

INNOVATIVE SURVEILLANCE AND ASSESSMENT TECHNIQUES USING SOCIAL MEDIA TO INFORM STD AND HIV PREVENTION ACTION

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CDC Health Information Innovation Consortium Forum

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- ▶ Pre-exposure prophylaxis (PrEP) reduces HIV transmission, yet only 2-5% of Americans who may benefit from it are using it
- ▶ Men who have sex with men (MSM) using PrEP show high rates of sexually transmitted infections (STI)
- ▶ Divergence of traditional STD prevention from HIV prevention raises new questions:
 - ▶ Is STI an indicator for PrEP? (as an STD program intervention)
 - ▶ What is the impact of PrEP on STI prevention?

BACKGROUND

- ▶ To evaluate social media site REDDIT as a novel data source for monitoring behaviors and attitudes relevant to PrEP
- ▶ To explore networks of attitudes and beliefs surrounding STD prevention in the context of PrEP

PURPOSE OF THE PROJECT

NCHHSTP-Epidemico Kickoff Deck 10-17-2016.pdf - Adobe Acrobat Reader DC

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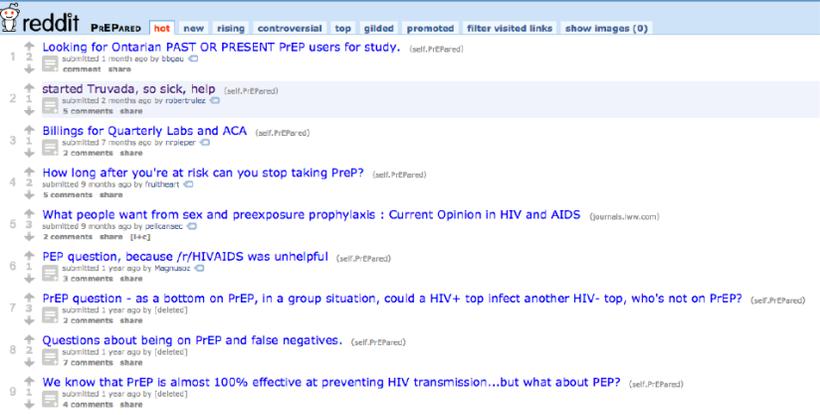
Supplemental Information **8**

ANATOMY OF REDDIT

DISSECTING REDDIT

Within a subreddit, users see a list of submissions. These can be statements, questions, images or links to other websites.

In the PrEPared subreddit, we frequently find people asking about symptoms, experiences, sources and perceptions related to pre-exposure prophylaxis.



The screenshot shows the r/PrEPared subreddit interface. The top navigation bar includes 'PrEPARED', 'hot', 'new', 'rising', 'controversial', 'top', 'gilded', 'promoted', 'filter visited links', and 'show images (0)'. The main content area displays a list of submissions:

- 1 Looking for Ontarian PAST OR PRESENT PrEP users for study. (self.PrEPared)
- 2 started Truvada, so sick, help (self.PrEPared)
- 3 Billings for Quarterly Labs and ACA (self.PrEPared)
- 4 How long after you're at risk can you stop taking PrEP? (self.PrEPared)
- 5 What people want from sex and preexposure prophylaxis : Current Opinion in HIV and AIDS (journals.lww.com)
- 6 PEP question, because /r/HIVAIDS was unhelpful (self.PrEPared)
- 7 PrEP question - as a bottom on PrEP, in a group situation, could a HIV+ top infect another HIV- top, who's not on PrEP? (self.PrEPared)
- 8 Questions about being on PrEP and false negatives. (self.PrEPared)
- 9 We know that PrEP is almost 100% effective at preventing HIV transmission...but what about PEP? (self.PrEPared)

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REDDIT IS AN OPEN FORUM PLATFORM THAT ALLOWS USERS TO SUBMIT AND COMMENT ON LINKS, IMAGES, AND STATEMENTS FROM ACROSS THE INTERNET.

