

Understanding Parkinson's Disease on-line

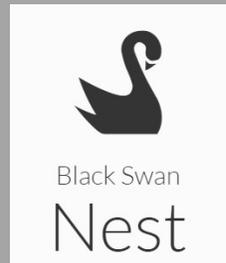


WHITE SWAN

Introduction and Methodology

- This study was produced for a charity wanting to better understand the content and sources of Parkinson's Disease (PD) conversation online.
- In order to explore this conversation, White Swan tracked all online mentions of 'Parkinson's' on Twitter, Blogs and Boards globally, within the date range of 10 Aug. 2016 to 10. Nov. 2016.
- On analysing this data, multiple layers of analysis were used. This included producing data science outputs, conducting analysis on the NEST (Black Swan's proprietary tool) and utilising qualitative coding to unearth themes and trends.
- This report summarises the findings of these analyses and offers recommendations off the back of these findings.

INFORMATION



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Key findings and recommendations

1. PD patients and caregivers are turning to each social channel for different types of information and support. Twitter is great for info-sharing, promoting new research and sharing quick tips, blogs are used to highlight personal experiences and stories and boards are where people turn to for detailed guidance and a sense of community. By tailoring outreach approaches to each site, the MJFF can deliver the information people need in the most appropriate forum. Twitter outreach could include engaging with influencers, trying to answer some of the top Google search questions and promoting genetic testing. Blog outreach could involve the MJFF sharing popular experience-sharing blog posts. Board outreach could involve experimentation in forum engagement to answer detailed questions and to educate around clinical trial participation.
2. Patients and caregivers appear to be reaching out to online sources and communities only in the later stages of the patient journey, once they've been diagnosed and are living with PD. People are not talking organically about going through genetic testing or about showing early signs of PD, and there is therefore a clear gap in conversation about these early stages. There is thus an opportunity to focus more outreach on boosting conversation surrounding getting tested and getting diagnosed. Google search questions suggest that people do turn to internet when they suspect they – or someone they love – could have PD, they just now need to be brought into the conversation.



How people talk about Parkinson's Disease on-line

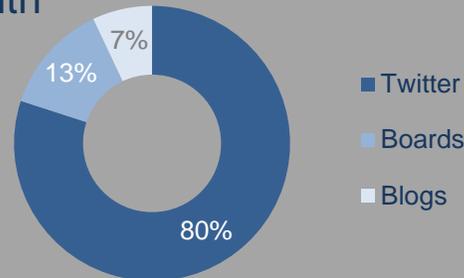


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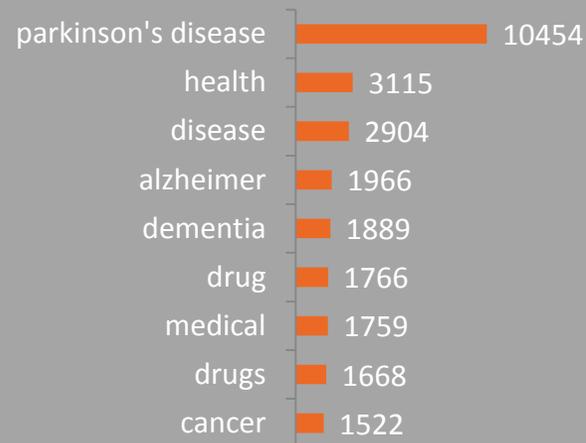
Overview: PD conversation at a glance

- Parkinson's conversation online is sizeable, amassing more than 27k mentions on Twitter, blogs & boards each month.
- Conversation is largely health and treatment-focused, as evidence by the top keywords. Parkinson's is also mentioned frequently in the context of other neurological diseases – such as dementia and Alzheimer's.
- PD experts – like the Michael J. Fox Foundation and Parkinson's UK – play an important role in guiding online conversation.

27.5k mentions
per month



TOP KEYWORDS



TOP @MENTIONS



1.8k mentions

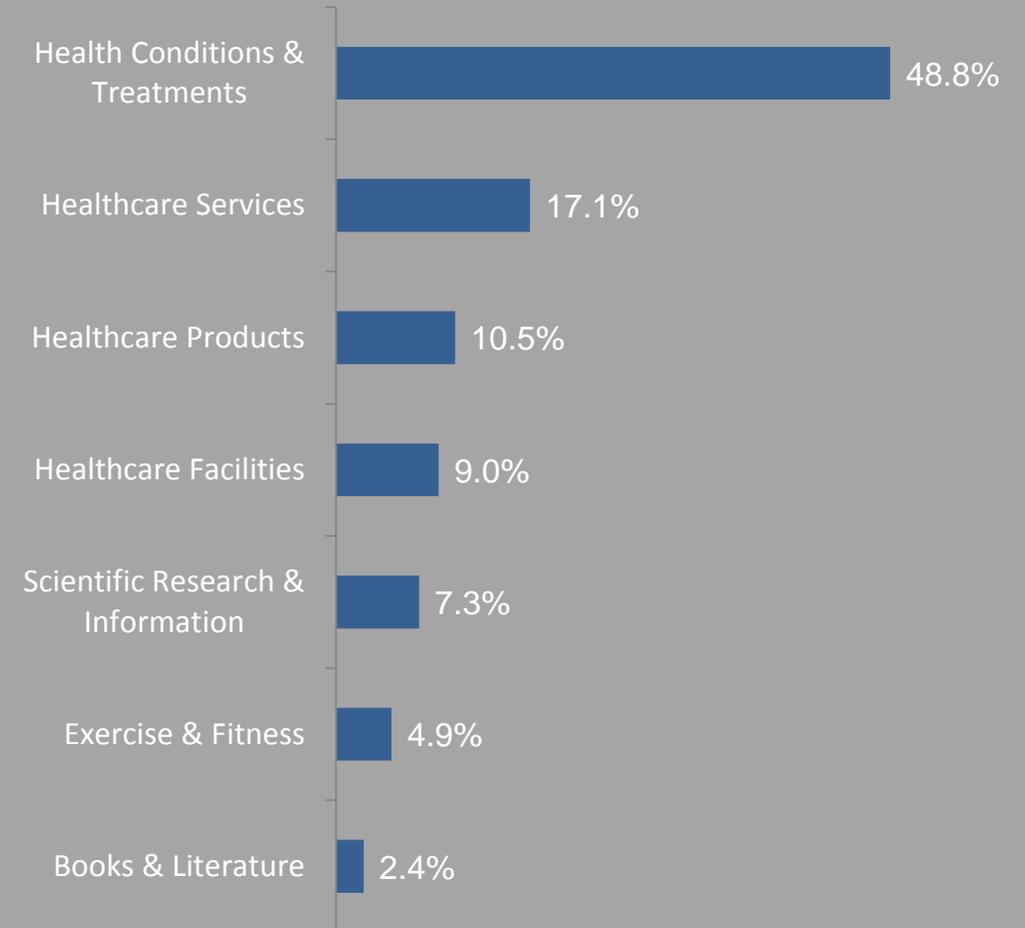


1.5k mentions

Overview:

Conversation Categories

- Health Conditions and Treatments makes up the largest conversation category, encompassing mentions of living with Parkinson's, of recognizing symptoms and of seeking treatment.
- Healthcare services is the second most buzzworthy category, covering posts about doctors visits and caregiver services and support. Healthcare products – which include drugs – and facilities are less discussed.
- Exercise and Fitness represents a small but important conversation segment, with patients viewing this as an important part of therapy and seeking new ways of staying active.
- Book and Literature appears on the list, thanks to online enthusiasm for self-help books, PD memoirs and poetry.

