Development and validation of a novel Quality of Life ontology (QoLo), used with natural language processing & online questionnaires to lower existing barriers to developing Patient Reported Outcome Measures (PROMs)

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BACKGROUND

PROMs capture outcomes that really matter to patients. They highlight the impact of the disease and treatment on Quality of Life (QoL) and are increasingly important in clinical trials. They allow clinicians to better understand the patient's perspective on their symptoms and impact on their daily life.

Our two published systematic reviews **highlight unmet need for the development and validation of PROMs able to measure the impact of inflammatory eye disease** encompassing uveitis, scleritis and optic neuritis. These three conditions are all sight-threatening, frequently requiring systemic treatment, and affecting patients throughout their life.

Barriers to PROM development include: limited workforce with skillset; external generalisability concerns and costs of recruitment.


Review > J Ophthalmic Inflamm Infect. 2022 Sep 5;12(1):29. doi: 10.1186/s12348-022-00304-3.

Evaluating patient-reported outcome measures (PROMs) for clinical trials and clinical practice in adult patients with uveitis or scleritis: a systematic review

Charles O'Donovan [1 2], Jesse Panthagani [1 2], Olalekan Lee Aiyegbusi [3], Xiaoxuan Liu [4 5], Susan Bayliss [6], Melanie Calvert [7], Konrad Pesudovs [8 9], Alastair Denniston [4 5], David Moore [1 2], Tasanee Braithwaite [1 2 10 11]

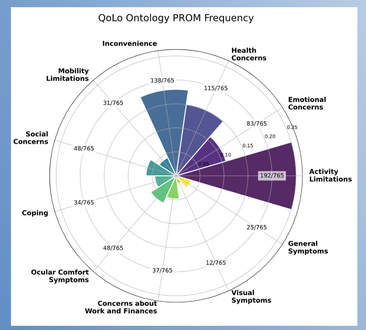

Review > Eye (Lond). 2023 Oct;37(15):3097-3107. doi: 10.1038/s41433-023-02478-z. Epub 2023 Mar 17.

Evaluating patient-reported outcome measures (PROMs) for future clinical trials in adult patients with optic neuritis

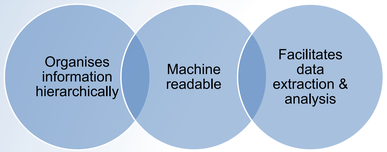
Jesse Panthagani [1 2], Charles O'Donovan [1 2], Olalekan Lee Aiyegbusi [3], Xiaoxuan Liu [4], Susan Bayliss [5], Melanie Calvert [6], Konrad Pesudovs [7], Alastair K Denniston [8], David J Moore [9], Tasanee Braithwaite [1]

AIMS

1. **Develop the first ontology for ophthalmic QoL**
2. Explore online questionnaires as an alternative text data source
3. Using uveitis as an exemplar validate these approaches to PROM item identification, through comparison to a 'Gold Standard' (Australian transcripts)



ONTOLOGY AS A SOLUTION



Ontology is a computational tool that organises information hierarchically. So Quality of Life, for example, might include 11 classes, like vision related symptoms, and within each of the these there are many individual items, like glare. We might find that glare is a QoL symptom which is common to cataracts and uveitis, and so in the ontology we can annotate where this item came from in the form of a link to the relevant published PROM. We can use ontology, in combination with natural language processing tools, to annotate unstructured text data flagging up each time a sentence, or paragraph contains an item from within the ontology. Thus we can annotate **vast quantities of text data in seconds**, rather than being limited to analyse focus group transcripts from small groups of people, we could instead annotate text from thousands of uveitis sufferers, sharing their experiences within each domain of QoL being prompted in a questionnaire.

QUALITY OF LIFE ONTOLOGY (QoLo): ANNOTATION OF CLASSES IN UNSTRUCTURED TEXT

11 high-level Classes / domains:

- Activity Limitation
- Convenience
- Coping
- Emotional
- Mobility difficulty
- General Health Symptoms
- Health concerns
- Ocular comfort symptoms
- Social
- Visual symptoms
- Concerns about work and finance

"I am quite lonely and sad. What started as dry eye and chalazion then a couple of episodes of uveitis which were never fully investigated, ended up causing a broken back and being isolated due to vulnerability and lack of mobility. The eye condition is the least of my worries at the moment."

Looking at this extract from one of our participants, it illustrates the concept of text annotation by items with each QoL domain. I have highlighted & colour coded here how our Quality of Life Ontology (QoLo) would tag important relevant individual items such as 'lonely' and 'sad' into the relevant over-arching Quality of Life domains (or classes) such as in this case the 'Emotional' domain.

