

# TINNITUS NARRATIVES: ANOTHER SOCIAL MEDIA PERSPECTIVE



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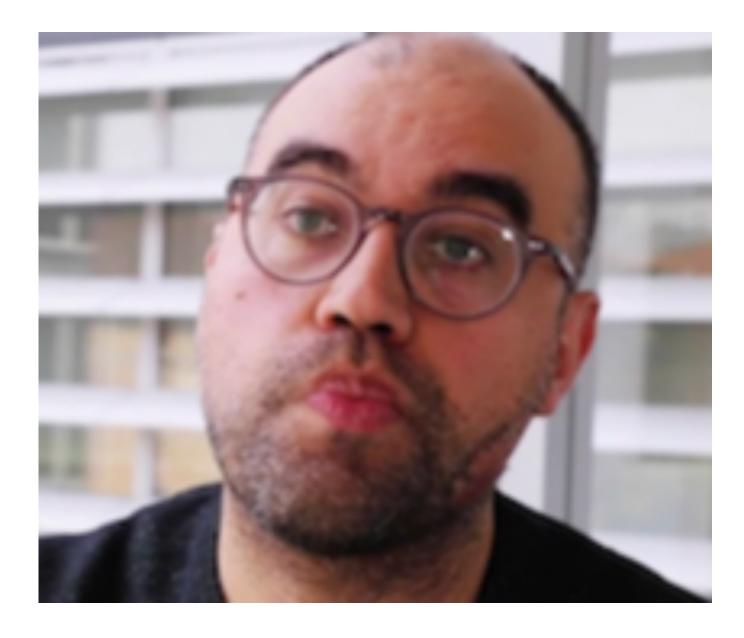
Aniruddha K. Deshpande Hofstra University, US



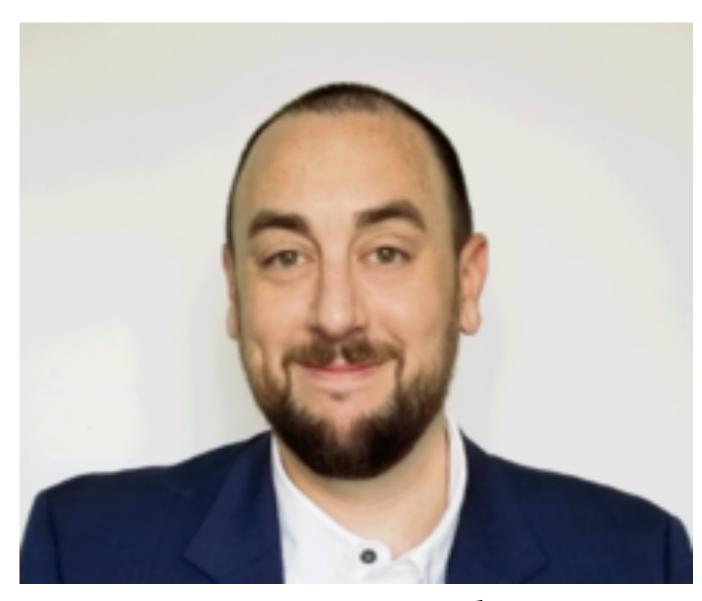
Alain Londero
Service d'ORL, Georges Pompidou France



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University of Toulouse, France



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PainkillAR, TELECOM ParisTech, France



Ryan Boyd
Lancaster University, UK

### THE STORY

- Online forums concentrate hundreds of thousands of spontaneous patients' reports, not biased by the medical interaction
- \* Machine learning proves to be a handy tool to extract information from these reports
- \* Comprehensive summaries of the heterogeneity of perceptions to provide insights

# SOCIAL MEDIA DATA AND MEDICAL RESEARCH



- Manchaiah, Londero, Deshpande, Revel, Palacios, Boyd & Ratinaud. What can we learn about tinnitus from Reddit data. Forthcoming, 2021.
- Ni, Bellon-Harn, Zhang, Li & Manchaiah. **Twitter Usage Using Common Reference to Tinnitus.** *American Journal of Audiology*, 2020.
- Deshpande, Deshpande & O'Brien. Hyperacusis and social media trends. Hearing, Balance and Communication, 2019.
- Manchaiah, Ratinaud & Andersson. Representation of tinnitus in the US newspaper media and in facebook pages: Cross-sectional analysis of secondary data. Interactive Journal of Medical Research, 2018.
- Deshpande, Deshpande & O'Brien. Study of Social Media Utilization by Individuals With Tinnitus. American Journal of Audiology, 2018.
- Basch, Yin, Kollia, Adedokun, Trusty, Yeboah & Fung. Public online information about tinnitus: A cross-sectional study of YouTube videos. Noise & Health, 2018.