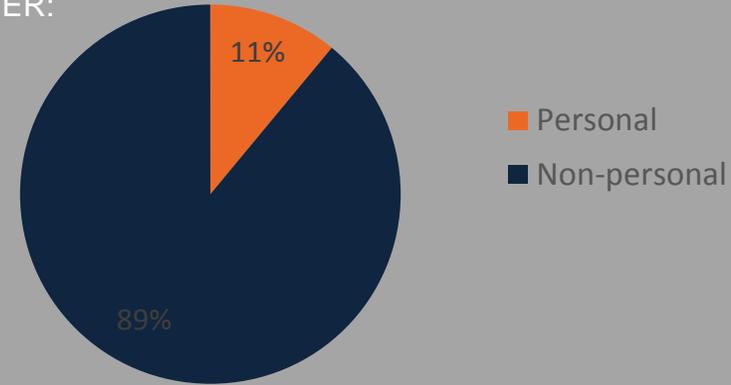


How people talk: Sharing personal stories

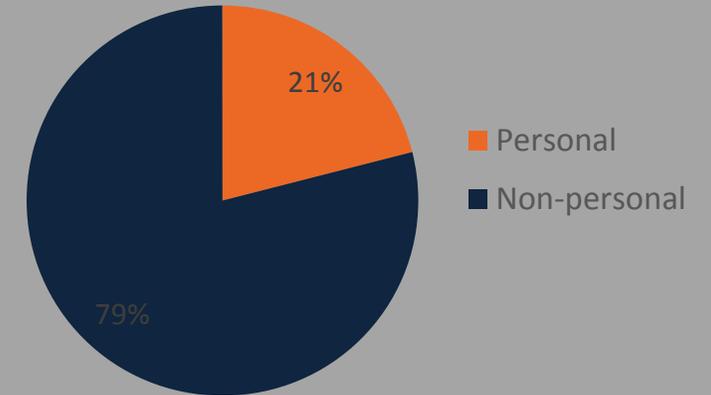
- A large variation exists in the nature of posts across channels. On Twitter, conversation is mostly shallow and nonpersonal, with people passively sharing information much more than actively telling their own stories. On boards, we see personal posting increase and on boards (forums), personal posts represent nearly half of conversation.
- These differences in posting behaviours suggest that people with PD, and their caregivers, seek out different types of information and support from different social channels.

SPLIT OF PERSONAL/NONPERSONAL POSTS

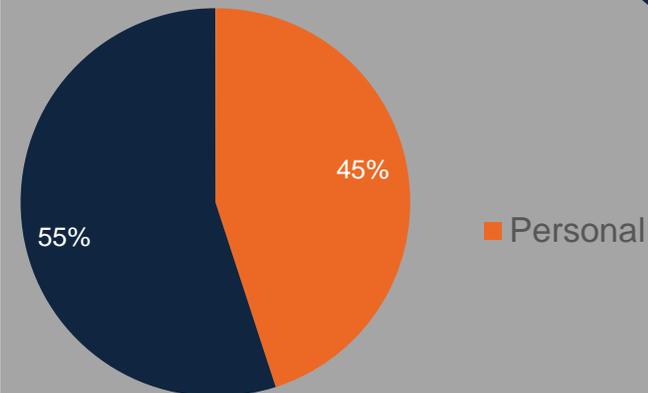
TWITTER:



BLOGS:



BOARDS:

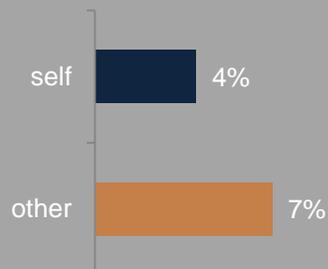


How people talk: Talking about oneself vs others

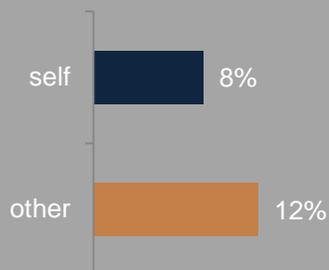
- What varies less across channels is the degree to which posts are written by Parkinson's patients or by their caregivers/loved ones. In each case, we see that posting about others surpasses posting about selves by 3-4 percentage points.
- The people who are turning to social channels to seek advice and support about PD are not just patients themselves, but also, and increasingly, their loved ones.

SPLIT OF SELF/OTHER CONVERSATION

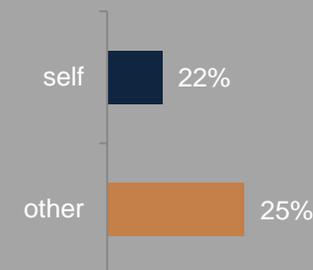
TWITTER:



