



# Using Social Listening to Understand the Patient Voice: The Daily Impacts of Sjögren’s Disease

Zachary Cline<sup>1</sup>, Maurice Flurie<sup>1</sup>, Colton Flowers<sup>1</sup>, Enming Zhang<sup>1</sup>, Annie Lau-Kilby<sup>2</sup>, Julia Taylor<sup>2</sup>, Chiara Baldini<sup>3</sup>, Ilias Alevizos<sup>2</sup>, Kristina Davidson<sup>2</sup>, Christopher DeFelice<sup>1</sup>, Maria Picone<sup>1</sup>

<sup>1</sup>TREND Community, <sup>2</sup>Amgen Inc, Thousand Oaks, California, United States, <sup>3</sup>Department of Clinical and Experimental Medicine, Rheumatology Unit, University of Pisa, Pisa, Italy

## INTRODUCTION

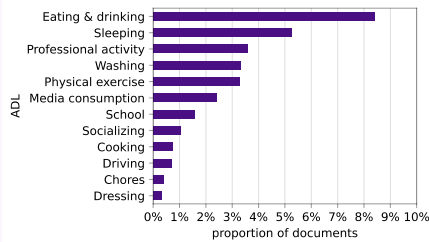
Understanding the everyday burden and management of a disease requires insight into patient perspectives. Social media groups dedicated to specific conditions act as a vital platform for patient conversations, providing valuable insights. These platforms allow patients to share, compare, and inquire about how their condition impacts activities of daily living (ADLs), such as physical exercise or work-related tasks. This study aims to explore the daily challenges faced by individuals with Sjögren’s disease through social listening.

## METHODS

We analyzed an online social media community using proprietary natural language processing (NLP) models to examine 84,034 posts and comments from the Reddit community r/sjogrens, spanning 11 years. A text classification model was employed to identify activities of daily living (ADLs), while clinical concepts were extracted and linked to a lexical knowledge base. Emotion words were categorized according to Paul Ekman’s six primary emotions. The association between ADLs and clinical concepts/emotions was measured using PMI<sup>2</sup>, and TFIDF identified non-clinical language related to ADLs.

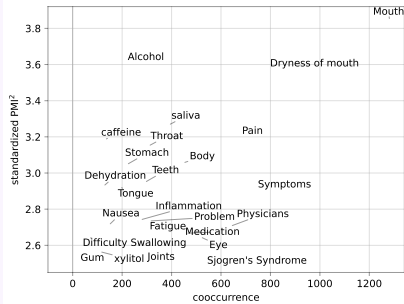
## RESULTS

Figure 1. Prevalence of ADLs



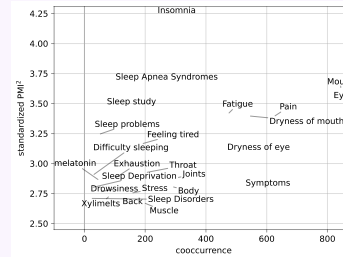
The ADLs that were discussed in the highest proportion of documents were Eating & drinking (8.4%), Sleeping (5.3%), and Professional activity (3.6%).

Figure 2: Clinical Concepts Most Associated with Discussion of 'Eating & drinking'



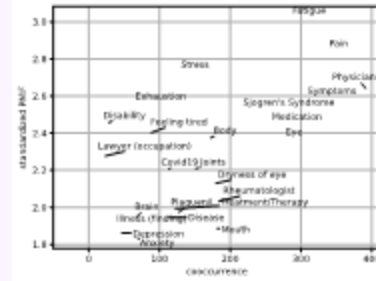
The top 25 clinical concepts most strongly associated with 'Eating & drinking' are displayed, with the vertical axis indicating the strength of association with mentions of 'Eating & drinking' and the horizontal axis showing the cooccurrence (by number of paragraphs) of the clinical concept and 'Eating & drinking'.

Figure 3: Clinical Concepts Most Associated with Discussion of 'Sleeping'



The top clinical concepts associated with 'Sleeping' were Insomnia, Sleep Apnea, and Mouth. Non-clinical terms included bed, hours, morning, and water.

Figure 4: Clinical Concepts Most Associated with Discussion of 'Professional Activity'



The main clinical concepts linked to 'Professional activity' were Fatigue, Pain, Stress, and Exhaustion, while non-clinical terms included job, full time, home, and disability. By PMI<sup>2</sup>, the strongest association between all ADL-emotion pairs was between fear and Professional activity. TFIDF revealed that words/phrases associated with fear mentions in Professional activity discussions included symptoms, brain fog, full/part time, side effects, go back, and able [to] work.

## CONCLUSION

Among the twelve identified ADLs, 'Eating & drinking' and 'Sleeping' were the two most common, likely due to the impact of a common Sjögren’s issue, dry mouth, and its impact on one’s comfort during meals and sleep. Language related to 'Professional activity' and fear suggests that symptoms, including brain fog and side effects, may impact a patient’s ability to maintain employment or be productive at work. Sleep-related discussions were primarily driven by pain and discomfort from dry mouth and dry eyes. Further research is needed to explore how other symptom clusters influence ADLs and the emotional well-being of those living with Sjögren’s so effective management strategies can be developed and deployed.

