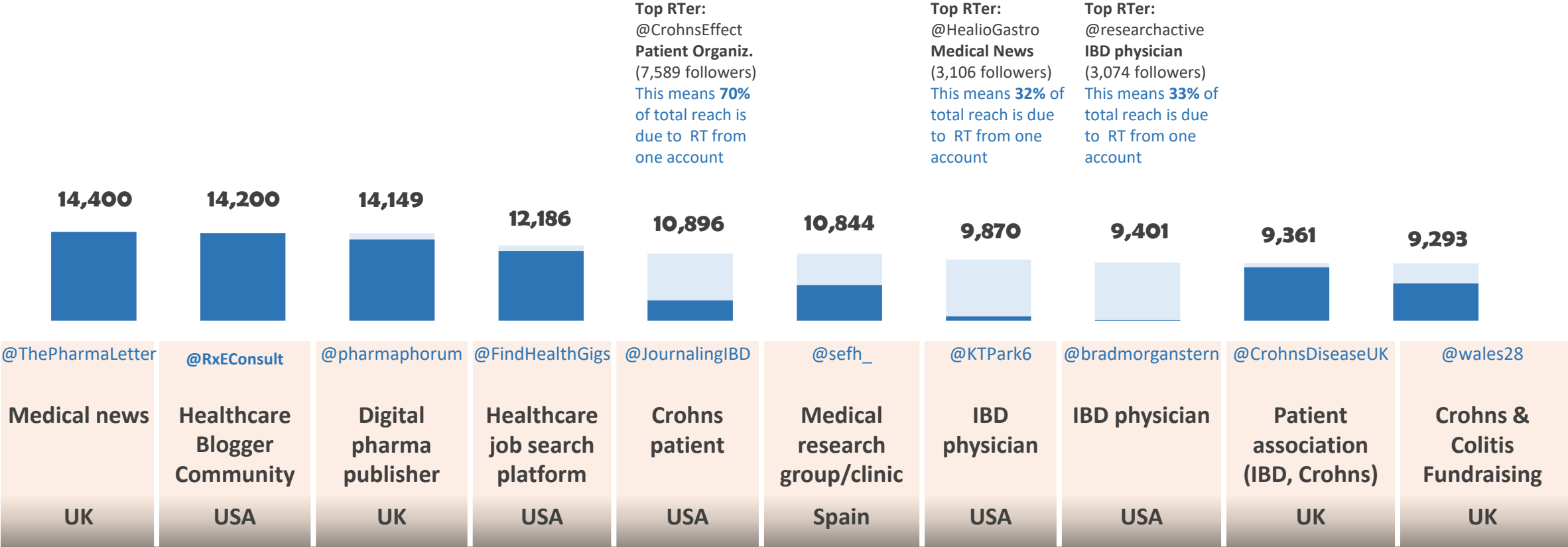
Note: Some achieve most of their reach through a single retweet by a large account

LEGEND

means: Total reach, composed of...

Retweet audience

Account followers



RELEVANCE



Jake Diekman @JakeDiekman · Jun 21
Infusion Tuesday! Pregame Entyvio gets the mind right... Well and the Gut.
#gutitout #neverequit #colitis #crohns



18

118

Some individuals have great reach

But who follows them, and how relevant is their content to the brand?

Texas Rangers pitcher Jake Diekman getting his Entyvio infusion

Tweeted to 19,500 followers, with 18 Retweets, 118 Likes

4 of the Retweets were from other IBD patients

RT by country: All US, many from Texas



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Some individuals have small reach


But they are able to engage others that are highly relevant to the brand, both in the US and internationally

Gastroenterologist in NYC with expertise in IBD

Tweeted to 158 followers, with 13 Retweets, 13 Likes

**9 of the Retweets were from other GI doctors
1 of the Retweets was from a GI nurse
2 of the Retweets were from individuals with interest in GI**

RT by country: 8 in US, 2 in Spain, 1 each in UK, Columbia and the Netherlands

 **Brad Morganstern, MD**
@bradmorganstern

Big news in IBD - we can finally check drug levels for vedolizumab (Entyvio) and certolizumab (Cimzia)

Edward Loftus @EdwardLoftus2
Miraca launches TDM assays for #IBD patients on biologics #infliximab #adalimumab #certolizumab #vedolizumab goo.gl/JbnONU

RETWEETS
13

LIKES
13

9:23 AM - 27 Jun 2016

13

13



Conclusions and Recommendations



Conclusions and Recommendations

- 1. Short infusion time for Entyvio is a highly patient-relevant benefit – make sure to communicate it well to prescribers.**
- 2. Infusion day is a special day – provide encouragement to patients on that day. Consider text messages, app based notification with supportive, positive content.**
- 3. Infusions are both boring and stressful – provide distraction: perhaps a fun app that patients can play while being infused, that lets them reach different levels based on length of time on Entyvio ...and can function as an adherence tracking tool indirectly.**
- 4. Some individuals are widely heard – but not necessarily speak to a relevant audience. Others have a smaller audience that may actually be more important to the brand. Engage individuals based on brand strategy, rather than just based on reach.**
- 5. Limited local content – a more in-depth analysis with focus on local organizations and individuals is required to understand country-specific peculiarities and needs.**



Want to get more insights into the patient journey?

Contact Creative Research Designs

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