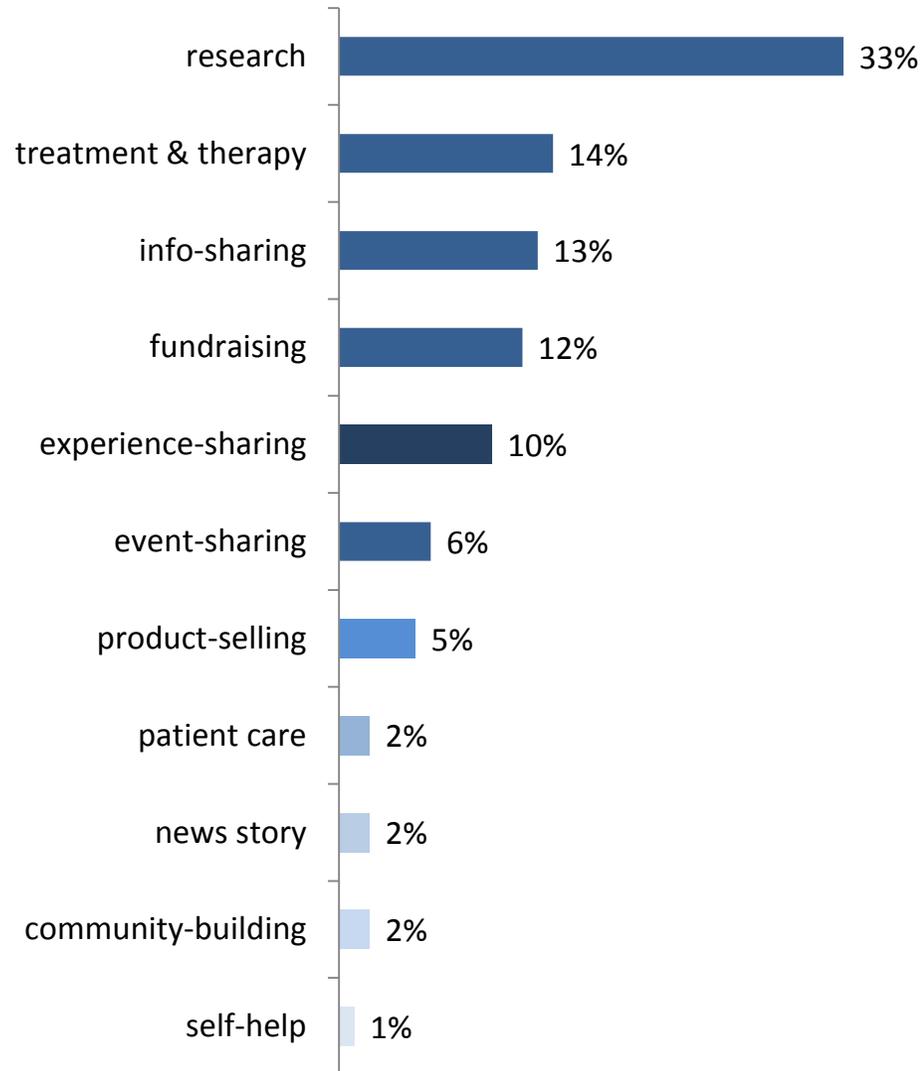
BLOGS:



BOARDS:



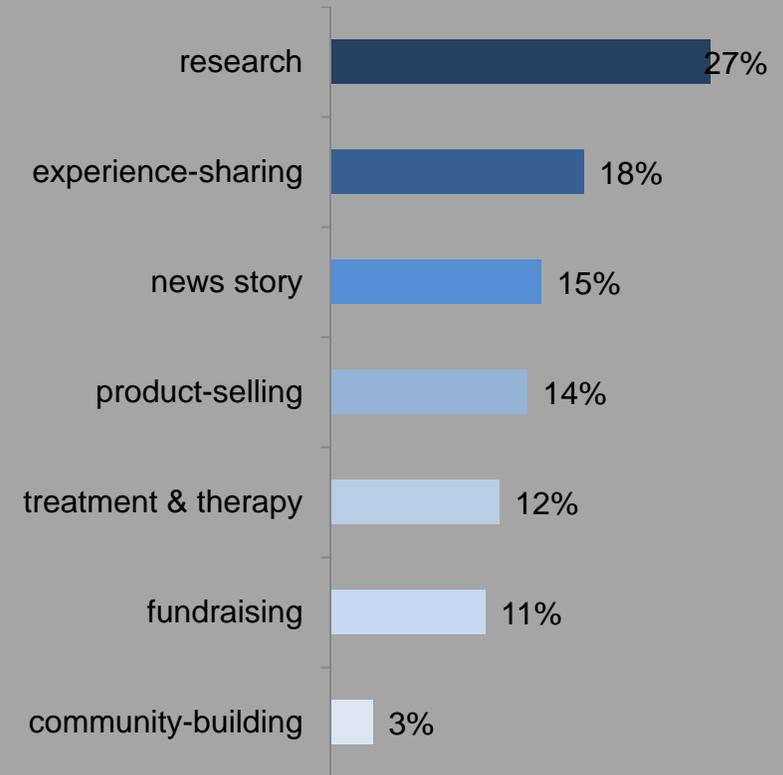
What people share: Twitter



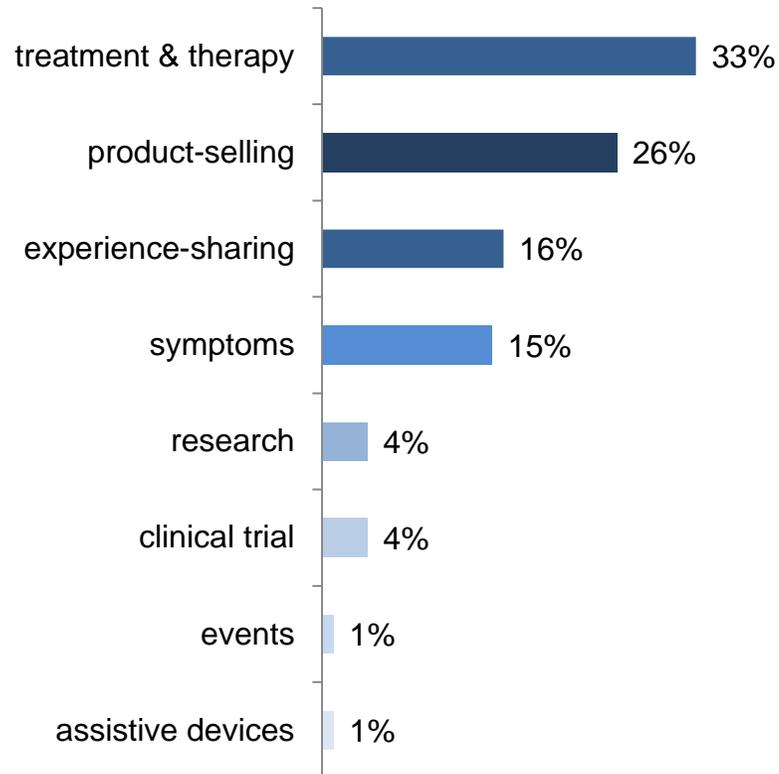
- On Twitter, conversation is largely clinical. Research-sharing leads posting activity, with people re-tweeting the latest study-releases and new drug announcements.
- Treatment & therapy is the second largest conversation category. This includes posts sharing exercise techniques, promoting cannabis use and encouraging music therapy.
- Twitter is also used to increase awareness of the signs, symptoms and causes of Parkinson's (infosharing), to support fundraising efforts, to share event information and to sell products.
- There is some experience-sharing taking place, though for the most part, this involves sharing a link to a longer blog piece.

What people share: Blogs

- On blogs, research once again leads the conversation categories, as people post and share full research studies and press releases.
- Experience-sharing is, however, the second-largest category. The longer-form nature of blogs allows people to share in-depth stories about living with PD.
- Product-selling is rife on blogs, as is the passive sharing of news stories that are tangentially connected to Parkinson's disease.
- Once again, treatment & therapy posting is led by posts about exercise and alternative therapies, such as cannabis.
- Finally, we see some community-building posts on blogs – announcing the meetings of PD support groups.