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ANATOMY OF REDDIT

DISSECTING REDDIT

Within a submission, users can comment in a threaded, hierarchical branching format.

Subreddit — GET +TESTED STD comments show images (2)

Submission Title — Is this herpes? (self.STD) submitted 5 days ago * (text edited 5 days ago) by throwawaaayyy5739 — **Submission Author**

Submission Text — <http://imgur.com/qH7rim4> I had unprotected oral sex and protected piv one week ago. I noticed that my urethra was red and it made me nervous. It's not a blister or lesion and it doesn't hurt to touch or urinate, I just decided to look inside and saw that it was red. (I tested negative for Gonnoreha and chlyamydia.)

8 comments source share hide all child comments

all 8 comments subscribe

sorted by: best

navigate by: submitter moderator friend me admin highlighted tagged gilded IAMA images videos popular new

Comment Text — [-] Maggost 1 point 5 days ago — **Comment Author**
Herpes in that location is pretty rare, looks like an UTI.

Comment Text — [-] throwawaaayyy5739 1 point 5 days ago — **Comment Author**
Hey, thank you for replying :,) put me at ease

Note: We use the term 'post' to refer to submissions and comments

Comment

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12:30 PM 7/20/2017

DISSECTING REDDIT POSTS

- ▶ Data collection and processing
 - ▶ Refine research questions, identify concepts of interest
 - ▶ Define sampling frame (subreddits -e.g. askgaybros, PrEPared)
 - ▶ Develop search and processing taxonomies
 - ▶ 20 search terms (product names, STI names, concepts from STI prevention)
 - ▶ Up to 40 concepts (e.g. stigma, side effects, adherence)
- ▶ Data analysis and output
 - ▶ Process queries (one time .csv data file with meta-tagged data)
 - ▶ Data explorer dashboard to conduct analysis/output

STEPS IN THE PROCESS

- ▶ What were the main topics of discussion regarding PrEP in 2015?
- ▶ How much uptake/use of PrEP was there vs. information seeking?
- ▶ What are main barriers to PrEP uptake?
- ▶ How are MSM talking with sex partners about PrEP?
- ▶ When discussing PrEP how often are STDs other than HIV discussed, which STDs are mentioned, and in what context?

REFINED RESEARCH QUESTIONS,

- ▶ Temporal visualization of mentions of PrEP and STIs
- ▶ Visualization of distribution of mentions across digital space
- ▶ Visualization of relationships between topics
- ▶ Provide a view of the “size or volume” of conversations about PrEP (but not the “shape or meaning” of the conversation)

DATA EXPLORER (DASHBOARD)

A decorative graphic consisting of several parallel white lines of varying lengths and orientations, located in the bottom right corner of the slide.

NCHM47H: Epidemics Meeting Deck 10/31/2016.pdf - Adobe Acrobat Reader DC

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REVIEW SEARCH TERMS

3

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GATHERING DATA

Term	Search Term
PrEP	PrEP, exposure prophylaxis
Truvada	truvada, tenofovir, emtricitabine
Condoms	Condoms, condom
Syphilis	Syphilis
Gonorrhea	Gonorrhea
Chlamydia	Chlamydia
Herpes	Herpes, HSV
HPV	HPV
HIV	HIV, AIDS
STD	STD, STDs, STIs, STI, sexually transmitted
Testing (STD/HIV)	test, tested, testing
Positive Serostatus	Positive, poz, undetectable, viral load
Negative serostatus	negative, clean

