Collaboration with patient partners and data scientists to develop a lexicon for artificial intelligence-enhanced medical communication

Poster 25

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Conclusions

- Harnessing diverse skillsets to co-create AI (artificial intelligence)-applied patient lexicons offers a promising approach to expedite the development of plain language materials.
  - Patient lexicons can facilitate transparency by supporting clarity, consistency, and readability of plain language writing.
  - Lexicon co-creation with patient partners is essential to ensure that the terms used are meaningful and accessible to non-specialist audiences.
- AI assistants can support the integration of patient lexicons into workflows more seamlessly than traditional formats.

Background

- Across the pharmaceutical and scientific publishing industries, there is increasing recognition of the importance of producing content such as plain language summaries (PLS) to make healthcare research more understandable to non-specialist audiences, including patients and caregivers.[1]
- For effective scientific communication, language must be clear, free from jargon, consistent, and meaningful for target audiences.
  - Developing and applying a patient lexicon, ideally as part of a co-creation process with patient partners, can facilitate consistent use of appropriate terms across plain language materials.
- AI is transforming medical publishing and communications. Used with appropriate human oversight, AI can assist in the creation of scientific content for non-specialist audiences, improving efficiency whilst maintaining accuracy and readability.[2,3]
  - However, the specific use of AI to apply a patient lexicon has not previously been explored.

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Objectives

- To co-create, with patient partners, a lexicon for the rare neuromuscular condition myasthenia gravis (MG).
- To apply the lexicon to MG-specific PLS, using an AI app to translate any technical terms into plain language.

Methods

1 Co-creation of the MG patient lexicon

- To understand the proposed application for the lexicon, we conducted interviews with eight internal pharmaceutical company stakeholders and reviewed existing materials previously produced by the company.
- We identified relevant scientific terms and patient-friendly alternatives through reviewing information about the lived experience of MG, including:

Published literature | Patient group websites | Patient social media posts

- Four patient partners living with MG took part in a 2-hour workshop to co-create the final lexicon:

1 patient from the UK | 1 patient from Belgium | 2 patients from the US

- We assessed patient partners' experience of the co-creation process using the Patient Focused Medicines Development Patient Engagement Quality Guidance,[4] adapted as a questionnaire.[5]

2 Development of the AI app

Our AI app used a large-language model to generate a backend directory of lexicon term variations, made visible on the frontend using the open-source Python library Streamlit.

3 Identification of sample PLS

We used PubMed[6] and internet searches (conducted 21 November 2024) to identify 19 PLS about MG.

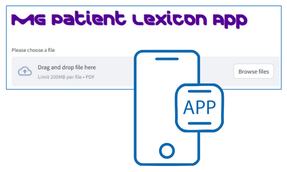
PubMed: (myasthenia gravis) AND (plain language summary)
(myasthenia gravis) AND (lay summary)
(myasthenia gravis) AND (hasplainlanguagesummary)

Plain Language Summaries: Archive search at: https://www.plainlanguagesummaries.com/publications/

Google: Search for: 'myasthenia gravis plain language summary'

4 Validation of the AI-applied lexicon using sample PLS

- We uploaded the 19 MG-specific PLS to the AI app.
- Based on the content of the lexicon, the AI app highlighted scientific terms and recommended patient-friendly alternatives, including singular/plural and hyphenated/unhyphenated variations.



Generalized myasthenia gravis
Recommended: MG affecting the whole body

Nerve conduction studies
Recommended: Test of how well electrical signals move along nerves

Seropositive myasthenia gravis
Recommended: MG that shows up in blood tests

- We gathered feedback about the app from internal stakeholders at the pharmaceutical company:
  - During a group testing workshop.
  - Via a feedback survey embedded into the app. Stakeholders were prompted to complete this survey whilst they were using the app.

Results

The final lexicon covers 118 terms related to MG, treatments, and clinical trials

Across 19 PLS, the AI app identified:

177 **total** recommended changes

80 **unique** recommended changes

For 1 sample PLS, a **highly experienced medical writer trained in plain language** stated that they would have incorporated

15/22 (68%)

of the recommended unique changes

Patient partners suggested 48 changes to the draft lexicon

Overall, patient partners' perceptions and experience of the co-creation process was positive. All four patient partners agreed that:

> *The outputs from the patient lexicon project could have a positive impact on stakeholders (for example, people living with MG and their caregivers, healthcare teams, and researchers)*

> *The patient lexicon project reflected the needs and interests of the target audience of the output from the project. (For example, the patient lexicon will be used to create PLS of relevant healthcare research for people living with MG and their caregivers)*

Internal stakeholders at the pharmaceutical company are using the patient lexicon to:

- **Create content for people living with MG**, including PLS, clinical trial materials, and disease state awareness materials
- **Improve communication** when working with patient partners

Overall, user feedback on the AI app was positive

All four attendees at the company group testing workshop agreed that:

> *The MG patient lexicon AI app will be useful for developing patient materials*

Amongst the six users who responded to the in-app survey:

All users found the recommendations helpful (5/6) or very helpful (1/6)

> *Very easy to use. Easy upload, and clearly displayed recommendations*

All users stated that the app fitted into their existing workflow perfectly (3/6) or with minor adjustments (3/6)

> *When developing patient research materials (i.e., interview guides), it will be helpful to use the lexicon to ensure 'patient friendly' terms are being used*

Priority features that users most wanted to see as the app further develops included the ability to upload a wider variety of document types, export text from the app, and generate text using the app

Limitations

- This pilot study was done in a single therapeutic area with a small panel of patient partners, analyzing a limited sample of PLS. Application across different therapeutic areas is planned.
- The version of the AI app that was user-tested was an early minimally viable product, which continues to be developed since the user testing reported here.

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Disclosures

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