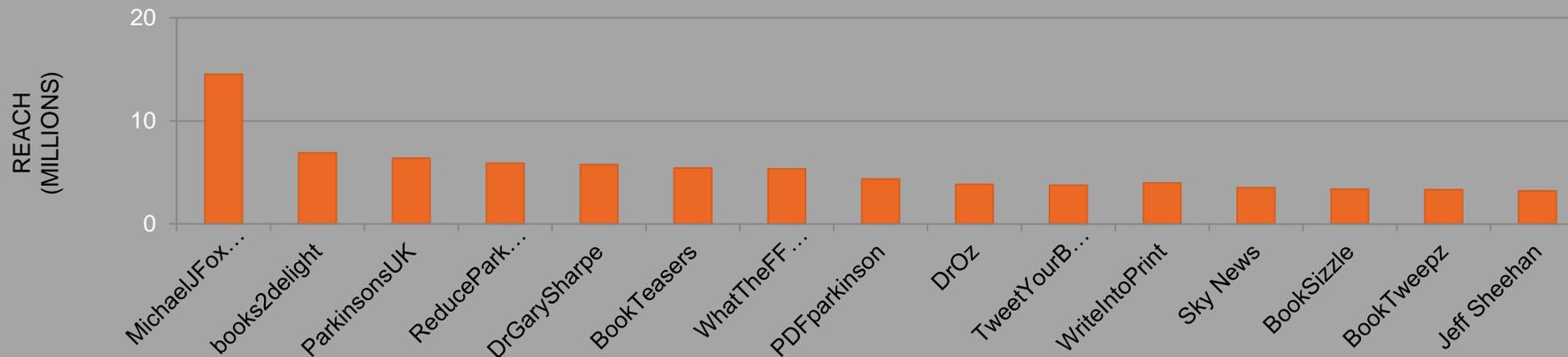
What people share: Boards



- On boards, categories are quite different, with research falling to 4% and treatment & therapy leading conversation. In this category, people discuss the different drugs they've tried and ask for opinions on others they haven't. There is also some discussion about physical therapy options.
- General experience-sharing is also very common on boards, and this is particularly the case for loved ones and caregivers, who use boards to reach out to one another.
- 'Symptoms' is a conversation category that we see appear only in boards. This encompasses posts where people share about the symptoms they're experiencing, seek counsel about diagnosing their conditions (perhaps as PD) or share solutions for managing symptoms.

Who is talking? Top influencers

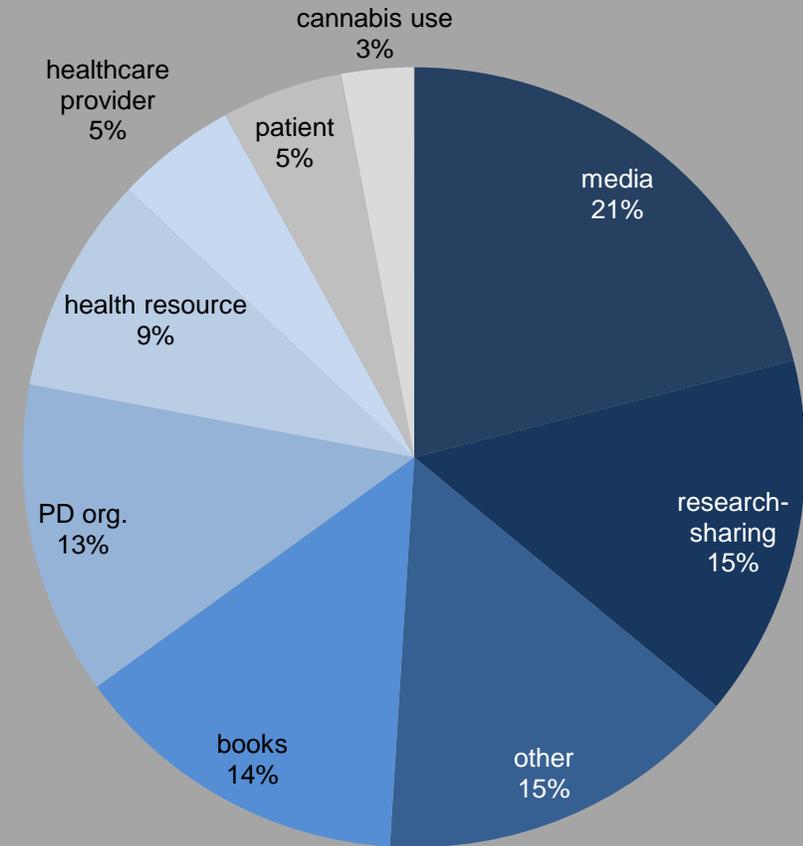
- As previously mentioned, the Michael J. Fox Foundation is the leading influencer on Twitter – reaching nearly 15 million people – and Parkinson’s UK sits in third.
- There are a number of influential book-related accounts, thanks to the aforementioned enthusiasm for self-help guides and memoirs.
- In terms of influential people, Dr. Gary Sharpe – a doctor and Parkinson’s patient who runs a popular ‘living with PD’ blog – and Dr. Oz – a doctor and American TV personality – lead the charge.



Who is talking?