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REVIEW CONCEPT TERMS

4

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TAGGING CONCEPTS

Term	Synonyms
Hookups	hookups, hook ups, hookup, hookups, hooked up
Partner	partner, partners, boyfriend, husband,
Bottoms	bottom, bottoms, bottoming
Tops	top, tops, topping
Oral Sex	oral, blow, blew, blowjob, went down, going down
Group Sex	threesome, threesomes, foursome, foursomes, orgy, orgies...
Bareback	bareback, raw, bare
Open Relationship	open, poly, polyamorous,
Communication/disclosure	disclose, disclosure, tell your, tell my, tell their...
Sex and Drugs	meth, crystal, tina, chem sex, PNP, party and play, poppers,
Mobile App Use	gridr, scruff, manhunt, jackd, tinder
Adherence/timing	adhere, adherence, every day, on time, missed my, missed a...
Patient-provider communication	doctor, doctors, nurse, nurses, clinic, clinics, RN, GP,
Stigma	slut, whore, truvada whore
Cost	copay, copays, coupon, insurance, confidentiality, cost, price...
Side effects	fatigue, kidney, GI problems, bloating, bloated, weird dreams...

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11:18 AM 7/26/2017

SEARCH TERMS AND CONCEPTS

NCHHSTP_Reddit_Data_(BAH_Proprietary) - Excel

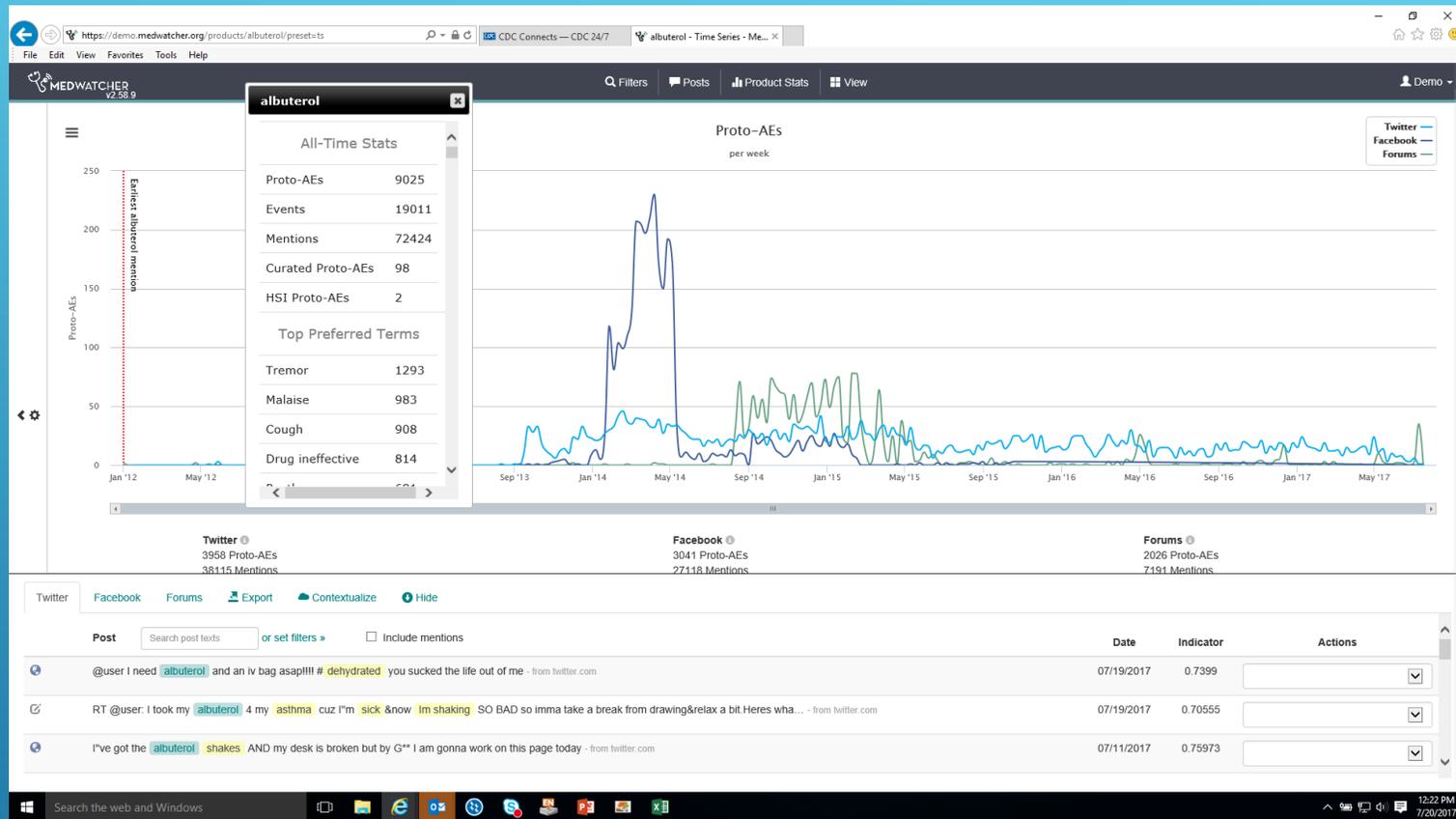
Kroeger, Karen A. (CDC/OID/NCHHSTP)

