

Co-creating a health literacy-sensitive tool for shared decision-making in esophagogastric cancer

Healthcare is moving from a paternalistic model, where professionals made decisions for patients, toward a patient-centered approach that treats patients as active partners. Shared Decision-Making (SDM) is central to this shift, ensuring treatment choices reflect patients' values, preferences, and lived experiences. In oncology, decisions are often preference-sensitive, emotionally charged, and made under stress, making patient involvement essential.

Target group

Individuals with Limited Health Literacy (LHL) face significant barriers to SDM. They struggle to understand medical information, express values, and navigate digitalized healthcare. Without tailored support, they risk being excluded from decision-making, increasing the likelihood of regret and reinforcing health disparities.

Goal and approach

This project explored how esophagogastric cancer patients with LHL can be better supported in decision-making. Conducted in collaboration with Amsterdam UMC, it applied systemic, service, and human-centered design methods. Research combined literature review, patient journey mapping, a case study of an outpatient clinic, a co-creation study with individuals with LHL, and expert consultations.

Applying Frame Innovation, systemic challenges were reframed into paradoxes that revealed opportunities for design. Among five other paradoxes, the frame discussed here inspired the final concept solution of Perspective Mapping.

Central paradox that obstructs effective communication

When patients' personal, religious, or cultural beliefs conflict with treatment plans, conversations often stall. Instead of dialogue, patient and HCP speak past each other, rooted in different frames of reference. What could be negotiation becomes a dead end, eroding trust and engagement. Yet beliefs are not barriers but essential parameters for care. If acknowledged early, they reframe the interaction from conflict resolution to co-creation, enabling approaches that are both clinically sound and personally meaningful.

Central design frame

What if treatment conversations were not about delivering advice, but about co-creating dialogue that respects both medical realities and patient beliefs? The goal becomes building bridges between worldviews and treatments, rather than simply understanding rejection.

Design goal:

"To support patients with LHL in articulating their values and information needs, while enabling HCPs to elicit these insights and adapt their communication and support accordingly."

Solution concept: Perspective Mapping

The final concept successfully addresses this design goal. Perspective Mapping: a modular communication tool that empowers patients to articulate preferences and participate meaningfully in SDM, while supporting HCPs in tailoring communication. Its iterative structure also fosters reflection, helping patients develop transferable decision-making skills throughout their care trajectory. It successfully addresses the design goal.



Perspective Mapping

Communication Support

- Determine and address misconceptions the patient has, before a treatment advice is given, to mitigate confusion and enhance understanding.
- Stimulates and empowers the patient to consider & argue their perspective during consultations.

The Healthcare Professionals

Clinical + practical information



The Patient

Personal perspective and life view



Representation during MDO



- Facilitates representation of the patient's perspective during the Multi-Disciplinary Meeting.

Support during consultations

- Provides an overview combining both clinical information & patient's perspectives.
- Early explanation of the decision-making process clearly, reducing patient uncertainty.
- Translates patient's input to easy to implement suggestions for communication strategy & tools for HCPs.

Treatment Decision Making

- Provides HCPs with tools and strategies for communication.
- Provides physical reminders of the patient's perspective, empowering them to engage, while keeping space for perspective adjustments over time.
- Facilitates iterative discussion, adaptation, and reflection throughout the care trajectory.

Sophie Kuipers
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Committee Dr. ir. M. Melles
S.C.M Brand-de Groot
Company Amsterdam UMC
M. van Eick