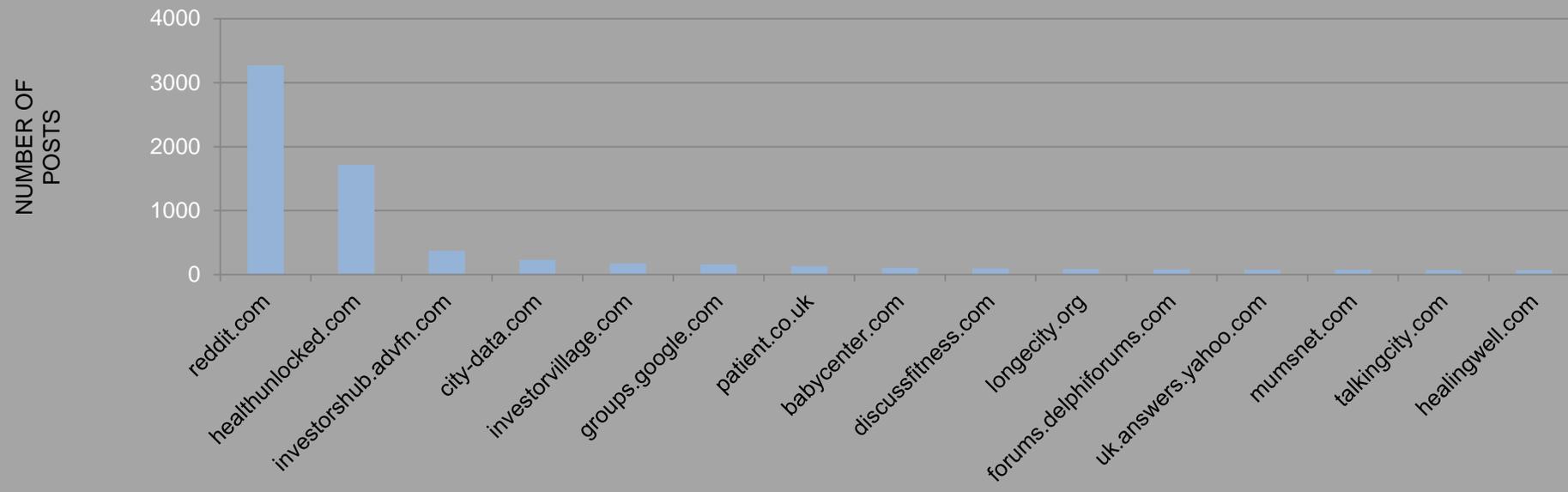
Influencer types

- Media sources see the highest amount of influence within PD conversation, thanks to their large Twitter followings and despite only publishing a handful of posts related to the disease.
- Once again, we see that PD-specific organisations play an important role in shaping online conversation, as do people/sites that share research updates.
- There is some influential activity from healthcare providers, such as clinics, as well as from general health-resource accounts.
- There are very few high-profile PD patients operating in this space.
- Accounts promoting the use of cannabis for treating pain and diseases such as PD are also influential in the category.



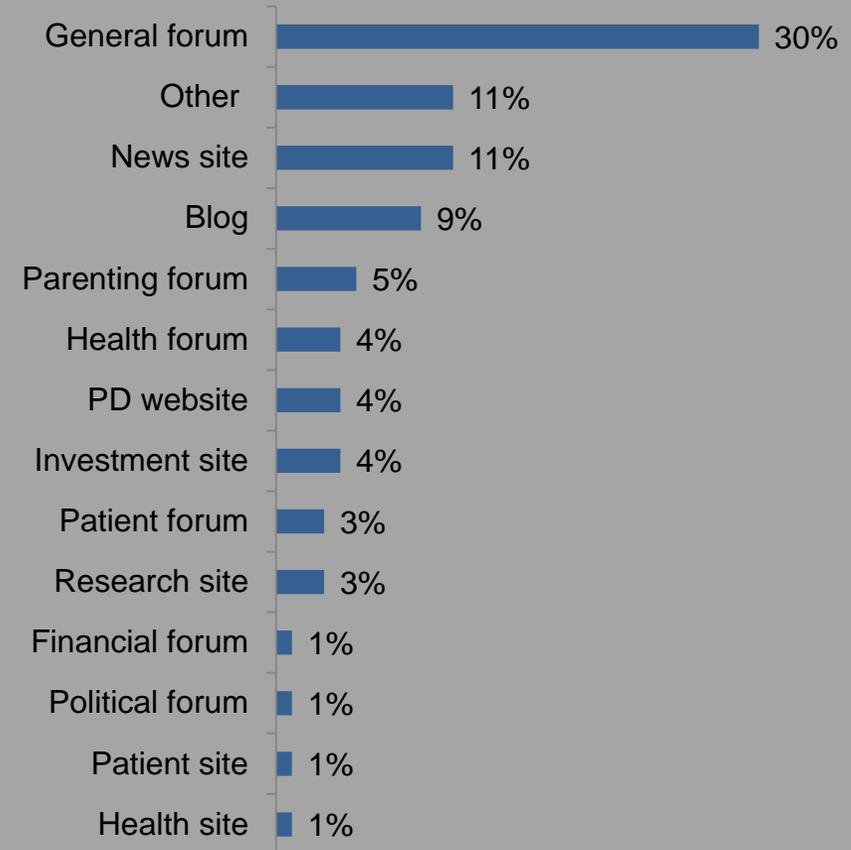
Where people talk: Top domains

- When looking at top domains, forums are much more frequented than blogs, and see higher levels of participation.
- Reddit is the top blog, amassing over 3k mentions. HealthUnlocked, however, is also a very important forum – one where rich conversations about treating and living with PD are discussed (as the slides in the next section will show).
- Investor blogs feature heavily in the list, thanks to conversations about investing in new drugs. Also featured are top parenting blogs and witness/wellness sites.



Where people talk: Domain types

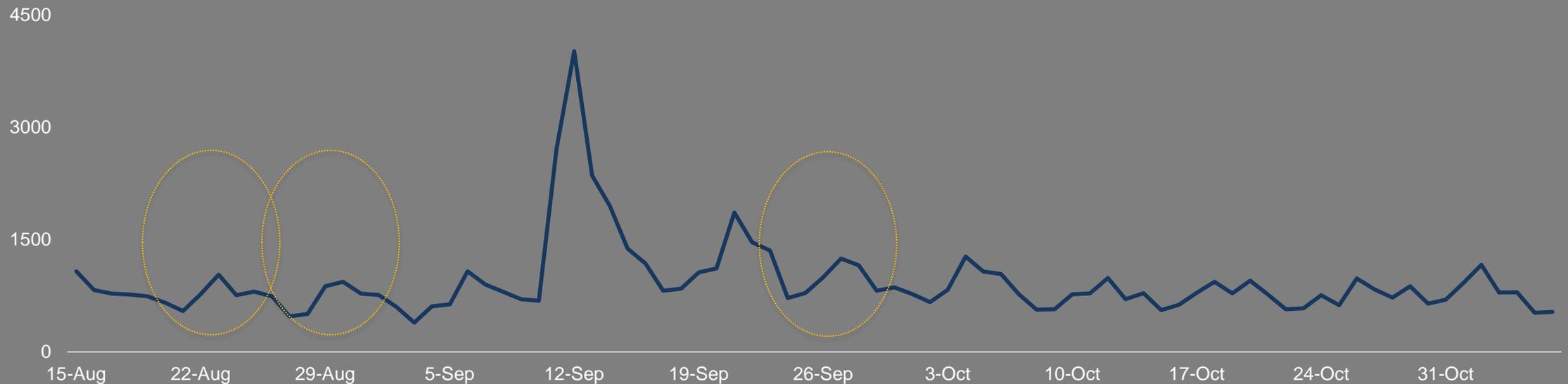
- General forums are the most active domain type for PD conversation, accounting for nearly a third of posts. These include forums such as Reddit and Google Groups, which encourage conversations on a wide range of topics.
- There is some activity on specific PD and patient sites, however relevant conversation takes place on a wide range of forum types, indicating that there isn't one single hub for PD posting.



