

Nordic AI Meet 2026

P2: AI in Health, Medicine, Care & Human Well-being

8. Discovering Patient Priorities in PCOS/PMOS Online Communities Using Large Language Models

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Abstract: Polycystic ovary syndrome (PCOS), recently reframed as polyendocrine metabolic ovarian syndrome (PMOS), is a heterogeneous condition spanning reproductive, endocrine, and metabolic health. However, these clinical domains may not fully reflect the concerns individuals prioritize in everyday life, including treatment experiences, psychological burden, diagnostic challenges, and unmet healthcare needs. Online health communities offer a unique source of spontaneously expressed patient narratives that can complement structured clinical and population-health data. We present an ongoing study developing an AI-assisted framework to characterize the dominant concerns expressed in PCOS/PMOS online communities. Large-scale discussions from PCOS-focused Reddit communities will be analysed using semantic text embeddings and unsupervised topic modeling to identify recurring themes without imposing predefined clinical categories. Large language models will then support the interpretation, consolidation, and labeling of the discovered topics. Themes will be mapped across reproductive, endocrine, metabolic, treatment-related, psychological, healthcare-system, informational, and social dimensions, while co-occurrence analysis will examine which symptoms, treatments, and healthcare experiences are commonly discussed together. The study will assess how patient priorities align with the emerging multidimensional conceptualization of PMOS and identify aspects of lived experience that extend beyond its core biological domains. By combining unsupervised topic discovery with LLM-assisted semantic interpretation, this work aims to transform large-scale unstructured health narratives into interpretable evidence on patient priorities and unmet needs. The approach may provide a scalable framework for incorporating patient-generated evidence into research on complex and underrepresented areas of women's health.