## DISCLOSURES



This study was funded by Amgen, Inc. Z.C. M.F., C.F., E.Z., are employees and stockholders of TREND Community. M.P. and C.D. are owners and stockholders of TREND Community. A.L.K., I.A., J.T. and K.D. are employees and stockholders of Amgen, Inc. C.B. reports payment for speakers' bureau (GSK plc., Sanofi, Novartis AG), payment for seminars and workshops (GSK plc., Sanofi), payment for consultancy (GSK plc., Sanofi), and financial grants for clinical trials (GSK plc., Viela Bio [now Horizon Therapeutics], Novartis AG).

**Title** (250 characters excluding spaces): Using social listening to understand the patient voice: The daily impacts of Sjögren's disease

**Authors:** Zachary Cline<sup>1</sup>, Maurice Flurie<sup>1</sup>, Colton Flowers<sup>1</sup>, Enming Zhang<sup>1</sup>, Annie Lau-Kilby<sup>2</sup>, Julia Taylor<sup>2</sup>, Chiara Baldini<sup>3</sup>, Ilias Alevizos<sup>2</sup>, Kristina Davidson<sup>2</sup>, Christopher DeFelice<sup>1</sup>, Maria Picone<sup>1</sup>

**Affiliations:** <sup>1</sup>TREND Community, <sup>2</sup>Amgen Inc, Thousand Oaks, California, United States, <sup>3</sup>Department of Clinical and Experimental Medicine, Rheumatology Unit, University of Pisa, Pisa, Italy

Total Character Count: 2,398/2,750 (excluding title, authors name, affiliations, disclosures)

### **Background/Purpose:**

Insights into the everyday burden and management of a disease relies on patient perspectives, and social media groups focused on specific diseases offer a valuable resource of authentic patient discussions to gain these insights. In particular, social media provides a platform for patients to discuss, compare, and inquire about the relationship between their condition and activities of daily living (ADLs) (e.g., physical exercise or professional activity). The aim of this study is to gain insight into the daily struggles of people living with Sjögren's through social listening.

### **Methods:**

A proprietary text classification model for recognizing activities of daily living (ADLs) in social media conversations was applied to 84,034 posts/comments spanning over 11 years from the Reddit community r/sjogrens. Additionally, spans corresponding to clinical concepts were extracted and linked to a lexical knowledge base using a custom clinical span recognition and linking model, and emotion words/phrases were matched to one of Paul Ekman's six primary emotions. The association between ADLs and clinical concepts/emotions was measured using PMI<sup>2</sup>. Finally, TFIDF was used to determine the non-clinical language associated with ADLs.

### **Results:**

The ADLs that were discussed most frequently were Eating & drinking (8.4% of documents), Sleeping (5.3%), and Professional activity (3.6%). Clinical concepts associated with Eating & drinking included Dryness of mouth, Saliva, Pain, and Throat; non-clinical words associated with Eating included sugar, dairy, gluten, and coffee. For Sleeping, the top associated clinical concepts were Insomnia, Sleep Apnea, and Mouth, and non-clinical words were bed, hours, morning, and water. Finally, for Professional

activity, clinical concepts included Fatigue, Pain, Stress, and Exhaustion, while non-clinical language included job, full time, and home.

The strongest association identified between the six primary emotions and an ADL was between fear and Professional activity. In documents discussing Professional activity, certain words and phrases commonly appeared in those mentioning fear. These terms included symptoms, brain fog, full/part time, side effects, go back, and able [to] work.

### **Conclusion:**

Of the twelve ADLs that the model was trained to recognize, Eating & drinking was by far the most common. The clinical language associated with those documents reveal that this is likely due to the effect that dryness of mouth, a hallmark symptom of Sjögren's, has on a patient's comfort level during consumption. Dryness of mouth also seemed to be affecting patient's sleep health. Finally, the clinical and non-clinical language associated with Professional activity, as well as the association with fear, suggest that a constellation of symptoms may be affecting patients' ability to maintain employment and/or be productive at work.

### **Funding Statement:**

This study was funded by Amgen, Inc.

### **Disclosures:**

Z. Cline, M.Flurie, C.Flowers, E.Zhang, G. Ho are employees and stockholders of TREND Community. M. Picone and C. DeFelice are owners and stockholders of TREND Community. A. Lau-Kilby, I. Alevizos, J. Taylor and K. Davidson are employees and stockholders of Amgen, Inc. C. Baldini reports payment for speakers' bureau (GSK plc., Sanofi, Novartis AG), payment for seminars and workshops (GSK plc., Sanofi), payment for consultancy (GSK plc., Sanofi), and financial grants for clinical trials (GSK plc., Viela Bio [now Horizon Therapeutics], Novartis AG).