

# Online Discussion Forums as Potential Sources of Adverse Drug Event Data

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# Some preliminary considerations

- What is a discussion forum?
  - Online resource where users can participate in “conversations” on a particular topic
- Usually topical
- Often used for seeking advice, reporting phenomena, and offering support

# How do discussion fora differ from other online information exchange resources?

	<b>Discussion Forum</b>	<b>Facebook</b>	<b>Twitter</b>	<b>Chat</b>
Topical?	Yes	Not always	Not always	Often
Can elucidate conversation?	Yes	Often	Not in sampled data	Yes
Can elucidate social network?	Difficult	Yes	Yes	No
Mode	Asynchronous	Asynchronous	A/synchronous	Synchronous
Privacy concerns?	++++	++++	++++	++++
Data available?	+++	+/-	++++	+/-
Syntax issues	+++	++	++++	+++
Focus of social media research	+/-	+++	++++	+++

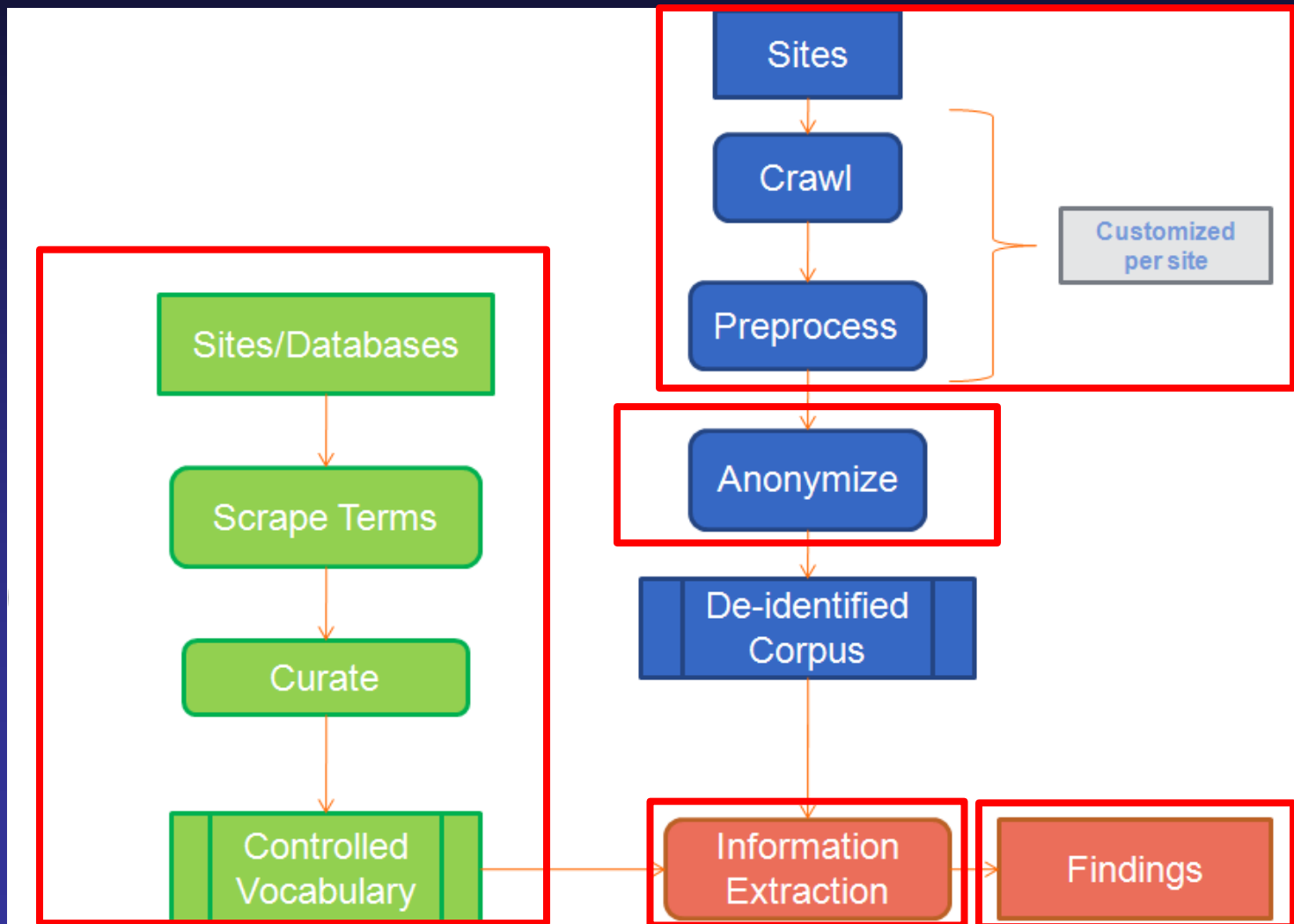
# Why study health-related discussion fora for adverse drug events?