id	author	subreddit	title	post_text	created_utc	Datetime	type	terms	groups	STI_mentions	Product_mentions	STI_or_Product_mentions	
4			Delivered to CDC-NCHHSTP under contract # 200-2016-M-91892. BAH Proprietary.										
5	3fd6io	Baconbits4e	askgaybros	Question About Anal	I am in a healthy relationship with my boyfriend	1.44E+12	7/31/2011 2:19	submission	[STD, Partner, Positive Ser	(Serostatus, STI, Sexu	1	0	1
6	3fe4ll	Virginbottom	askgaybros	First gay experience	Well it was long ago though I still remember it,I	1.44E+12	7/31/2011 9:22	submission	[Condoms, Oral Sex, Botton	(Product, Sexual Beha	0	1	1
7	3ffk0a	[deleted]	PrEPared	Is it immoral to advocate PrEP wh	Pretty much as the title says. A month of PrEP cc	1.44E+12	7/31/2011 18:54	submission	[Patient-provider communi	(Product, Product Infc	0	1	1
8	3fg2w4	asaawwww	askgaybros	what is it with guys trying to fuck	I've had this happen several times. I go over to a	1.44E+12	7/31/2011 21:30	submission	[Condoms]	(Product)	0	1	1
9	3fg4n8	cirrus_sc	askgaybros	How do you decide when (if ever	Hey bros,My question is just that was there a pc	1.44E+12	7/31/2011 21:46	submission	[STD, Condoms, Testing (ST	(Product, STI, Service,	1	1	1
10	3fg1m	GeorgeGnyc02	askgaybros	No condom, but PrEP?	A couple wants to invite me in for a threesome a	1.44E+12	8/1/2011 0:03	submission	[Condoms, HIV, Tops, Grou	(Product, STI, Sexual E	1	1	1
11	3fg09e	jujusee	gaybros	In Some Ways, AIDS in America	Has Gotten Worse	1.44E+12	8/1/2011 0:45	submission	[HIV]	(STI)	1	0	1
12	3fgyzf	Letha_Arajh	askgaybros	People are saying I'm overreactin	EDIT: Since I can't change the title, I didn't get te	1.44E+12	8/1/2011 2:31	submission	[Condoms, Positive Serosta	(Serostatus, Product,	1	0	1
13	3fhg9b	scaredthrowaway	askgaybros	I'm scared	I'm really scared that I may have contracted HIV,	1.44E+12	8/1/2011 5:44	submission	[Negative serostatus, Testi	(Serostatus, STI, Servi	1	0	1
14	3fjn7f	Obversa	askgaybros	[23F] Question about Blood Dona	Hello /r/askgaybros! This is my first time asking	1.44E+12	8/1/2011 21:01	submission	[STD, Condoms, Oral Sex, T	(Product, STI, Service,	1	1	1
15	3fkvyv	fwioudwif	gaybros	Best STD Dating Sites for STD	Singles in 2015	1.44E+12	8/2/2011 3:38	submission	[STD]	(STI)	1	0	1
16	3fkyft	gaidatingexpert	askgaybros	Should we use protection?	Hello gaybros!So, I'm 19 and my bf is 18. We've b	1.44E+12	8/2/2011 4:02	submission	[Condoms, Oral Sex]	(Product, Sexual Beha	0	1	1
