

# MY DAUGHTER LOVES THE NEW PENS! QUANTIFYING THE PATIENT EXPERIENCE WITH MACHINE READING AND APPLIED SEMANTIC COMPUTING

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**OBJECTIVES** Real-world experience of disease treatment lies at the heart of patient centricity. Conventional methods of developing patient-reported outcome (PRO) instruments and value assessments are often costly, burdensome, even impossible (e.g. in rare diseases, paediatrics). Our goal was to generate patient and parenting insights from online forums on lupus nephritis (LN) and Crohn’s, respectively. These insights would be applied to decision-making towards reducing disease and social burden: in PRO development, formulation, HEOR, market access, and beyond.

**METHODS** Machine reading analyzers “read” publicly available, anonymized forum posts: 22,500+ on lupus and 13,000+ on Crohn’s. Posts were split into sentences, and custom word embeddings and Pharma-specific knowledge graphs represented the meaning necessary for entity and relation extraction. Decision makers identified relevant texts and supervised/unsupervised topics, e.g. sentiment, symptoms, and convenience. Quality was assessed by algorithmic confidence and expert evaluation. After initial training, all texts were analyzed algorithmically, with both supervised topics and unsupervised clusters of common expressions structured and summarized in dynamic visualisations for real-time insights research.

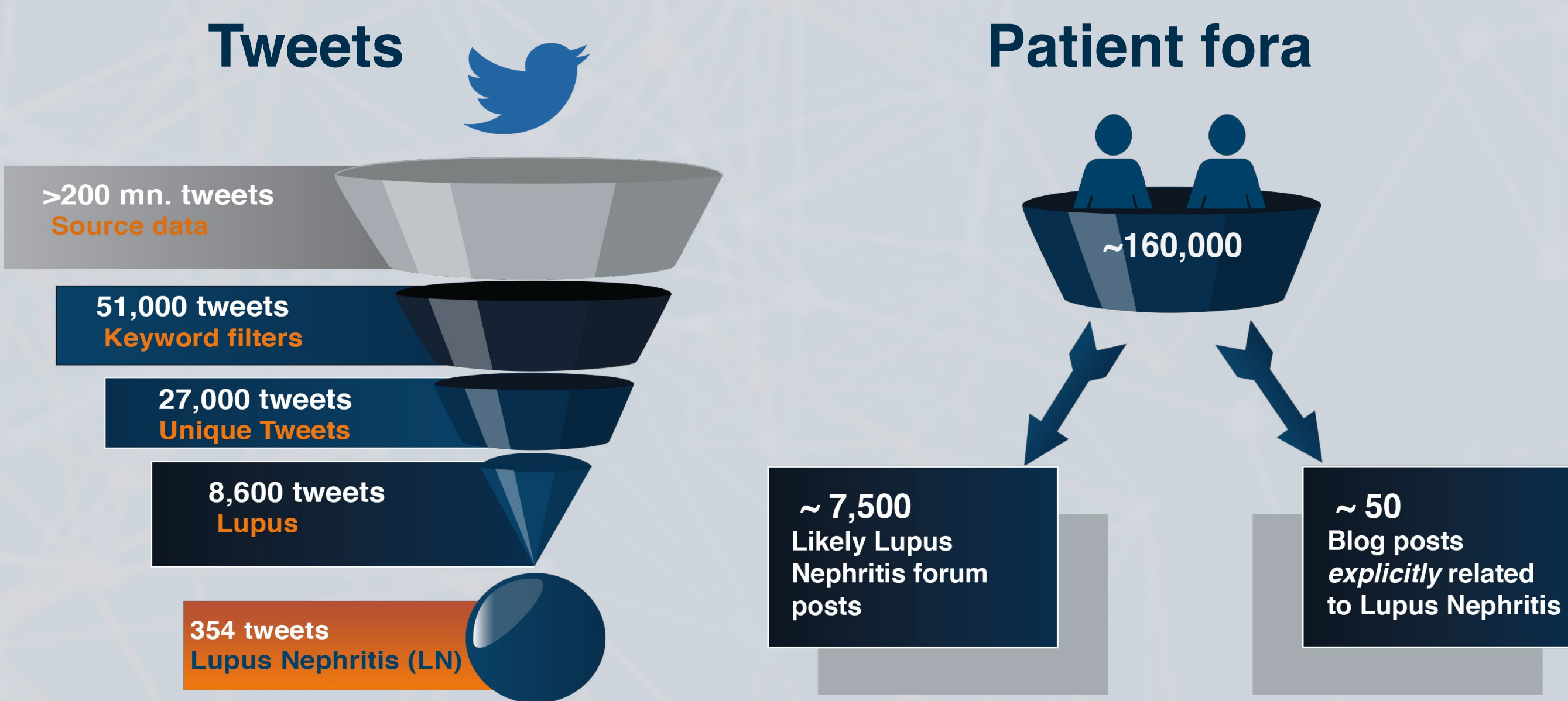


Figure 1 Identifying lupus nephritis patient conversations

**INTELLIGENCE QUESTIONS**  
 Can machine reading AI be used to understand the patient experience in lupus nephritis? Can those insights inform patient reported outcome measures that will be accepted by KOL’s, regulators, and payers?

„I was also inexplicably **swelling**, especially in my legs, but apart from that and the **rash** I felt fine. My parents **assumed** that it was some kind of sun allergy but after a few weeks it didn’t go away and I got **nervous** and went to see the **healthcare/specialist**. She recognised the **rash** and suspected **lupus** but sent me for **some blood tests** and to see a **dermatologist** for a second opinion. **At the hospital** they discovered that I was **losing a lot of protein in my urine** and took **more tests**.”

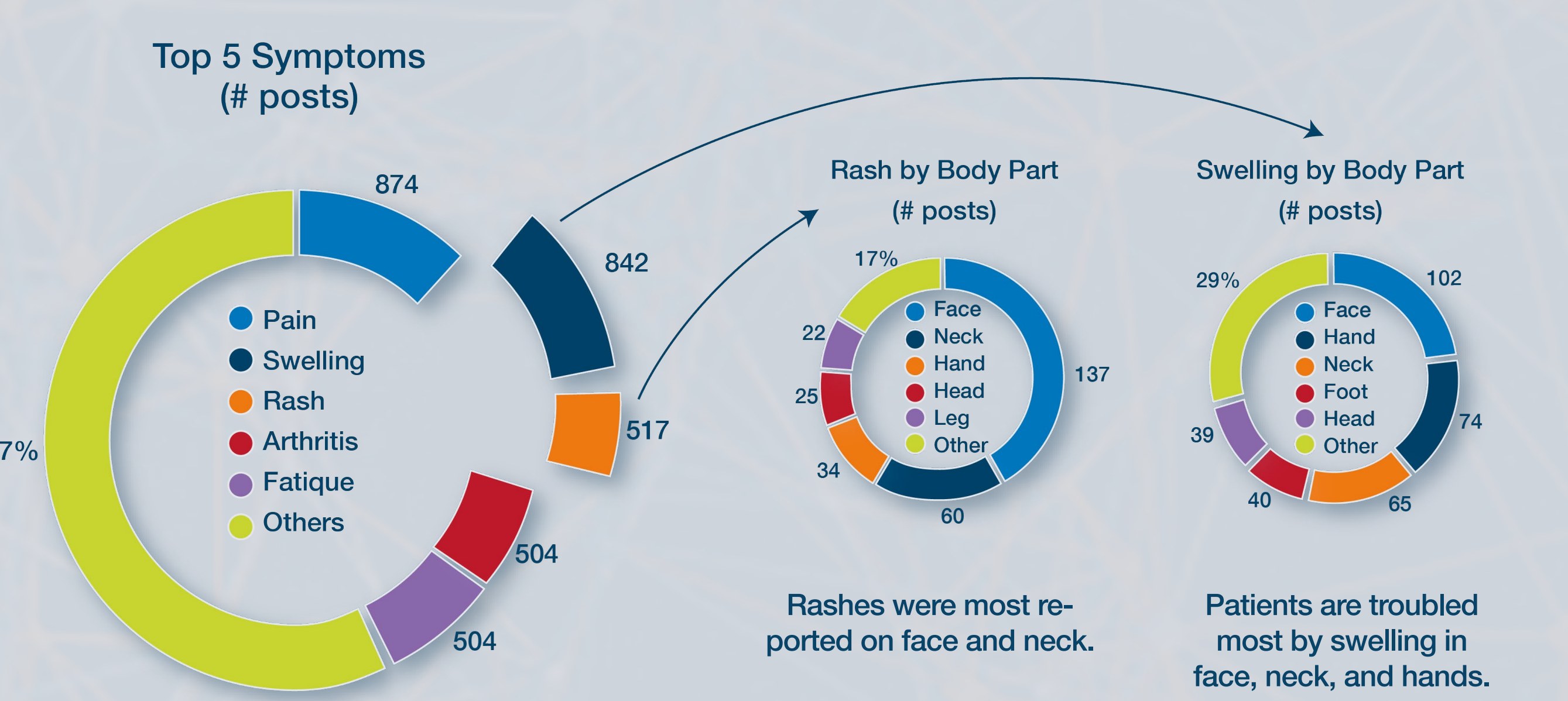


Figure 2a Example lupus nephritis patient statement  
 Figure 2b Symptoms and conditions in ~7,500 LN-related posts

