Development of a Patient-friendly Lung Cancer Lexicon

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Key Takeaways

The language used in scientific discourse continues to be difficult for patients and caregivers to understand, despite efforts towards patient centricity

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
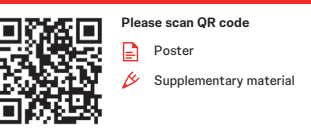
The patient-friendly lung cancer lexicon was developed with the hope that widespread adoption in the medical community could help advances in lung cancer research be more easily understood among patients and caregivers

Conclusions

Using the right words is part of the scientific community's responsibility to patients, families, and the wider lung cancer community. 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 lexicon contains 19 terms, categorized under safety, efficacy, and other. Each term includes use cases for both high and low complexity, specifying the appropriate context for use within the scientific community. The complete lexicon is available and can be accessed by scanning the Quick Response (QR) code below

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Background

- Making scientific language more accessible, understandable, and empathetic can help minimize confusion and empower patients and study participants
- Although recent trends in the scientific literature point to the increasing use of patient-centric titles, some language used in scientific discourse (including that meant for lay audiences) continues to be overwhelming and overly technical for patients and caregivers
  - Commonly used terms are sometimes not inclusive or empathetic to the patient's lived experience
- The International Association for the Study of Lung Cancer (IASLC) Language Guide[1] promotes the adoption of preferred language that is person centered, eliminates blame, ends stigma, and is equitable
- This project was inspired by the IASLC Language Guide and aims to develop a patient-friendly lexicon for lung cancer communications that is intended for adoption within a major pharmaceutical company
- The objective of developing this lexicon was 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
- This novel 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

Results

- A total of 19 terms were included in the lexicon and grouped in 3 categories: safety, efficacy, and other
  - The full lexicon is available and can be accessed by scanning the QR code in the lower left portion of this poster
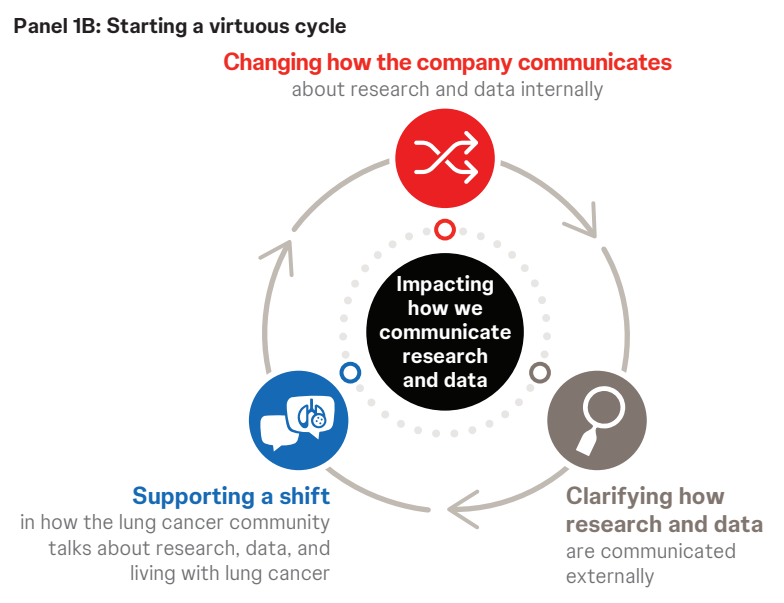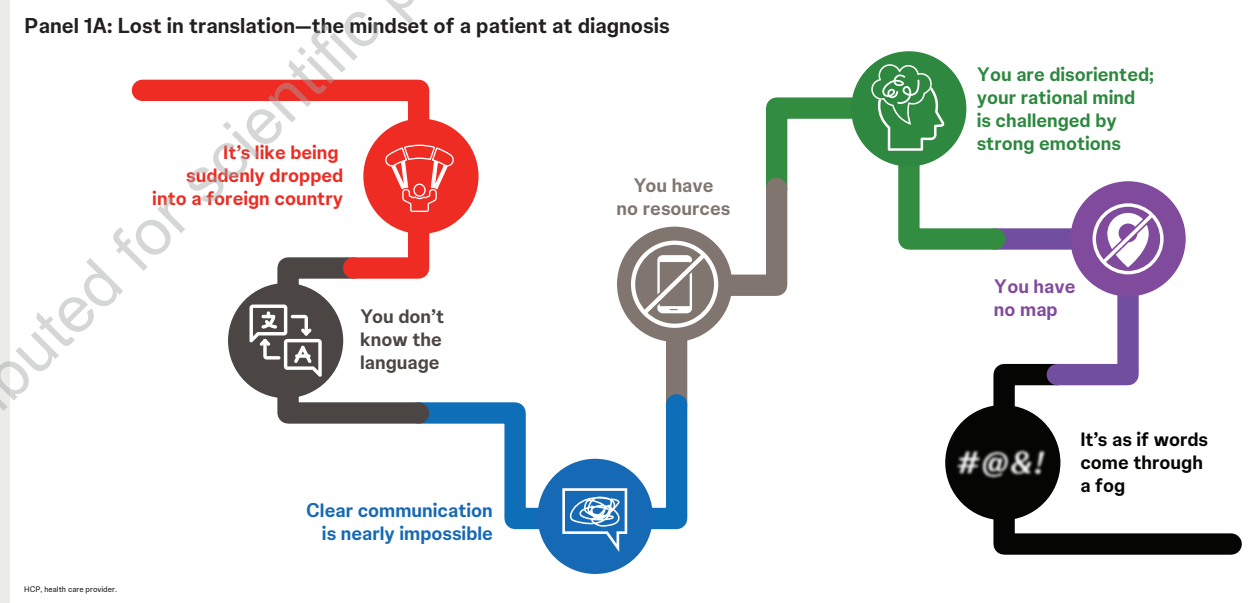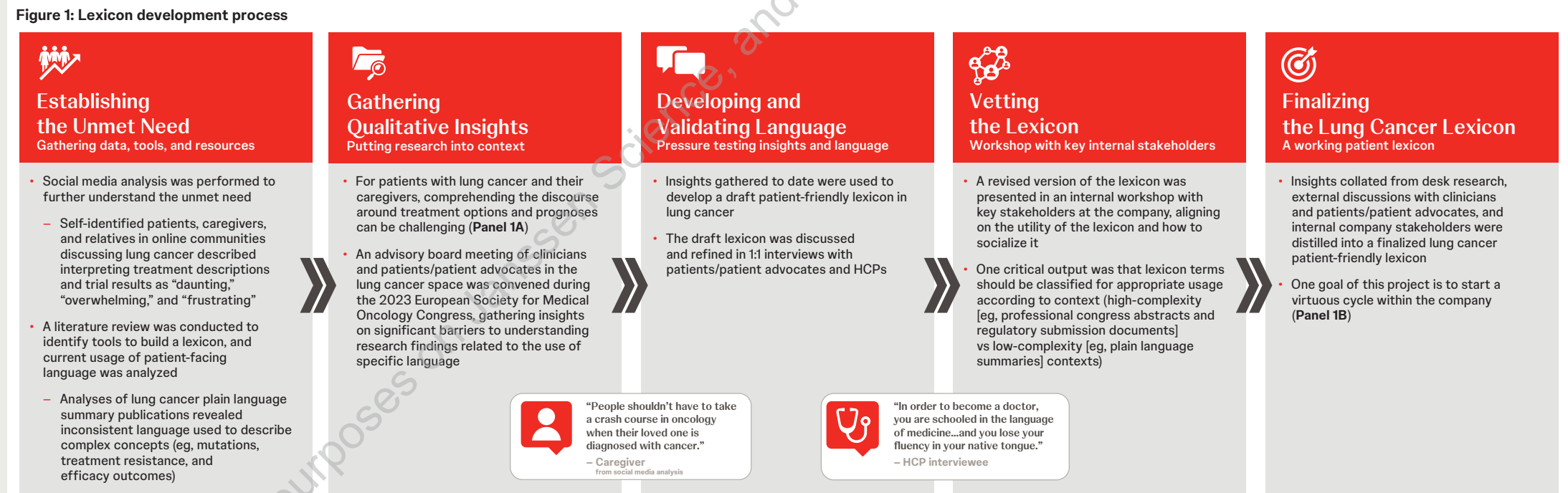- A sample of lexicon terms is shown in **Table 1**