17	3fkyip	theszak	gay	The strategy. BEFORE sex get	tested TOGETHER for A VARIETY OF STIs then make ar	1.44E+12	8/2/2011 4:03	submission	[STD, Testing (STD/HIV)]	(STI, Service)	1	0	1
18	3f182i	Oz_93	gaybros	"Hereâs What We Actually Know	About The Pill That Prevents HIV" - An interest	1.44E+12	8/2/2011 5:45	submission	[HIV]	(STI)	1	0	1
19	3f1lag	nudz3s	TopsAndBottoms	Ex ruined my hole?	So here's the story: when I was 17 I had a boyfrie	1.44E+12	8/2/2011 6:13	submission	[Partner, Condoms, Botton	(Product, Sexual Beha	0	1	1
20	3flv38	britlit	gay	Aging and HIV issues	I recently fell down a rabbit hole looking at agin	1.44E+12	8/2/2011 11:03	submission	[STD, Patient-provider com	(Sexual Behaviors, STI	1	0	1
21	3fpenp	kokujinmatto	gaybros	Any bros that live in Amsterdam?	I posted in /r/Amsterdam, but wanted to cover n	1.44E+12	8/3/2011 3:36	submission	[Condoms, PrEP]	(Product)	0	1	1
22	3fpykv	robertrulez	askgaybros	Went bareback for the first time.	So I had a slip up this past weekend. I've never h	1.44E+12	8/3/2011 7:06	submission	[STD, Bareback, Condoms, T	(Product, STI, Service,	1	1	1
23	3frqpx	justraging	askgaybros	just an angry and scared rant -	fuck I'm in a fuckin pickle bros. I met a guy I really lik	1.44E+12	8/3/2011 17:29	submission	[Condoms, HIV, Patient-prc	(Serostatus, Product,	1	1	1
24	3ft233	advocate4avocado	PrEPared	Taking PrEP into my own hands	(I in short, you can get PrEP prescribed where I liv	1.44E+12	8/3/2011 22:57	submission	[Patient-provider communi	(Product, Product Infc	1	1	1
25	3fuc6p	bihere	askgaybros	21M here, not able to top my boy	So I've been a bottom only before, but always w	1.44E+12	8/4/2011 5:33	submission	[Partner, Adherence/timin	(Product, Product Infc	0	1	1
26	3fvkhw	blissed_out_cossac	askgaybros	What's the mechanics of catching	So a 'friend' just got this unpleasant STI treated	1.44E+12	8/4/2011 14:03	submission	[STD, Oral Sex]	(STI, Sexual Behaviors	1	0	1
27	3fw9b7	cjrutherford	askgaybros	Am I crazy? Am I being too hard	o About a month ago, I found an article that refere	1.44E+12	8/4/2011 17:02	submission	[Condoms, Communication	(Product, Sexual Beha	0	1	1
28	3fwbuw	red_lambda	gay	I contracted Herpes	I have no one else to tell in my life besides fami	1.44E+12	8/4/2011 17:20	submission	[Herpes]	(STI)	1	0	1