#### REDDIT DATA

- ➤ Posts from February 2011 to September 2019
- ➤ 101,000 posts created by 12,000 users were retained after data processing

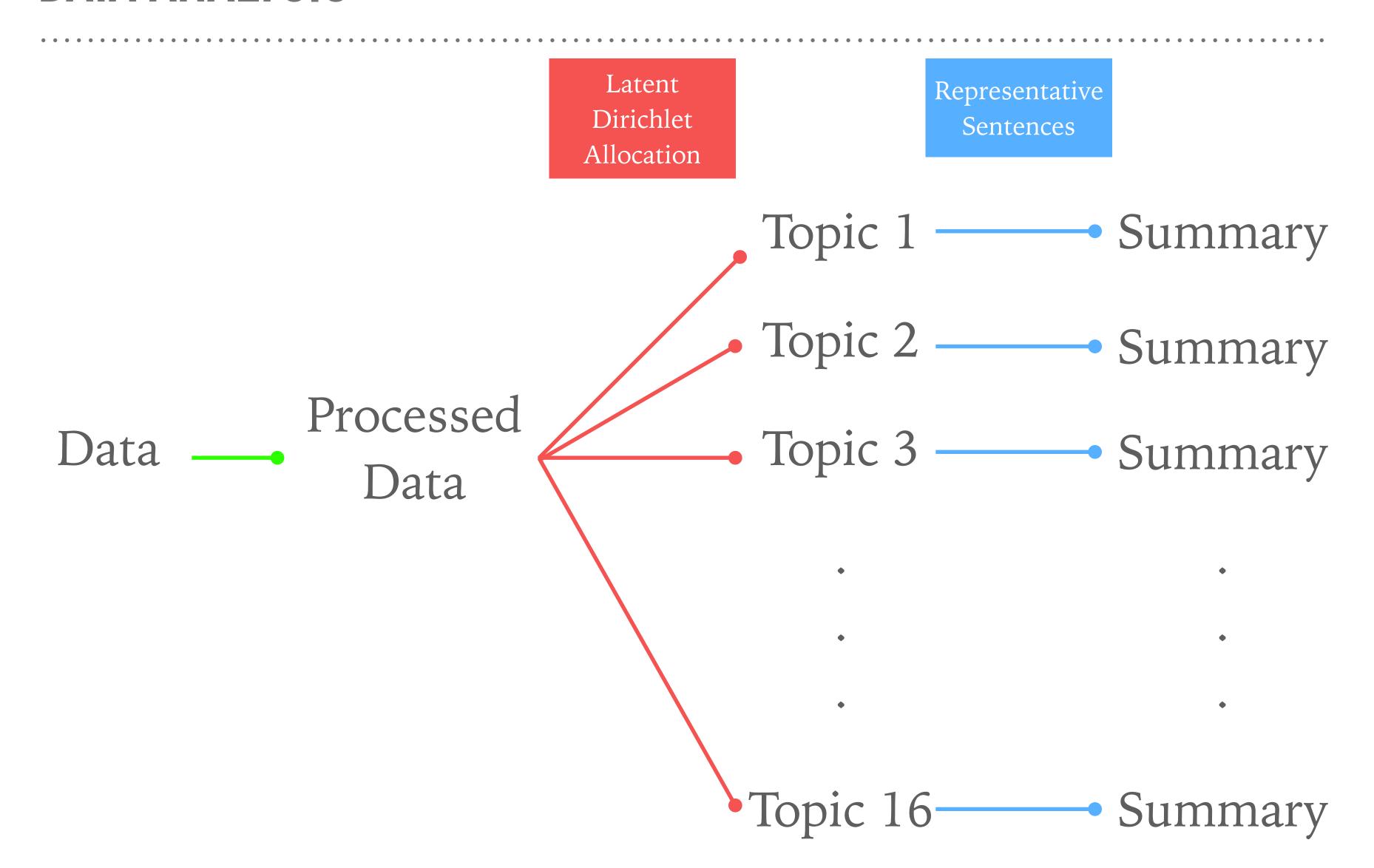


Medical Interactions Controlled and Filtered



Online Anonymity Heterogeneity of perception

### DATA ANALYSIS



# LATENT DIRICHLET ALLOCATION

#### Hello I like cats

#### hello, I ate an orange

# Hello! I like cats and dogs

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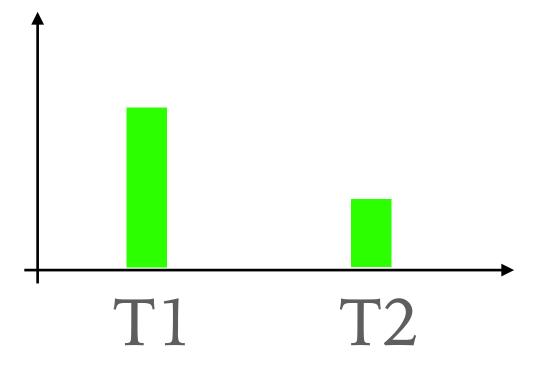
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Corpus