When people talk: Weekly trends

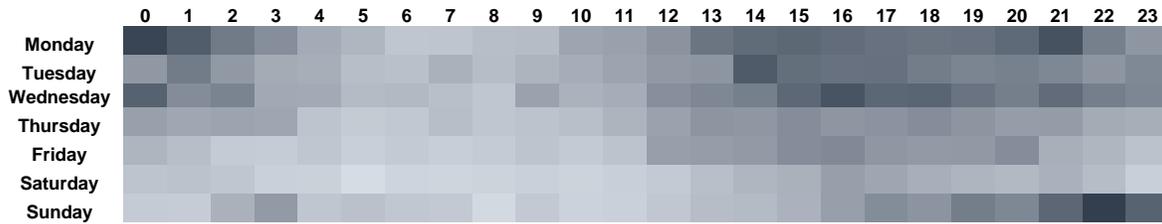
- Looking at posts over time, there is a clear trend in posting activity during the week: volumes spike on Tuesday/Wednesday and then gradually slow down near the end of the week. This suggests that the best time to connect with the PD audience is early-to-mid week.

POSTS OVER TIME

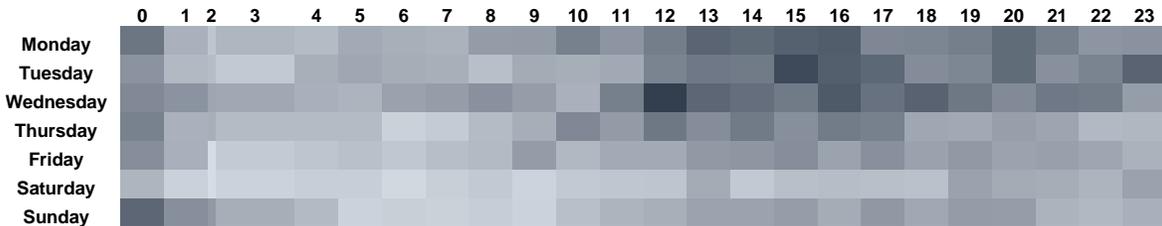


When people talk: Key dates and times

TWITTER



BLOGS & BOARDS



- The early-to-mid week trends holds true across Twitter, blogs & boards.
- Posting on those days is concentrated in the late afternoon and early evening, for both UK and US times.
- On Twitter, Sunday evening is another hot time for activity.



What people search: Top Google questions

- Top search questions on Google cover a range of topics associated with recognising, diagnosing and living with Parkinson's.
- Two of the major topic themes are explored in the following slides.

1	Are Parkinson's tremors constant?	9	Are Parkinson's and dystonia related?	17	Can Parkinson's disease cause eye problems?	25	Do Parkinson's patients cough?
2	Are Parkinson's and ALS related?	10	Are Parkinson's symptoms intermittent?	18	Can Parkinson's cause heart problems?	26	Do Parkinson's patients shake when they sleep?
3	Are Parkinson's symptoms worse in the morning?	11	Can Parkinson's disease cause death?	19	Can Parkinson's disease symptoms come and go?	27	Do Parkinson's patients sleep a lot?
4	Are Parkinson's and dementia related?	12	Can Parkinson's disease cause short breath?	20	Where did Parkinson's disease originate?	28	Do Parkinson's tremors come and go?
5	Are Parkinson's and Multiple Sclerosis related?	13	Can Parkinson's disease cause seizures?	21	Do Parkinson's patients have seizures?	29	Do Parkinson's patients get dementia?
6	Are Parkinson's and Alzheimers related?	14	Can Parkinson's be cured?	22	Do Parkinson's patients wear leg braces?	30	Does Parkinson's disease cause coughing?
7	Are Parkinson's and Tourette's related?	15	Can Parkinson's disease be treated?	23	Do Parkinson's patients have hallucinations?	31	Does Parkinson's affect sleep?



What people search for: Symptoms a key concern

- PD symptoms represents a major search term theme, accounting for 40% of the top Google questions. This suggests that there is some confusion surrounding what it means to have Parkinson's, how it can be recognised and how symptoms can be managed after diagnosis.

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8	Are Parkinson's and MS related?	16	Can Parkinson's patients drive?	24	Do Parkinson's patients get pneumonia?	32	Does Parkinson's disease cause seizures?



What people search for: PD and other neurological diseases/disorders

Another major search theme is the association between Parkinson's and other neurological diseases/disorders, with these search questions accounting for 7 out of the top 10.

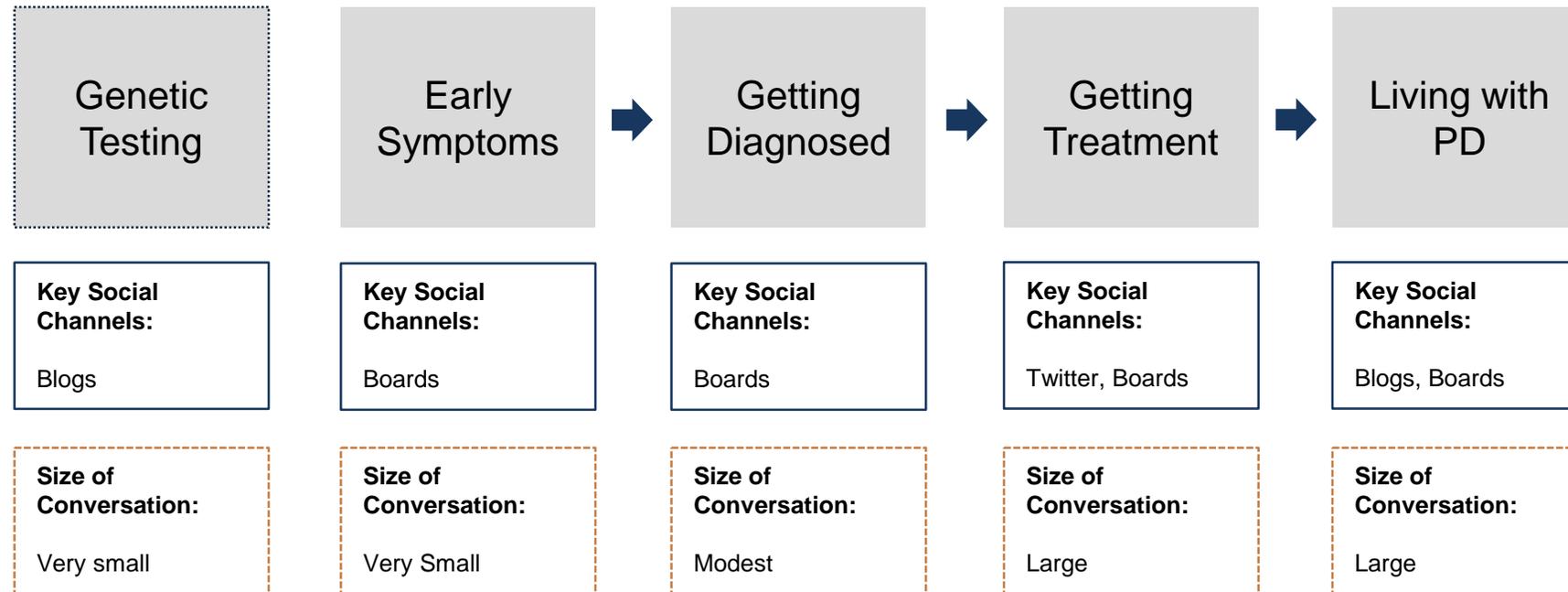
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Tracking the patient journey



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Tracking the patient journey: Overview



Genetic testing: Posts largely scientific

- There is very little conversation surrounding genetic testing in the wider PD category. Of the 82.5k total category volumes, 'genetic testing' is mentioned only 34 times and 'genetic mutation' 33.
- A larger body of conversation exists around 'genes' and 'genetics' (~700 mentions), but this is limited to research-sharing, rather than experience-sharing from those considering/undergoing genetic testing.
- During this stage on the PD patient journey, very few people are sharing their experiences on social channels.