Table 1: Sample terminology from the patient-friendly lung cancer lexicon

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

OS, overall survival; PFS, progression-free survival.

Methods

- A multistep process was conducted to develop the patient-friendly lung cancer lexicon (**Figure 1**)

Figure 1: Lexicon development process

Establishing the Unmet Need
Gathering data, tools, and resources

- Social media analysis was performed to further understand the unmet need
  - Self-identified patients, caregivers, and relatives in online communities discussing lung cancer described interpreting treatment descriptions and trial results as "daunting," "overwhelming," and "frustrating"
- A literature review was conducted to identify tools to build a lexicon, and current usage of patient-facing language was analyzed
  - Analyses of lung cancer plain language summary publications revealed inconsistent language used to describe complex concepts (eg, mutations, treatment resistance, and efficacy outcomes)

Gathering Qualitative Insights
Putting research into context

- For patients with lung cancer and their caregivers, comprehending the discourse around treatment options and prognoses can be challenging (**Panel 1A**)
- An advisory board meeting of clinicians and patients/patient advocates in the lung cancer space was convened during the 2023 European Society for Medical Oncology Congress, gathering insights on significant barriers to understanding research findings related to the use of specific language

Developing and Validating Language
Pressure testing insights and language

- Insights gathered to date were used to develop a draft patient-friendly lexicon in lung cancer
- The draft lexicon was discussed and refined in 1:1 interviews with patients/patient advocates and HCPs

> "People shouldn't have to take a crash course in oncology when their loved one is diagnosed with cancer."
> — Caregiver from social media analysis

Vetting the Lexicon
Workshop with key internal stakeholders

- A revised version of the lexicon was presented in an internal workshop with key stakeholders at the company, aligning on the utility of the lexicon and how to socialize it
- One critical output was that lexicon terms should be classified for appropriate usage according to context (high-complexity [eg, professional congress abstracts and regulatory submission documents] vs low-complexity [eg, plain language summaries] contexts)

> "In order to become a doctor, you are schooled in the language of medicine…and you lose your fluency in your native tongue."
> — HCP interviewee

Finalizing the Lung Cancer Lexicon
A working patient lexicon

- Insights collated from desk research, external discussions with clinicians and patients/patient advocates, and internal company stakeholders were distilled into a finalized lung cancer patient-friendly lexicon
- One goal of this project is to start a virtuous cycle within the company (**Panel 1B**)

Panel 1A: Lost in translation—the mindset of a patient at diagnosis

- It's like being suddenly dropped into a foreign country
- You don't know the language
- Clear communication is nearly impossible
- You have no resources
- You are disoriented; your rational mind is challenged by strong emotions
- You have no map
- It's as if words come through a fog

HCP, health care provider.

Panel 1B: Starting a virtuous cycle

Changing how the company communicates about research and data internally

Clarifying how research and data are communicated externally

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

Impacting how we communicate research and data

Reference
1. International Association for the Study of Lung Cancer. IASLC Language Guide. Accessed November 1, 2023. https://www.iaslc.org/IASLCLanguageGuide

Lung Cancer