#### Hello I like cats

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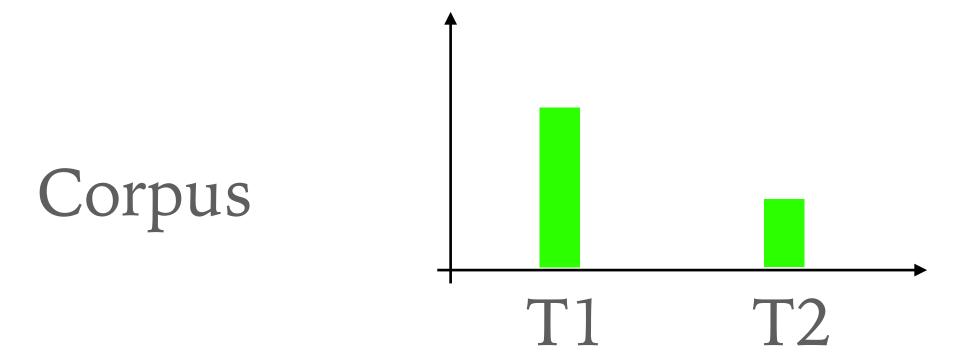
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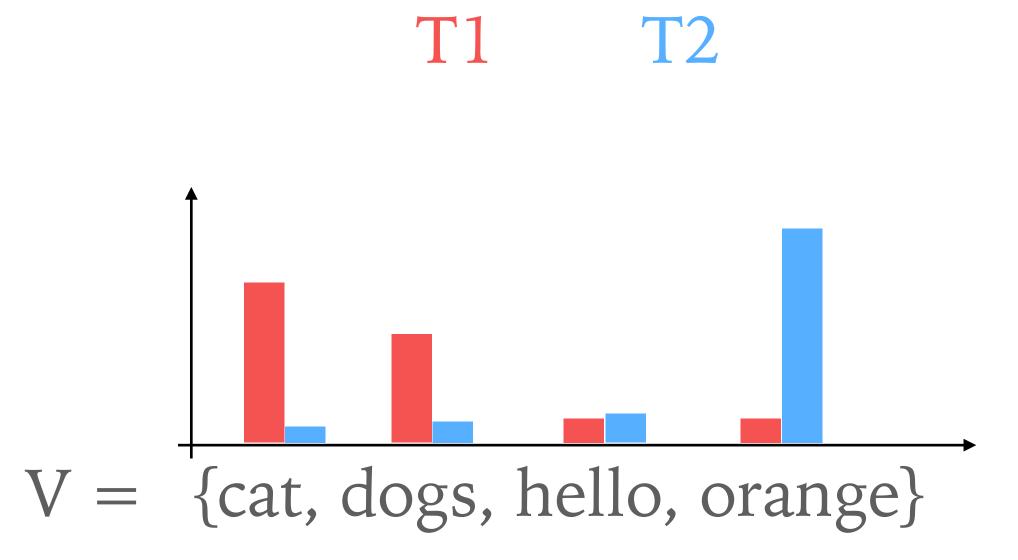
