

INSPIRATION

VISION

Patient information pathways

CONCEPT

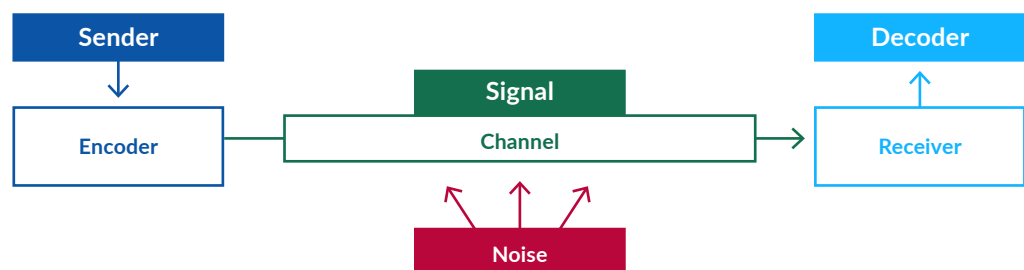
In the “Trusted Health Ecosystems” project we are creating a concept and a product vision for a national health platform of the future. This text is part of the overall concept which is published at www.trusted-health-ecosystems.org.

Understanding information transfer as a process

Many health information providers have good intentions. They strive to have a positive impact on the individuals health behaviour, assisting them in managing illnesses and making crucial treatment choices. However, in today’s digital age, a significant portion of this well-intentioned information fails reach its intended audience, who find themselves inundated in the ever-growing flood of information in the ongoing struggle for their attention. Setting up context-sensitive information pathways could thus offer valuable support and mitigate the losses resulting from scattered information.

When it comes to producing and providing health-related information, it is often assumed that this information is best transmitted from a sender through a channel to a recipient, who then comprehends the information and converts it into new

Depiction of the Shannon-Weaver model of communication (1949)



Source: The authors, based on Shannon and Weaver 1949.

* Trusted Health Ecosystems

knowledge. Once a message is transmitted, it can influence an individual's behavior and decision-making process. However, this sender-receiver model, originating from the 1940s, doesn't accurately reflect real-world practices. The process of acquiring knowledge is far from a one-time occurrence; rather, it's a complex and multifaceted learning process that is influenced by various factors.

One field that is dedicated to the complexities associated with acquiring knowledge and skills is education science. Pedagogy experts have long since questioned simple sender-receiver models and resisted approaches to learning that attempt to forcibly convey or "funnel" knowledge into learners. Instead, the field of education science sees learning as a process in which learners organize knowledge in their unique ways. The acquisition of knowledge and skills is never seen as a one-time snapshot, but rather as an ongoing, manageable process that takes place in equal parts on the cognitive and emotional levels. This process is best described as a learning path or information pathway, and it provides advice as to which information is likely to be needed at any specific moment.

*"Knowledge can never be transmitted as such from one person to another. The only way an organism can acquire knowledge is by constructing and configuring it for itself."
Ernst von Glasersfeld (1987)*

Selective information processing

Human attentional resources are limited. In other words, we do not consciously absorb and process all of the information that comes our way. In fact, to capture our attention, information must hold some relevance to our circumstances and correspond with the context in which we find ourselves. This principle holds especially true for health information, as patients go through various phases of illness over time and face shifting informational needs along the way.

These phases can be described in terms of an individual treatment pathway. The path often begins with acute care and an initial diagnosis, which usually prompts a patient's need for basic information about their condition. The next phase involves making decisions with regard to treatment and possibly also choosing a specialist for further care. During the rehabilitation or medical aftercare phase, patients typically shift their focus away from diagnostic and treatment procedures, and instead prioritize obtaining information and support on effectively managing and living with their specific condition.

The findings on the influence of different phases on selective attention can be related to the classical model of coping with illness. According to this model, when a patient is diagnosed with a serious illness, the first phase they enter is one of fear, anxiety and sometimes even denial of the diagnosis itself. This initial shock

often leads to anger, followed by despair and a profound sense of personal vulnerability. After passing through a process of inner self-negotiation, the patient enters the final phase in which they accept the illness. The phases described here, as well as the emotions associated with each phase, can play a significant role in how information is received and processed.

Health information is often generated with the aim of minimizing risky behavior and exerting a positive influence on individual health choices. In the quest to determine which information is important at what moment, one useful tool is the “Stages of Change” model used in the field of health sciences to understand patient behavior. These models postulate that people undergo a process of development involving several different stages on the path to changing their behavior.

Between the ideal and the reality

The stages of change models, commonly applied in the realm of health sciences, underscore the significance of employing a well-structured and process-driven approach to information transfer, particularly in the pursuit of promoting informed decision-making and enhancing individual health literacy. These models suggest that patients be offered only information that is actually relevant in each respective phase of illness, coping and care.

In reality, however, the situation is much different. Patients are often confronted with an overwhelming flood of information from diverse sources, each of varying quality. They navigate through medical consultations, explore search engine results, find themselves lost in information bubbles and social media echo chambers, read pamphlets from health insurance companies, and receive enthusiastic advice from friends and family. This usually takes places simultaneously and without any coordination.

“Searching for information on the internet is like asking for a glass of water and being served with a fire hose, all the while not knowing where the water is coming from.”
Michael Scholz (WHO) 2003

The uncoordinated provision and dissemination of health information as practiced to date lacks promise as a strategy to empower individuals in making well-informed decisions related to their health, particularly in light of the information overload prevalent in our contemporary digital era. In 2019, the German National Action Plan Health Literacy emphasized the need for establishing a systematic method of information management that spans the entire course of an illness. Following this thought, the provision of health information should be embedded into a structured learning pathway that meets patients’ needs, depending on the

specific situational and support context (see Discover more, search less – prototype of a national health platform).

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