# Social Listening for Cardiac Safety

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# Meeting Outline

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| Session 1 - **Review of current safety surveillance methods and overview of social listening** | |
| Speakers | 900-920 |
| Panel Discussion | 920-1025 |
| Break 1 | 1025-1035 |
| Session 2 - **Practical considerations of social listening for cardiac safety – why this is valuable** | |
| Speakers | 1035-1055 |
| Panel Discussion | 1055-1200 |
| Lunch | 1200-1245 |
| Session 3 - **What evidence is needed to inform use of social listening for cardiac safety** | |
| Speakers | 1245-105 |
| Panel Discussion | 105-210 |
| Closing remarks | 210-230 |

# Please keep in mind

- Our Goal: stimulate discussion on how to leverage social listening for cardiac safety.
- Please keep in mind:
  - social media - complementary data source
  - think beyond the “adverse event” box
  - don’t fixate on the limitations
  - (public) perception is reality (public’s view of benefit/risk, importance of AE, etc.)

# Definitions

- **Social Listening** - the act of identifying and monitoring public conversations in various digital channels to obtain an understanding about what is being said for a particular topic. This is a passive process and no attempt is made to enter into the conversation.

- **Cardiac Safety** - For the purpose of this meeting, “cardiac” safety anything from cardiac related safety issues to safety issues for cardiac treatments.

- **Pharmacovigilance** - the science and activities relating to the detection, assessment, understanding and prevention of adverse effects or any drug-related problem (WHO, 2002).

- **Proto-AE** – a social media post in which a potential adverse event is discussed within the context of drug use

## Digital Media as a mainstream communication channel

- 38 years for radio
- 13 years for telev
- 1.5 years for Face

## rug Use

- 85% of adults use the internet

- 6% of adult internet users have posted comments, questions or information about health or medical issues on a website of any kind

- 3-4% of adult internet users have posted their experience with health care service providers or treatments in the previous 12 months


**How can we listen to what patients are saying online?**

# Key Limitations of Social Listening

- Validity of the data – what is said on social media may not reflect reality
- Vernacular terminology requires subjective translation (how to you translate “look like a lobster” into medical terminology)
- Follow-up may not be possible
- Lack clarity on how to analyze data (qualitative versus quantitative)
- Every potential type of bias/confounding may exist in social media
- Social Media is dynamic and constantly changing, from site to site, on the same site over time, etc.
- Lack of regulatory guidance on use of general social media for drug safety (non-company sponsored, non-company controlled)
- Lack of representativeness, can results be generalized
- People who are upset post at a different frequency than people who are happy (duplicate posts).
- A post that appears today may be gone tomorrow
- Large volumes of “noisy” data
- We don’t know what we don’t know

# Commonly asked questions

- **Regulatory**
  - How will data be shared with regulatory agencies?  Individual reports?  Summary analyses?
- **Privacy**
  - How do we ensure privacy?  Are the instances where we should “break” privacy, such as reaching out to an individual to help with a particular safety concern?
- **Data rights**
  - Should we inform people we are collecting their publically available data?
  - Should an individual have the right to dictate what we do with the data, when it should be deleted, etc.?
- **Legal**
  - What do you do if you see evidence of potentially illegal activity?
- **Utilization**
  - How do these data fit into an overall pharmacovigilance strategy?