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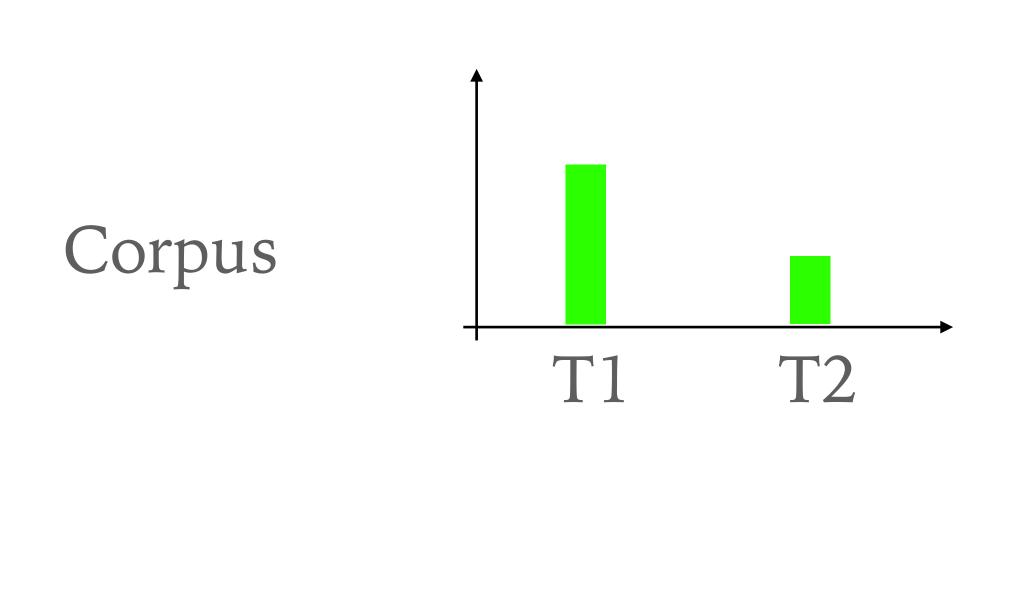
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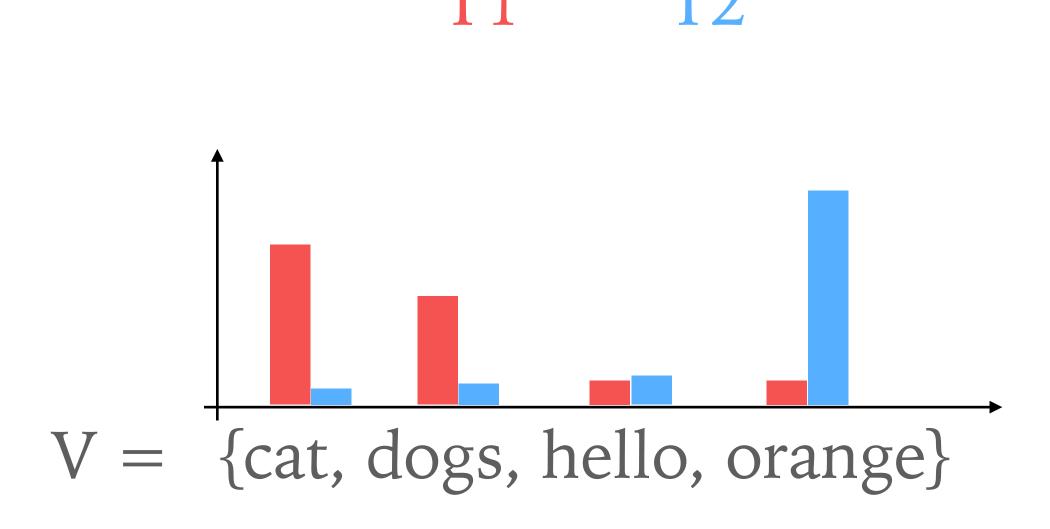




