Imagine two treatment options. One is aggressive and might extend your life but comes with severe side effects. The other is gentler, with fewer side effects, but a shorter life expectancy.
Which would you choose?
There is no universally “right” answer, because it depends entirely on what matters most to you.

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SafePolyMed.eu

Improving Safety in Polymedication by Managing Drug-Drug-Gene Interactions

Safety in Polypharmacy training 2026

Session 5 - Video 2/2

Fundamental concepts in reporting treatment side effects

Reporting ADRs, Grading Systems & Patient Preferences

Tamika Lang, Olga Millán

LeukaNET Leukemia Advocates Network

Patvocates PATIENT ENGAGEMENT IS IN OUR DNA

Funded by the European Union

AI Disclosure: *Avatars, voices, and some visual elements in this video were generated using HeyGen & Copilot. The educational content was created by humans and subsequently edited and summarised with AI assistance.*

What Is a Patient-Reported Outcome (PRO)?

Any outcome directly evaluated by the patient and reported based on their own perception of a disease and its treatment.



- **Perceived health state**
- **Pain & unobservable symptoms**
- **Physical / mental / social functioning**
- **Health-related quality of life**
- **Treatment satisfaction**

Reported directly by the patient, no filter, no interpretation. A genuine, quantitative source of evidence.

European Medicines Agency(EMA) Reflection paper on the regulatory guidance for the use of health-related quality of life (HRQL) measures in the evaluation of medicinal products. London: European Medicines Agency; 2005./ https://link.springer.com/article/10.1007/s40258-023-00827-3

PROMs: The Tools Behind PROs

PROs are measured using PROMs, patient-reported outcome measures. The questionnaires and tools patients use to report their outcomes.

STRENGTHS

- Patient-centred, holistic insight
- Improves engagement & empowerment
- Comprehensive treatment data
- Can influence policy & regulatory approvals

WEAKNESSES

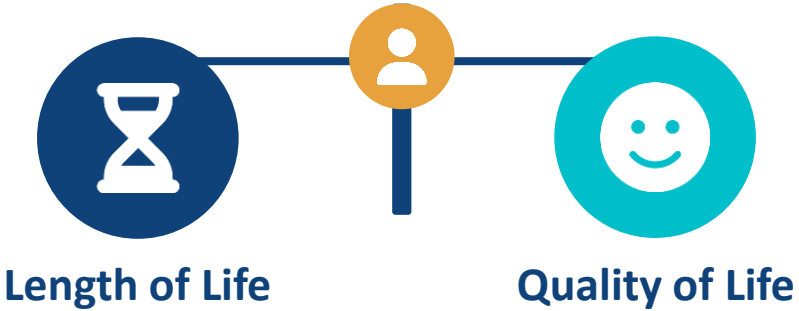
- Subjective. Variability & bias between individuals
- Validation & standardisation is challenging
- Providers need training to integrate them
- Consistent response rates are hard to achieve

FDA Guidance on Patient-Reported Outcome Measures / https://link.springer.com/article/10.1007/s11136-013-0596-1

Patient Preferences: What Matters Most to You

Beyond reporting how they feel, patients hold preferences, their desires, values, and priorities about their healthcare choices. These vary enormously from person to person.





There is no universal right answer, only what matters most to you.

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Patient Preference Studies (PPS)

Structured research capturing patients' preferences on treatment attributes, benefits, risks, and the trade-offs patients are willing to accept.

Conducted by:



Patient groups



Researchers



Healthcare providers



Public & private partners

PPS include:

- ✓ Health-preference assessments.
- ✓ Stated-preference health surveys.
- ✓ Health preference research.
- ✓ Patient-centred research.

Every individual is unique, but patient preference studies can reveal meaningful commonalities across groups or valuable patterns for treatment design and communication.

https://www.imi-prefer.eu/news/news-item/?tarContentId=943828

How Patient Preference Data Gets Used



To inform decision-making in drug development and commercialisation

Patient preferences are not just a "nice to have" They are a genuine input into how medicines are developed and brought to market.

Conceptual inspiration: Isabelle Huys, What are patient preferences?, PREFER webinar (2021).

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Key Takeaways

- Don't stay quiet about side effects
- Your preferences and priorities matter just as much as the clinical data
- Importance of education, reporting, and patient-informed research
- PROs capture how you actually feel in your own words

Session 5 complete ✓

▶ Next: Session 6 — Safety Signal Reporting & Digital Health Tools.

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Credits & Attributions

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AI disclosure

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Figures

- Treatment trade-off and Patient preference data-use illustrations generated using Microsoft Copilot and reviewed and edited by humans. The concepts in the patient preference data-use illustration were informed by Isabelle Huys, What are patient preferences?, PREFER webinar (2021).

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