29	3fwqdo	Fcb12	askgaybros	Starting on PrEP?	So I am a young professional with not too great f	1.44E+12	8/4/2011 18:56	submission	[Cost, PrEP]	(Product, Product Infc	0	1	1
30	3fxc3g	throwaway8491919	askgaybros	"Relationship" help?	So I met a guy almost a year ago now at a party, a	1.44E+12	8/4/2011 21:25	submission	[Partner, Condoms, Oral Se	(Product, Sexual Beha	0	1	1
31	3fyvg6	dandelion-floatie	PrEPared	PrEP interaction with other medic	I just started PrEP a few weeks ago. Sure I resear	1.44E+12	8/5/2011 5:08	submission	[PrEP]	(Product)	1	1	1
32	3g14jc	uboaaaaaaaaaa	askgaybros	Celibacy and not letting anyone	k This seems to be something I've observed, appa	1.44E+12	8/5/2011 18:00	submission	[STD, Testing (STD/HIV)]	(STI, Service)	1	0	1
33	3g306r	anatheadsjim	gay	check out this gay condom compa	nâs brilliant marketing	1.44E+12	8/6/2011 2:30	submission	[Condoms]	(Product)	0	1	1
34	3g30tp	trifurcate	goy	9/11 is the gentrification of AIDS	One of the best critiques of the way AIDS declin	1.44E+12	8/6/2011 2:36	submission	[HIV]	(STI)	1	0	1
35	3g3e1l	prinsengracht	askgaybros	Basic Questions	I'm still in the closet to most of my family and fri	1.44E+12	8/6/2011 4:39	submission	[STD, Mobile App Use, Tops	(STI, Sexual Behaviors	1	0	1
36	3g3qr6	Mootank	askgaybros	Advice.. hes still in a relationship	Hello guys first time posting on this but really ju	1.44E+12	8/6/2011 6:58	submission	[Partner, Adherence/timin	(Serostatus, STI, Prodi	1	0	1
37	3g5rez	[deleted]	askgaybros	I was diagnosed as HIV+ yesterda	I'm 18 years old, and I was diagnosed as HIV+ yes	1.44E+12	8/6/2011 18:50	submission	[HIV]	(STI)	1	0	1
38	3g668l	boyinthewild	askgaybros	Do you think this subreddit shoul	Part of why I like this subreddit over /r/gaybros i	1.44E+12	8/6/2011 20:36	submission	[HIV]	(STI)	1	0	1
39	3g7dme	apollo151	askgaybros	"The Normal Heart"	Anyone else watch this movie?It's a pretty heart	1.44E+12	8/7/2011 2:53	submission	[HIV]	(STI)	1	0	1
40	3g91fo	helpful_person	askgaybros	Lube suggestions?	My boyfriend and I are in the market for a new li	1.44E+12	8/7/2011 15:26	submission	[Partner, Condoms]	(Product, Sexual Beha	0	1	1
41	3gaxdb	gaythrowaway65	gay	Had my first gay experience, wor	This last Tuesday, I went on Grindr and finally de	1.44E+12	8/8/2011 1:27	submission	[STD, Condoms, Oral Sex]	(Product, STI, Sexual E	1	1	1