- Which drugs and supplements people use
- Therapeutic effects experienced by posters or others
- Side effects posters or others have experienced
- Attitudes, beliefs, and sentiments
- Identification of possible sentinel events
- Conversational platform

# Threats to discussion fora research

- Restrictive terms of service policies
- User aliasing (“sock puppets”)
- Thread drift
- Discussion continuing across threads
- Syntax
  - ☺ ☹️ 🤔
  - Srly, bbl, IMHO
  - “tammy”

# How do we do research on discussion fora?



# An Example

Using the Internet to identify adverse drug effects  
(RC1LM010342)

Goal: Understand the frequency and content of side effects and associated adherence behaviors discussed by breast cancer patients related to using aromatase inhibitors (AIs), with particular emphasis on AI-related arthralgia.

Mao JJ. Chung A. Benton A. Hill S. Ungar L. Leonard CE. Hennessy S. Holmes JH: Online discussion of drug side effects and discontinuation among breast cancer survivors. *Pharmacoepidemiology & Drug Safety*. 22(3):256-62, 2013.

# Methods

- Mixed methods study to examine content related to AI associated side effects posted by individuals on 12 message boards between 2002 and 2010
- Determined frequency of and association between side effects and AIs and identified themes using content analysis
- 1,000 randomly selected messages related to arthralgia were coded by two independent raters



# An Example Thread

The only SEs i had on **Tamoxifen** were **weight gain** and hot flashes/night sweats. Has anybody been suffering from **chapped, cracked lips**, especially at the corners of your mouth, since being on **Arimidex**? I had this problem many years ago but always could fix it by taking vitamin B complex. The vitamin B complex isn't helping any more and I am wondering if **Arimidex** is causing this.

My eye doctor says my **dry eyes** are probably from age --- but he thinks **Arimidex** made them worse and sent a letter to my DR. saying so.

2/07 Moved to Aromasin & Zometa because of **Arimidex** triggering RA & **Lupus** I've also had **conjunctivitis** 4 times. My onc said this wasn't a SE of **arimidex** but I know it is!

I'm now on **arimidex**. I am doing fine with BC but have developed **fibromyalgia**. After about 1.5 years on **Aromasin**, my cholesterol which is normally 186 was at 254. Something I have not noticed anyone talking about is **high cholesterol**.

oh, should add.....rather significant impact....of **aromasin** - was **vaginal dryness**. I am on **aromasin** and have developed **dry eyes**. does anyone else have this problem?

slammed back with flushings, terrible night sweats, bad **mood swings**, now have bad joint pain(mostly in my ankle and right hand/thumb). oh ugh with the **femara**!

Is there a side effect, that is B9, from **Femara** that causes **vaginal discharge**? I just got home from a cruise to AK and upon wake up this a.m. [sic] I had a discharge. Not real bloody but kind of like the very last day of a light period.

# Results

- Among 25,256 posts related to AIs, 4,589 (18.2%) mentioned at least one side effect.
  - Joint/musculoskeletal pain (N = 5093)
  - Hot flashes (1498)
  - Osteoporosis (719)
  - Weight gain (429)
- 12.8% mentioned discontinuing AIs, while another 28.1% mentioned switching AIs
- Many also offered support and advice for coping with AI-associated arthralgia

# What can we glean from this?

- Patients taking AIs seem to experience side effects more frequently than noted on the labels
- There is no denominator: interpret cautiously!
- However, these results are suggestive of important phenomena
- Validation is needed!

# Some thorny regulatory issues confronting social media researchers

- Consent!
- Protecting user privacy and confidentiality
  - Need for anonymization poses computational difficulties
- Complying with provider requirements
  - Terms of Service and Data Use Agreements
- Serendipity
  - What to do when a serious event is uncovered, outside the scope of an approved protocol?

# In conclusion...

- Discussion boards potentially rich sources of hypothesis-generating text
  - Different from other social media
- Mining discussion board data can be challenging
  - Regulatory (statute or corporate) constraints
  - Technical and computational issues
  - Interpretation and direction moving forward