 $w_1, w_2, w_3 \cdot w_4$ 

- \* Choose the topic T of the first word
- \* Given the topic T, choose a word  $w_1$
- \* Repeat for all the words





# TINNITUS NARRATIVES ON SOCIAL MEDIA

| C1 - 6.3%  | C2 - 4.6%  | C3 - 5.3%   | C4 - 9%   | C5 - 9%   | C6 - 3.9%  | C7 - 6.8%  | C8 - 4.4%  |
|--|--|---|---|---|--|--|--|
| life live feel thing deal learn time depress habitu accept part mind point ignor cope abl hard posit                     | wa year didnt thought start becaus time sinc befor back made wasnt felt rememb couldnt told ago point realli end               | day month week time start back ago everi year notic hour stop coupl spike onli happen befor onc | ear left jaw infect pressur pain feel caus tmj wax neck ring full pop tube remov teeth muscl side sinus       | loud music ear headphon earplug volum listen wear plug protect concert db level nois play club damag                                  | ive ring ha notic sinc anyon alway ani louder veri realli long els time recent feel onli loud happen heard                     | nois sleep night tri work mask white play quiet sound room fan listen focus silenc background bed put video app      | caus brain damag case perman problem nerv relat possibl sever hyperacusi issu hair condit trauma due         |
| C9 - 5.2%  | C10 -8%  | C11 - 4.4%  | C12 - 5.5%  | C13 - 6.7%  | C14 - 4.8%   | C15 - 8.5%   | C16 - 7.6%   |
| sound high pitch sometim head veri tone mine frequenc low chang differ turn someth doe constant louder lower volum usual | cure work treatment research studi therapi effect ha trial devic result drug clinic interest money patient current inform base | peopl dont becaus lot mani thing someth whi talk person everyon problem reason differ isnt      | make tri thing wors stress lot anxieti work le doe drink bodi chang good reduc eat medit mind exercis alcohol | doctor ent<br>ani medic<br>check<br>effect caus<br>side anyth<br>possibl<br>symptom<br>told<br>recommend<br>noth issu<br>wait suggest | hear loss<br>test onli<br>normal<br>ani<br>audiologist<br>veri aid<br>frequenc abl<br>year fine<br>deaf<br>khz rang<br>probabl | dont realli wors bad make becaus yeah doesnt fuck mine pretti care worri feel shit bother probabl wont anymor honest | hope good read give post tri ill find advic sorri luck pleas great ani question mayb comment guy answer edit |

| Time Perception |  |
|-----------------|--|
| Peer Support    |  |
| Cure and Coping |  |
| Life's Impact   |  |
| Causes          |  |

- ◆ Tinnitus Chronology
- ♦ Ever lasting Tinnitus
- **♦** Experience Sharing
- ♦ Support System
- ♦ Hope
- ♦ Complaints
- ♦ State of Research
- Stress Management
- Interactions with Doctors
- ♦ Sleep Issues
- **♦** Depression
- **♦** TMJ
- Brain Damage
- ♦ Hear Loss
- ◆ Loud Music

Benefit of having people that understand

Deception of lack of understanding from the doctors

Identify sources of stress in caffeine, sugar, drugs...

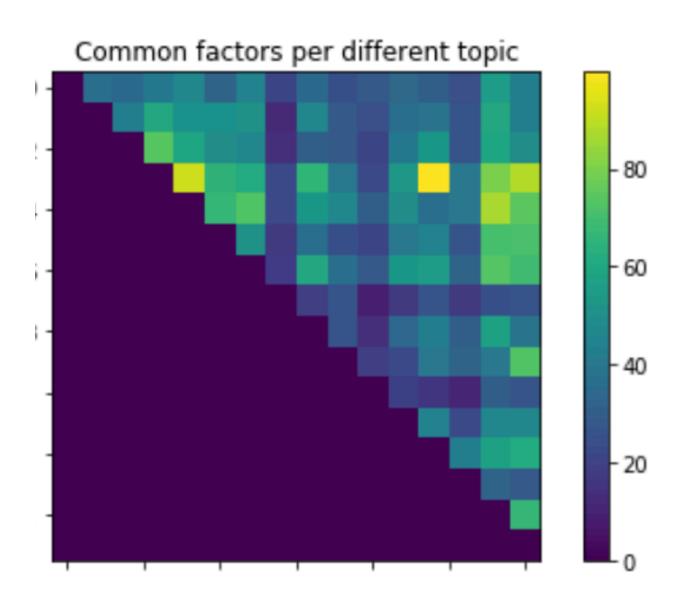
Management with vitamins, natural products (mg)