The screenshot shows a Twitter thread with three tweets. The first tweet is from Neuroscience News (@NeuroscienceNew) with the title "Single Mutation in Recessive Gene Increases Risk of Earlier Onset Parkinson's Disease". The second tweet is from Nanotechnology AGENT (@nanotechnol_age) with the title "Gene Therapy produces Dopamine in the Brain as path to Parkinsons treatment #brain". The third tweet is from Paul Tuite (@Tuite002) with the title "Interest in genetic testing in Parkinson's disease patients with deep brain stimulation". Below the tweets is a poll titled "Performance on questions assessing gene" with a bar chart showing 100% for all options. To the right of the poll is a text box titled "Interest in genetic testing in Parkinson's disease patients w..." with an objective and background information, and a link to mdsabstracts.org.

Neuroscience News @NeuroscienceNew Follow

Single Mutation in Recessive Gene Increases Risk of Earlier Onset Parkinson's Disease

Nanotechnology AGENT @nanotechnol_age Follow

Gene Therapy produces Dopamine in the Brain as path to Parkinsons treatment #brain

Paul Tuite @Tuite002 Follow

Interest in genetic testing in Parkinson's disease patients with deep brain stimulation

Performance on questions assessing gene

Question	Percentage
Identify individuals at risk for Alzheimer's disease (True)	100%
Identify individuals at risk for Huntington disease (True)	100%
Identify individuals at risk for diabetes (False)	100%
Identify individuals at risk for a heart attack (False)	100%
Identify individuals at risk for breast cancer (True)	100%
Identify individuals at risk for Crohn's disease (True)	100%
Identify individuals at risk for depression (False)	100%
Identify individuals at risk for autism (True)	100%
Identify individuals at risk for Parkinson's disease (True)	100%
Identify individuals at risk for schizophrenia (False)	100%
Identify individuals at risk for multiple sclerosis (True)	100%
Identify individuals at risk for sickle cell anemia (True)	100%
Identify individuals at risk for cystic fibrosis (True)	100%
Identify individuals at risk for phenylketonuria (True)	100%
Identify individuals at risk for Tay-Sachs disease (True)	100%
Identify individuals at risk for sickle cell anemia (True)	100%
Identify individuals at risk for cystic fibrosis (True)	100%
Identify individuals at risk for phenylketonuria (True)	100%
Identify individuals at risk for Tay-Sachs disease (True)	100%

Interest in genetic testing in Parkinson's disease patients w...

Objective: To determine interest in genetic testing in Parkinson's disease (PD) patients with deep brain stimulation (DBS).
Background: Approximately 27% of early-onset PD patients with...

mdsabstracts.org

Early symptoms: Hereditary concerns

- There are again few mentions of people discussing seeing early symptoms of Parkinson's, pre-diagnosis.
- There is a lot of conversation surrounding 'symptoms' broadly (5k mentions), but this is mainly reserved for people who have already been diagnosed with PD.
- Those with relatives who have/had PD are aware of early symptoms and take to boards to express their worries that they may have the disease. There doesn't appear, however, to be a lot of people reaching out for advice and help outside of this group.
- People may not be reaching out to PD support groups until after they've received a diagnosis, particularly as PD symptoms can be similar to other neurological diseases/disorders.

"My whole nervous system feels like it's been interfered with. All my back, legs, head just can't stop shaking. It feels like my breathing is affected too and a feeling of sickness. I keep waiting for something to happen to me, like I'm going to go into a fit or something. It's really scary. I'm going away in December, and am worried as I don't want to feel like this. I feel anxious all the time, but without the panic attacks, although I have had those in the past.

I worry I might have Parkinson's disease as my mum had it. She passed away last year, and that has broke my heart. She was my world."

Emma143, HealthUnlocked.com

Ram41910, Patient.info *"At random moments during the day, my hands would tremor slightly. I would also get cramps and muscle spasms in my abdomen and legs. These symptoms worry me because it makes me think that I might have Parkinson's or Lou Gerhig's Disease (ALS/Motor Neurone)...During the past six months, I have tried to research and browse the internet to find what illness that I could have."*

"I do wonder about neurological vulnerability though, with Alzheimer's and Parkinson's in my parents generation."

Anonymous, HealthUnlocked.com



Getting diagnosed: Diagnosis process

- There is a fair amount of conversation surrounding the diagnosis process (1.5k mentions) but this consists largely of people talking about their diagnosis years later. Posts from people who have just received their diagnosis account for less than 200 posts. It appears to take people quite some time after they are diagnosed to reach out to online communities, with many first-time posters sharing that they were diagnosed 1-3 years prior.
- When people talk about their diagnosis, a common complaint is that the process is lengthy and difficult. It takes a long time for them to get a concrete answer about what they're suffering from.

"Because I tremor very little; however, have many other symptoms it has been a challenge to get a good diagnoses until recently. It is a quandary for the neurologist and myself."

Opt8, HealthUnlocked.com

"Hi, I am Roy and I was diagnosed with PD about 6 years ago but the symptoms had been there for at least 2 years before."

Roy, HealthUnlocked.com

"My husband has had Parkinsons for at least seven years, only diagnosed 4 years ago."

Fontaine, HealthUnlocked.com

"I'm new. age 61, diagnosed one year ago with tremor starting two years ago. no meds, and i hope to keep it that way."

Ennas, HealthUnlocked.com

"Hi i am 57years old. I live in the UK and I eork as a sales assistant in a dept store. I have been diagnosed with pd 3yrs ago.My hobbies are reading and sewing . I am an outgoing person and love travelling ,meeting people and very chatty and friendly and I am also very spiritual.I found this website accidentally utility I am so happy that I did because it is nice to know that I am not the only one with this horrible nd debilitating condition."

Niludi, HealthUnlocked.com



Getting treatment: Clinical trials

- As previously mentioned, treatment talk is one of the largest categories in PD conversation. A key theme within the treatment category is access to clinical trials.
- People express keenness at participating in promising trials and seek peer advice on trial participation.
- The Michael J. Fox Foundation is frequently viewed as a key resource/gatekeeper in accessing clinical trials, again highlighting their importance in the PD category.

