

**About those posts:  
ONLY QUESTIONS, NO ANSWERS**

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# Question 1:

## How do we handle processing and reporting?

- Do we just throw everything in a database? Or only a 'select few'?
- What happens with all our other data and our signaling if we 'dilute' or 'enrich' (pick one!) the DB?
- Are these spontaneous 'reports'? The 'spontaneous part of the equation applies (perhaps), but how about the intent to 'report'?
- Does it add value to report out to regulators? Technically, anything can be done, but is it in the interest of the patient?

## Question 2:

How do we handle the potential volume?

- What volume do we expect anyway for a given product or disease? Is it really ‘big data’?
- Based on analysis of 29 products in WEBRADR:

Metric	# Posts with Adverse Events for product; per month	# Posts with product mentioned; per month
MEAN	15.4	439.4
MEDIAN	0.6	139.1
MIN	0.0	1.2
MAX	220.5	5274.6

- Looks more like ‘Medium Data’

# Question 3:

## What does one do in a regulatory and legal vacuum?

- Obviously: let's work together (this workshop!)
- Proceed with caution
- Pilot and assess learnings critically
- Share those learnings!
- Example 1: what is a company-sponsored site anyway:
  - Is funding enough to make it company-sponsored?
  - Is the real determinant the ability to control content?
  - Or does influencing the font size qualify?
- Example 2: how about follow-up?
  - Is seriousness a consideration, eg an **unexpected cardiovascular event** with fatal outcome that is likely related to drug. It just so happens to be popping up on a blog → can/should Company X contact this person?
  - What drives the balance between privacy – individual patient care – public health?

# Question 4:

## What is the 'natural role' of social media in a sea of data?

- We have spontaneous reports, solicited reports, clinical trial data, quality data, Electronic Health Records, Claims Data, Internet Search Logs on the internet (or is this social media??)
- And then Social Media comes along. How to use this:
  - Additive to spontaneous reports, same bucket
  - Independent for hypothesis generation or signal detection
  - As needed for signal strengthening
  - Ad hoc; 'it depends'
- Does the role of social media vary from one disease area (or product) to the next eg one could investigate the following hypothesis:
  - CV population might offer additional insight into rare and serious side effects (thus making it a better candidate for signal detection)
  - Population with Psychiatric / Neurological disorders may share more QoL issues that are non-serious but very important to the patient.
- Added complication: rapidly changing landscape: where do youngsters hang out (Answer: now on Instagram but this is changing), where does the mature community hang out (Answer: NOT on Instagram but that might change)

ONE BIG DIFFERENCE: Direct patient communication - voice of the patient

No other data source is so immediate. Theoretically could be an early warning system to other sources. Whether it delivers in that promise is a differing question

# Question 5:

## Quality and Credence

- OK, volume seems to be 'medium' at best
- But quality? There is plenty of poorly worded rants out there
- Would you want to slog through this:

I know that I have to look at all of the things that other people put on Facebook. Some things are funny and some sad some and some are annoying. There is a time and a place for everything and right now is the time and here is the place to get serious. This issue and many other issues need to be addressed. We at times have to cut our grass or wash our clothes or other responsibilities that we have to do, or our lives become a mess. Everyone's complacency and "don't care about anything" as long they have their stupid phone in their hand and Facebook is up and running, is blowing my mind. These things do matter. How many of your grandfathers or fathers fought in a war to protect our freedoms? How many of you lost loved ones in a war to protect our freedoms? How many of our young men now are coming home dead or blown to pieces with legs and arms missing? All so our politicians can play politics with their lives and their bodies. Lets either kick the enemies a\*\*\*\* or get our precious young men and women the h\*\*\* out of that God forsaken h\*\*\* hole!!! It is not a game people. What is our generation doing right now to protect those freedoms? Why are our lives any more precious than those that have gone before us? NEWS FLASH....Our lives are no more precious but we d\*\*\* sure act like they are because we are doing NOTHING as a people to sustain the hard work and ultimate sacrifice that so many before us have made. I am ashamed of all of us. We are lazy and 70 percent of the people are on pills because you don't want to deal with life and you are medicating your children and crushing their spirit all the way into adulthood because maybe they were a little high strung and hard to deal with. Did Someone Or-other put Opie on Ritalin every time he got in trouble? You all know the answer to that. He made an effort to spend time and be a real daddy and now we don't make that effort about anything anymore! I have had enough and I am not going to sit back and take it. If any of you don't like what I said and am just too much reality, then please delete me. Facebook isn't my world so I could care less. I just want any of you that give a d\*\*\* and want to be informed, to watch this video and the others related to this. This is important to our country whether you care to believe it is or not.

# Question 6:

## Novelty

- Is there really anything in social media that we do not already know about our products?
- Not much, most of it is well-known
- How to look for that needle in a Twitter stack ?
- Again: may be disease-specific
- Maybe CV is a better candidate?
- Resources are of course a consideration → how many physicians do you want to burn out through Twitter-fatigue?