MY DAUGHTER LOVES THE NEW PENS! QUANTIFYING THE PATIENT EXPERIENCE WITH MACHINE READING AND APPLIED SEMANTIC COMPUTING
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 impractical (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 (25,500+ on lupus and 13,000+ on Crohn’s). Posts were split into sentences, and custom word embeddings and Pharma-specific knowledge graphs were used to identify relevant texts and supervised/unsupervised topics, e.g. sentences, and custom word embeddings and Pharma-specific knowledge graphs. Quality was assessed by algorithmic conformance 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.

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 the LN vs. lupus-only group. Symptoms were differentiated by body part; rash and swelling in face, hands, 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 pediatric experience of Crohn’s treatment. In negativity, parents were troubled struggling “nagging” about doing the injections and discovered unknowns can inform decisions across the development and commercialisation pipelines.

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, quantifying the patient experience where it is already abundant: in social media and support fora. With a relatively small investment, insights from online forums on lupus nephritis (LN) and Crohn’s, respectively, promise to reduce disease and social burden; in PRO development, formulation, HEOR, market access, and beyond.

Figure 1 Identifying lupus nephritis patient conversations

Figure 2b Symptoms and conditions in ~7,500 LN-related posts

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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.