Development of a patient-friendly lung cancer lexicon

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Background

The mission

- Make scientific language more accessible, understandable, and empathetic to help minimize confusion and empower patients and study participants
- This project aims to develop a patient-friendly lexicon for lung cancer communications intended for adoption within a major pharmaceutical company

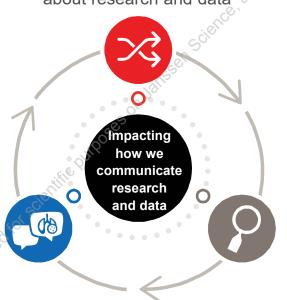
The lexicon objective

- To make it easier for patients to understand advances in lung cancer research by leveraging language that is more broadly understood outside of the medical and lung cancer expert community
- The lexicon is NOT meant to:
 - Suggest that members of the medical community change their language in how they communicate as researchers and colleagues
 - Suggest that health care providers change how they communicate with patients
 - Compromise the integrity of scientific communications



Purpose: Starting a Virtuous Cycle

Changing how the company internally communicates about research and data 🆠



Supporting a shift in how the lung cancer community talks about research, data, and living with lung cancer

Clarifying how research and data are externally communicated



Methods: The Lexicon Development Process

A multistep process was conducted to develop the patient-friendly lung cancer lexicon



Establishing the Unmet Need

Social media and literature analyses were performed to further understand the unmet need



Gathering Qualitative Insights

 An advisory board of clinicians and patients/patient advocates gathered insights on barriers to understanding research



Developing and Validating Language

 A draft patient-friendly lexicon was refined in 1:1 interviews with patients/ patient advocates and HCPs



Vetting the Lexicon

 A revised lexicon was presented to key company stakeholders who aligned on appropriate use cases



Finalizing the **Lung Cancer** Lexicon

Learnings were distilled into a finalized lung cancer patient-friendly lexicon



Results

- A total of 19 terms were included in the lexicon and grouped into 3 categories: safety, efficacy, and other
- A sample of lexicon terms is shown below

Technical language	Patient-friendly reframing	Rationale
Adverse event	Side effect	Simpler term with meaning
Median outcome (eg, PFS, OS)	Half of patients on treatment (eg, did not progress until, survived beyond) Alternatively, use landmarks (eg, 45 of 100 patients were without disease progression at 12 months)	Median can be a difficult concept for patients to understand and for physicians to explain Landmarks are easier to comprehend
Genetic mutation	Genetic alteration	Reduces stigma



Conclusions

- As pharmaceutical companies strive to be more inclusive of patients (eg, including patients as partners in research, advisory boards, steering committees, and strategic planning), they must incorporate and utilize language that allows patients to be included in the dialogue
- The patient-friendly lung cancer lexicon was developed for use at a major pharmaceutical company and includes terminology that can be utilized in scientific discourse that is more empathetic and inclusive
- By employing the lexicon, the company hopes to change how research is communicated and shift scientific discussions to be more patient centric; the lexicon will allow the company to evolve more effective partnerships with patients, caregivers, and advocates
- The full poster and complete lexicon are available and can be accessed by scanning the QR code below



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