Teeth and Dental Surgeries
Neck and shoulder tensions
Jaw clinching and misalignment

# FURTHER RESEARCH

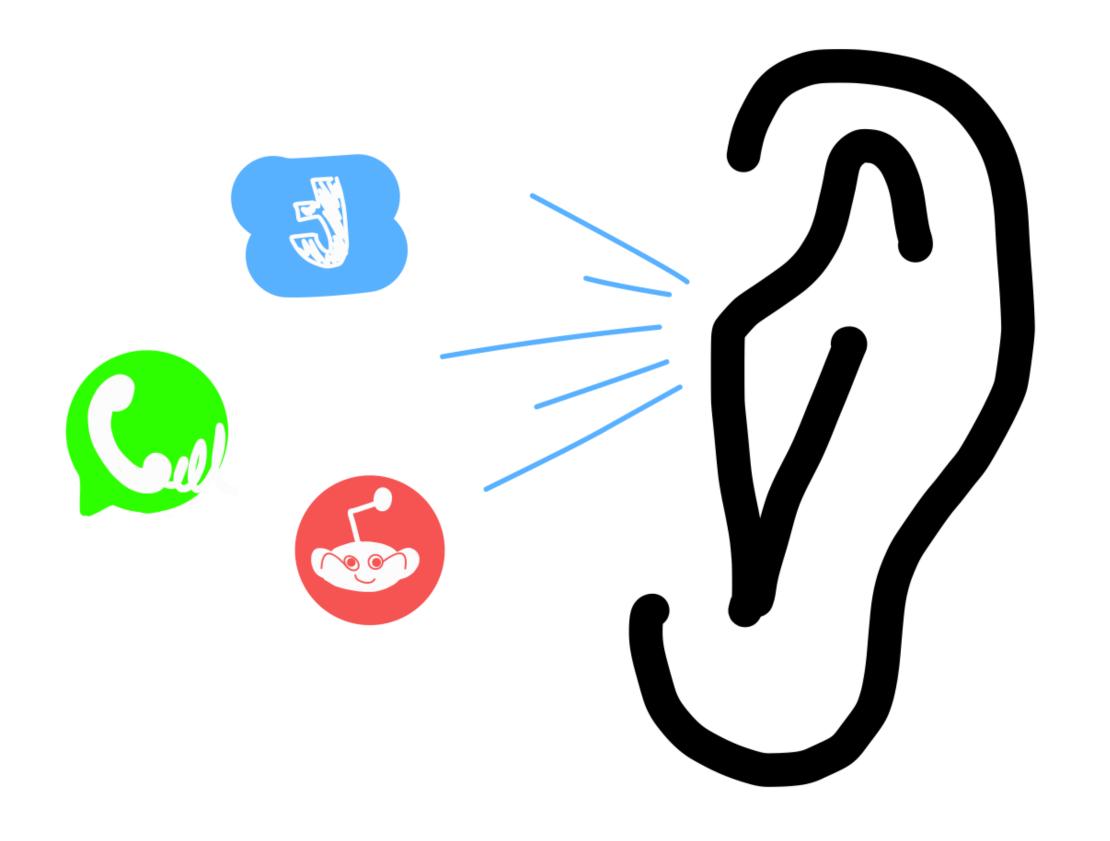
## TOPIC DYNAMICS

➤ Leverage the users dynamics to quantify cooccurrence of topics



#### CONCLUSION

- \* Tinnitus online data can be a complementary way to interact with the patients symptoms, provided that the large amount data can be digested comprehensively
- \* There is a lot of room for further collaboration with therapists and practitioners to make the most from these analyses



# THANK YOU!