Working in concert: Knowledge Graph, NLP, Statistical Inference, Classic AI, Machine Reading

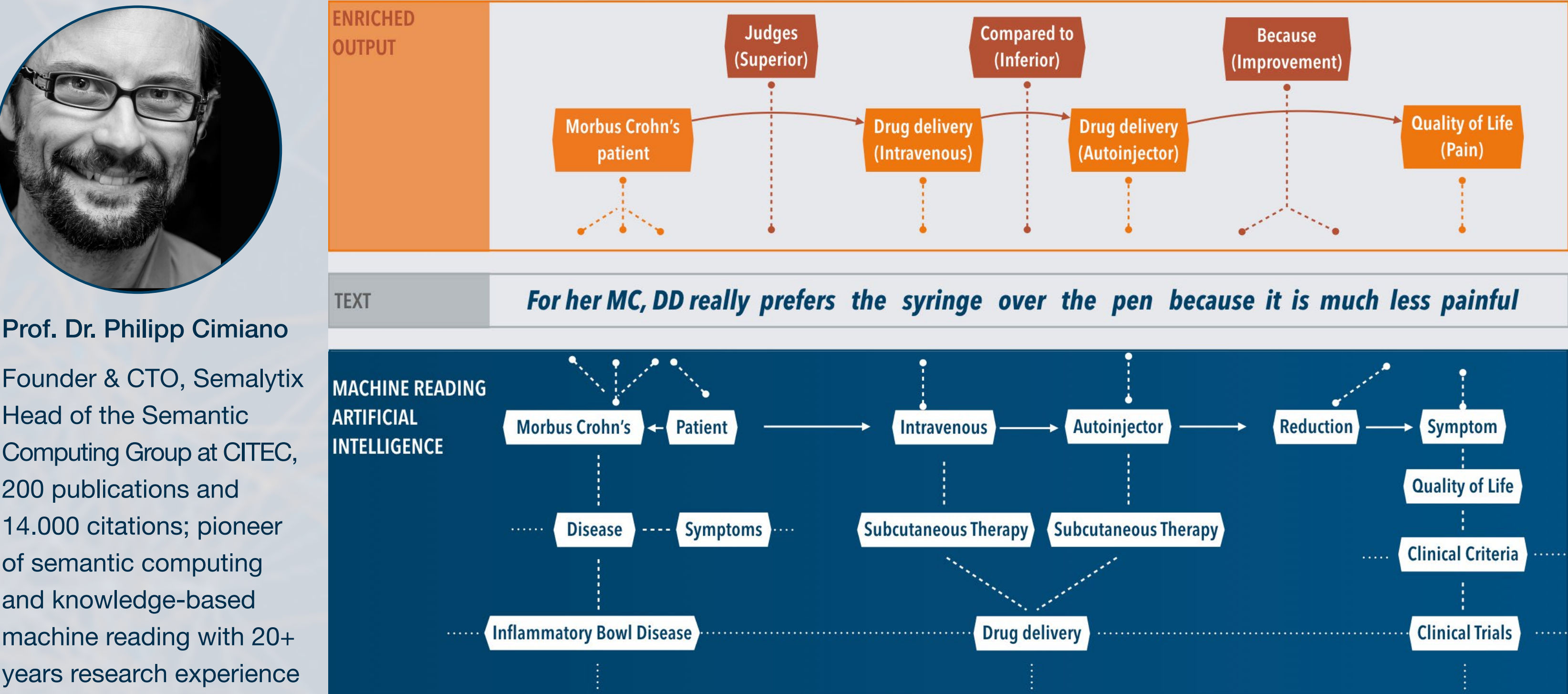


Figure 3 Machine reading example

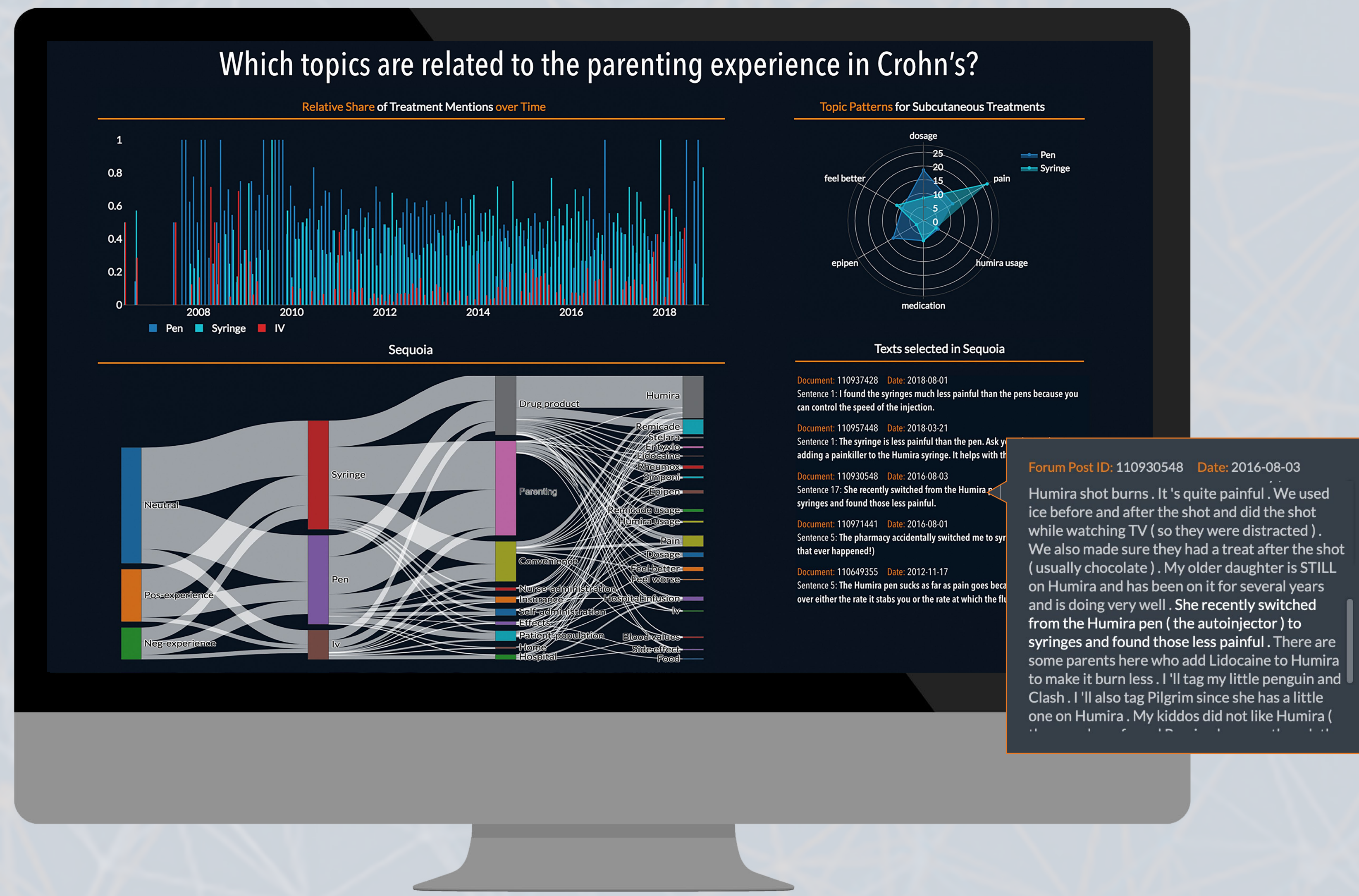


Figure 4 Living report for insight generation

crohnsforum.com: rich, idiomatic, authentic

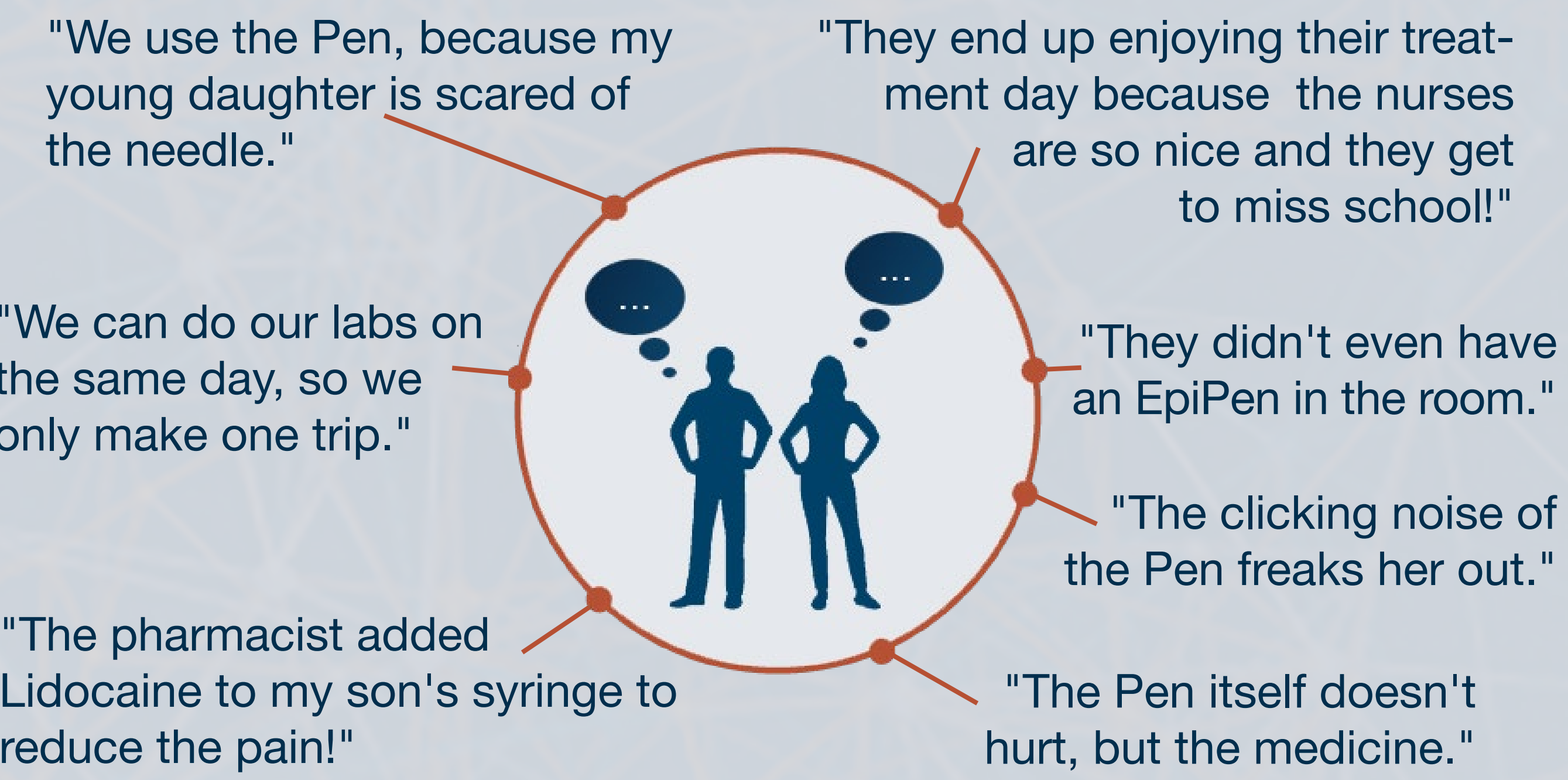


Figure 5 Example parents' advice on managing children's Crohn's

**RESULTS** 7,562 lupus posts were estimated to relate to the rare subtype lupus nephritis. Pain and rash were discussed in equal volume in the groups, but swelling 3.5 times as often in the LN vs. lupus-only group. Symptoms were differentiated by body part; rash and swelling in face, hand, and neck accounted for 53-69% of mentions. The expressed burden of symptoms on this exposed, visible skin was disproportionately greater than medical incidence rates predicted.

In the next study, unlike adults’ preference for subcutaneous syringes or pens, positivity for treatment by IV was high in the parenting/paediatric experience of Crohn’s treatment. In negativity, experiences with nurses and systemic allergic reactions predominated; positivity was reported for convenience, reduced pain, dosage flexibility, children’s preference, and eliminating the power struggle (“nagging” about doing the injections) from the home. Discussions on convenience (52.4% among supervised topics) and pain (42.5% among unsupervised topics) revealed novel strategies for managing infusion time: occupation, distraction, and rest. Algorithmic performance in detecting sentiment amounted to 90% precision. Negative sentiment was the least precise, and false negatives (22%) exceeded false positives (10%).