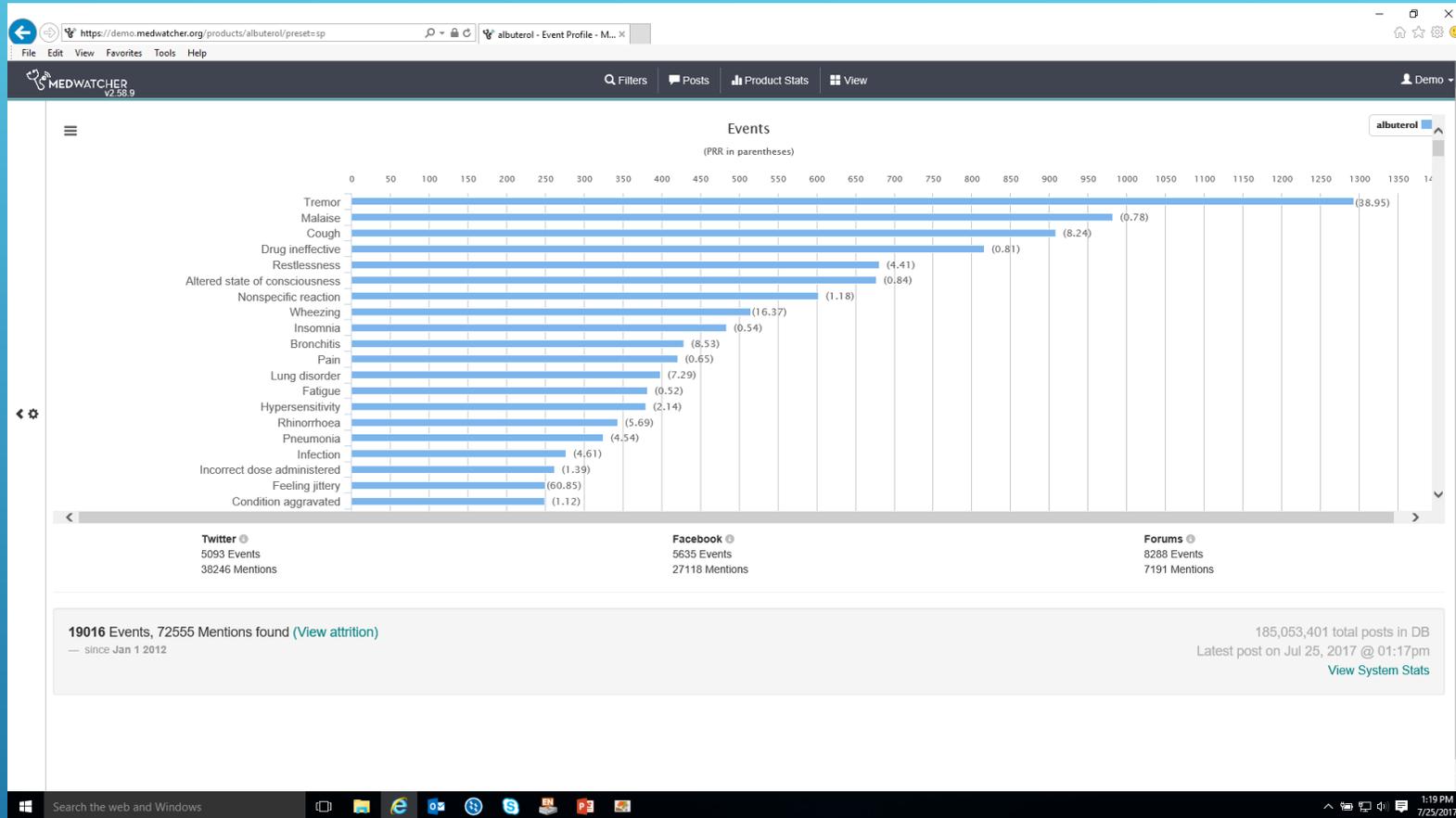
8363 POSTS FROM 6 SUBREDDITS
 (2411 MENTIONS OF "PREP")
 JAN 1-DEC 31, 2015

▶ <https://demo.medwatcher.org/>

DEMONSTRATION



DEMO EXAMPLE: MEDWATCHER



DEMO EXAMPLE: MEDWATCHER

- ▶ Use completed dashboard to explore the volume and content of conversations about PrEP and STIs
 - ▶ Attitudes, perceptions
 - ▶ Barriers, facilitators
 - ▶ Context of PrEP use (e.g. behaviors, sex partners)
- ▶ Evaluate potential utility of subreddits and search terms for future surveillance use
- ▶ Evaluate potential for network analysis (topical content) and subsequent qualitative analysis

NEXT STEPS

- ▶ DSTDP
 - ▶ Kyle Bernstein
 - ▶ Sevgi Aral
- ▶ Epidemico
 - ▶ Michael Gilbert
 - ▶ Chi Bahk
- ▶ CDC Health Information Innovation Consortium

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