Because we have annotated the ontology classes with patient-preferred synonyms & antonyms, it would also tag these, enhancing the capture of important meaning from this questionnaire response

METHODS

1. QOLO DEVELOPMENT

Started with 600 items in 11 QoL domains from **6 Rasch-validated, published ophthalmic PROMs** from the Eye-Tem Bank project (Pesudovs et al.)

- **Version 2** • Symptoms added from BNF under each medicine used to treat uveitis
- **Version 3** • Synonyms added, using Roget's Thesaurus
- **Version 4** • Antonyms added to relevant domains
- **Version 5** • 11 open-access published PROMS (6 visual specific and 5 general PROMS)

2. GATHERING DATA



Secondly, to identify relevant QoL content related to uveitis participants we recruited 116 participants via ten uveitis charities and seven Facebook groups, to complete online questionnaires via Qualtrics. This questionnaire was split into two – Part 1 focused on questions about their uveitis and its treatment. Part 2 explored impacts of uveitis and treatment, by ten QoL domains.

3. QOLO APPLICATION TO ANNOTATE UNSTRUCTURED TEXT DATA

Written text data from 116 uveitis participants → Natural Language Processing approach → PROM items identified

To identify new items which are unique to uveitis-related quality of life, and not contained within other published ophthalmic PROMs, using written text data from our 116 uveitis participants we used an natural language processing (NLP) approach which takes seconds to search for & count the frequency of items in questionnaire data, in comparison to time consuming manual annotation.

Qolo ensures relevant terms can be tagged or 'annotated' **without the manual involvement of a uveitis specialist**. Individual questionnaires were cleaned and then a Python toolkit, was used which has NLP capabilities. Data was annotated via the PhraseMatcher function with ontology concepts: classes and metadata (synonyms & antonyms) to identify PROM items.

To validate these approaches to PROM item identification, we compared our method of identifying items compared to items found in a 'Gold Standard' (focus group/interview transcript data, n=41),

3. QOLO VALIDATON

Traditional NVivo approach → Novel QoLo approach

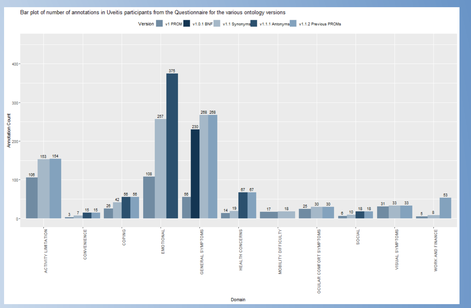
To validate QoLo, we also used two online written structured text data from participants who had completed our questionnaire. We then annotated these and compared domains and items (and frequency) identified from the traditional approach (using content analysis) compared to QoLo v2.0 analysis of the same text data.

We wanted to test the hypothesis that the number of domains and items identified by QoLo is non-inferior.

protégé

GitHub

RESULTS



There was an increase in domain annotations in uveitis participants over each ontology iteration.

When comparing our QoLo v2.0 there was **64% overlap** (n=133/203) with the Australian transcripts (gold standard) When we compared Content Analysis compared to our Quality of Life ontology, there was **overlap of 75%** (21 of the 28 'meaning units').We looked at the 7 meaning units not identified and found 6 were novel to uveitis and one had a different spelling so should have also been identified by QoLo, and we have added this to our QoLo.

CONCLUSION

We have identified a way to rapidly automate the identification of the known knowns and the unknown (for a new eye disease PROM) knowns (based on last ophthalmic PROMS).

This novel method for PROM content identification offers an **accelerated & low-cost approach for annotating text data, lowering current barriers to PROM development.**

REFERENCES

1. Panthagani J, O'Donovan C, Aiyegbusi OL, Liu X, Bayliss S, Calvert M, Pesudovs K, Denniston AK, Moore DJ, Braithwaite T. Evaluating patient-reported outcome measures (PROMs) for future clinical trials in adult patients with optic neuritis. Eye (Lond). 2023 Mar 17:1–11.
2. O'Donovan C, PJ, Aiyegbusi OL, Liu X, Bayliss S, Calvert M, Pesudovs K, Denniston AK, Moore D and Braithwaite T. Evaluating patient-reported outcome measures (PROMs) for clinical trials and clinical practice in adult patients with uveitis or scleritis: a systematic review. Journal of Ophthalmic Inflammation and Infection, 2022.