"There are a few good websites. The Michael J Fox. Foundation one is wonderful. It has all of the latest research, has a interactive engine to find clinical trial he may be a good fit for, and has a ton of good information."

Ennanie, BabyCenter.com

"Phase II trials of the most promising new treatment for Parkinson's disease in decades might be delayed because of a feud between a key scientist and the influential Michael J. Fox Foundation, which donates more money to Parkinsons than all other donators combined."

P-oui, HealthUnlocked.com

*"Here is some info on recent study conducted on NAC and it showed what looks like strong results: news-medical.net/news/20160...
Here is a clinical trial.
clinicaltrials.gov/ct2/show...
Anyone have any insight on NAC? If you are in the clinical trial I would love to hear about it."*

P-oui, HealthUnlocked.com

"Well, sadly, I was turned down in being part of the clinical trial for focused ultrasound. Since June I've been believing I would be part of this study, they even gave me a date for the procedure, but it wasn't to be. I told you that I'd inform you of my results. Now where do I turn? DBS? My neuro doesn't think DBS will be so good for me because my symptoms are mostly nonmotor. But I cannot walk without sinenet. And diskenesia is so bad."

Micaela13, HealthUnlocked.com



Getting treatment: Drug chatter

- Drugs alone receive 5k mentions, making this an important topic not only within the treatment category but also wider PD discussions.
- On Twitter, drug mentions focus on the release of new drugs to treatment the symptoms of Parkinson's.
- On boards, people extensively discuss the merits of certain drugs over others and seek advice from peers about which ones work best. We also see links here with other diseases, with people talking about using cancer drugs, for instance, to treat PD.
- Pain is one of the top ten keywords used within this conversation and represents a key driver for better drugs. The desire to curb PD pain also accounts for the increasing cannabis chatter.



"I was very impressed with what I learned about medical cannabis, and I personally cannot think of anything I could find wrong with it from a health perspective. It really helped me with some very significant pain, and I recovered more health in Seattle than I did at any time I can recall since my diagnosis."

Nathan Frodsham, MedicalMarijuana411.com

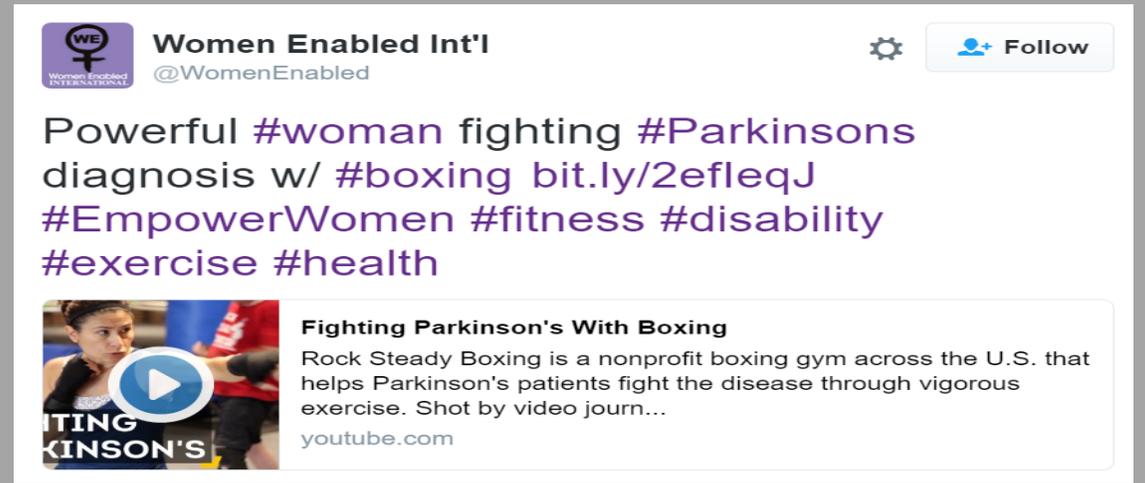
"I've been taking Mirapex for many years with these excellent results. People with parkinson's take it for their tremors. You might want to check it out. They call what I have RLS, restless leg syndrome."

CoalTrain, GreenTractorTalk.com



Living with PD: Exercise

- Living with PD is the stage that sees the highest volume of conversation, as people share their experiences, build communities and seek advice about how to manage symptoms and lead a full life. An example of the latter is exercise, which receives 1.3k mentions.
- A trend within exercise conversation is the emergence of new workout classes designed specifically for people with Parkinson's. Two that are particularly popular are dance classes and boxing.



Women Enabled Int'l @WomenEnabled

Powerful #woman fighting #Parkinsons diagnosis w/ #boxing bit.ly/2efleqJ #EmpowerWomen #fitness #disability #exercise #health

Fighting Parkinson's With Boxing
Rock Steady Boxing is a nonprofit boxing gym across the U.S. that helps Parkinson's patients fight the disease through vigorous exercise. Shot by video journ...
youtube.com

Dance class moves to minimize Parkinson's tremors



Declan Groeger @DeclanGroeger

Canton's Rock Steady Boxing hits back at Parkinson's disease
cantonrep.com/sports/2016110 ... #parkinsons #ms #exercise

Living with PD: PT and OT

- Another key conversation theme for people living with PD is physical and occupational therapy. People view PT & OT as important parts of managing PD and turn to peers for advice and guidance (particularly when they are unable to find information elsewhere).
- Part of the appeal of PT & OT is that there is a desire for “natural”, non-drug therapies. People complain that drugs can sometimes worsen symptoms and express frustration at finding the right drugs for them. PT & OT thus become more favourable alternatives.

“On the first day of my diagnosis of Parkinson's I was given no information on steps to stop the progression of this disease. Through a local network I now have information on diet and exercise along with recommendations for additional supports. Has anyone else experienced this lack of referrals to other therapists, physical therapists, yoga or exercise programs??”

Jannienannie, HealthUnlocked.com

“A dear friend had DBS for Parkinson's and then a stroke after the surgery. Her left side is paralysed from the stroke and she is currently having therapy. However her severe dyskinesia on her right side inhibits her physical therapy. Dr. does not want to activate her DBS until she is finished with therapy. Has anyone ever experienced this? It is a "catch 22" and extremely frustrating.”

Sankay, HealthUnlocked.com

“And in these cases I believe fundamentally in rehabilitative therapy : physical therapy, logotherapy, occupational therapy. At first Takis resisted, but it gave him more independence and also, before his fall, he'd improved a bit....”

Inesrivero, RareConnect.org

“Has anyone ever tried to ween themselves off of sinemet. My mom is 80 years old and has had Parkinson's for six years. She has a very mild form of Parkinson's and I think the Parkinson's medicine is making her worse and other areas. I'd like to see her try something natural instead. She fights dizziness even while sitting. Her BP is all over the place. She will have extended periods where the meds don't do anything.”

Bsaggio, HealthUnlocked.com



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