**CONCLUSIONS** Machine reading technologies can identify and quantify the patient experience where it is already abundant: in social media and support fora. With a relatively small investment in time (3-4 months), GDPR-compliant experience data can be found and extracted even in rare disease and specialised segment populations. Insights from both hypothesis-driven research and discovered unknowns can inform decisions across the development and commercialisation pipelines.

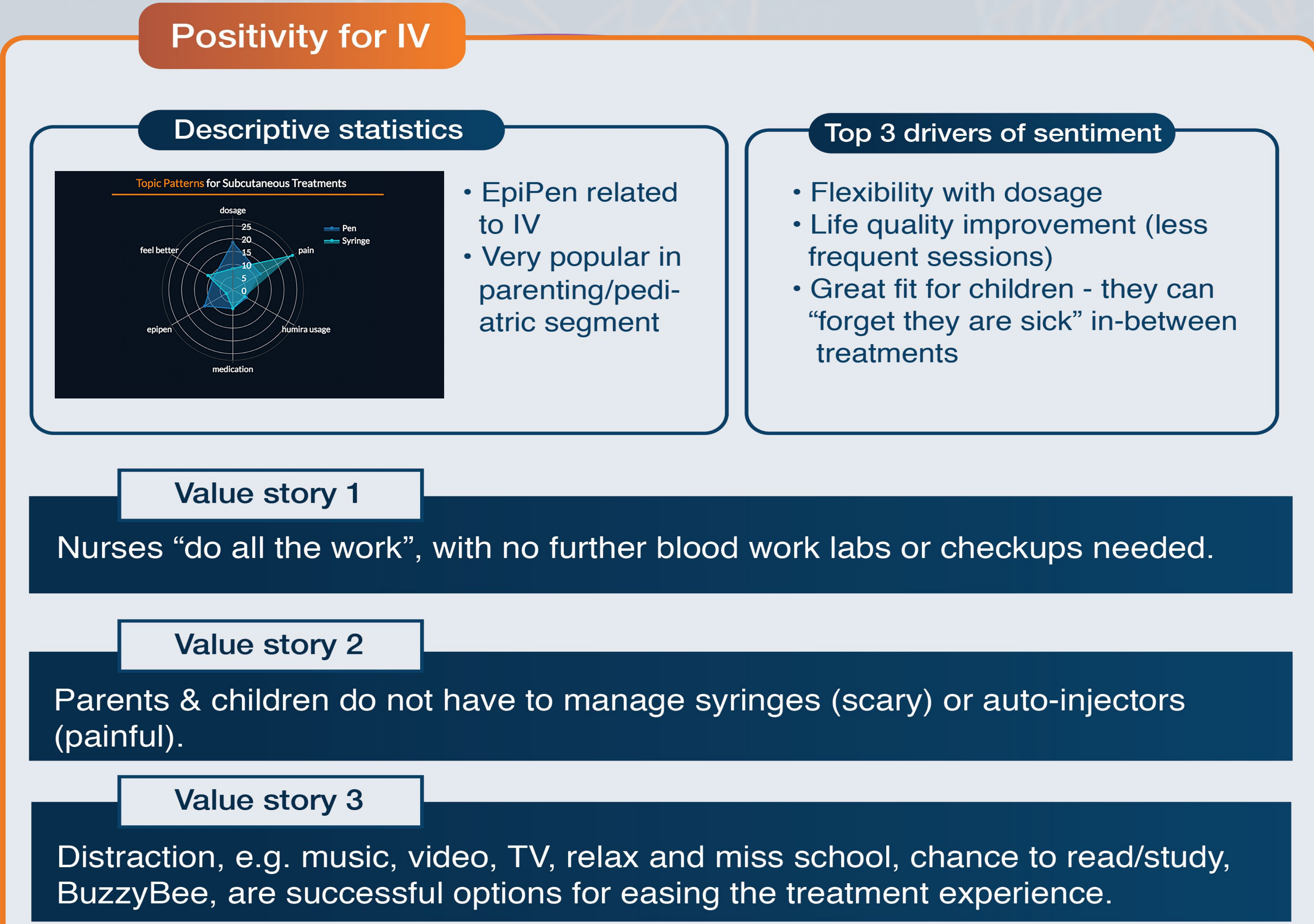


Figure 6 Example insights on popularity of IV in this patient population