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

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40 PUBLICATIONS 256 CITATIONS

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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 (~25,000+ 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 visualizations for real-time insights research.

RESULTS 7,962 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 LN vs. lupus-only group. Symptoms were differentiated by body part; rash and swelling in hands, face, and neck accounted for 33-69% 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 pediatric 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 (63.4% 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 (21%) 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 (~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.