

Title: Social Listening and Pulmonary Artery Hypertension

Performer: INSPIRE

Principal Investigator: Erik Jones

Project Duration: 9/14/2017 – 7/31/2018

Regulatory Science Challenge

People living with a condition are uniquely positioned to inform the understanding of the therapeutic context for drug development and evaluation. In 2012, the U.S. Food and Drug Administration (FDA) established the Patient-Focused Drug Development (PFDD) initiative to more systematically obtain the patient perspective on specific diseases and their currently available treatments. PFDD meetings are unique among FDA public meetings, with a format designed to engage patients and elicit their perspectives on two topic areas: (1) the most significant symptoms of their condition and the impact of the condition on daily life; and, (2) their current approaches to treatment. Following each of these meetings, FDA publishes a “Voice of the Patient” report summarizing the input shared by patients and patient representatives during the meeting. Although each report reflects a diverse set of experiences of living with the condition, meeting participants may not fully represent the diverse population living with the condition. There may be symptoms, impacts, treatments or other aspects of the condition that are not raised during the meeting and/or included in the meeting summary report.

Project Description

Using posts from the online INSPIRE patient community, topics and themes for a particular condition will be compared to FDA’s Voice of the Patient summary report for pulmonary artery hypertension (PAH). Natural Language Processing (NLP) will be used to identify key points. Manual curation will be used to check for accuracy.

Project Goals

- Use topic modeling to provide insight into PAH discussions, including depth and tone.
- Develop a summary of major themes and identify the concerns that are most important to patients with PAH.
- Demonstrate the utility of using NLP to identify themes in different sources of free text data.
- Identify any significant differences between views expressed at the PFDD meeting and in an online patient forum.

Project Results

The final report from the researchers to the FDA included the following results:

- Several key differences were identified in the communications between the patients from the PFDD meeting and the online community
 - Patients participating in the PFDD meeting were more likely to view their PAH diagnosis as a primary disorder, as opposed to a part of another disease process, such as scleroderma or sarcoidosis.
 - Patients from the online community tended to be more recently diagnosed and less aware of treatment options.
 - Many patients posted online only once. This limited the insight that could be gained regarding how patients' view their disease and treatment over time. (Note: Patients' view of their disease over time can be captured via PFDD meetings).
- NLP can be useful in analyzing large amounts of free text data related to the patient experience.