

Chapter #21

THE INFORMATION DESIGNER ROLE ON HEALTH EDUCATION: PARTICIPATORY METHODOLOGIES TO CITIZEN EMPOWERMENT

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ABSTRACT

The authors, Design research experts, explore Design Thinking's holistic methodology in this article. This burgeoning concept is gaining recognition and application in various contexts. Their aim is to emphasize the importance of collaboration and interdisciplinary work, fostering interactions among individuals from diverse domains and merging specialized and practical knowledge. This approach cultivates a participatory culture and stimulates innovative solutions. In this article, the authors present a segment of research conducted by (Santos, 2020), focusing on health education message co-creation and Information Design's role in healthcare, enabling population autonomy. After an extensive literature review involving health, Information Design, and Design Thinking experts, the study examined the clinical analysis report model used by the Portuguese National Health Service. Through co-design involving designers, users, and healthcare professionals, the study developed a prototype for a new clinical analysis report, which is showcased as a successful example in this paper. In conclusion, there's an urgent need to reassess longstanding power dynamics in decision-making centers. The authors stress that citizens/users shouldn't be relegated to passive content recipients based on assumptions but should be integral to the co-creation process, right from the beginning. With this paper, the authors aim to empower all individuals as direct agents of social innovation in their daily lives.

Keywords: design thinking, information design, health message, co-creation design, visual literacy.

1. INTRODUCTION

There is no easy or definitive answer to the challenges of our age where environments are complex, as is the case with health or education. However, Design Thinking offers an integrative and flexible approach that makes it possible to identify, develop and deliver services that respond more effectively to the needs of the community and the individual. This approach requires existing systems in society (health, education, economy) to have the capacity to recognize and articulate the latent needs and desires of stakeholders, to involve a wide range of voices (mainly outside the system) and to work constructively with the different perspectives (tensions) rather than trying to identify one as the right one at the expense of the others, that they quickly begin to carry out small tests of the various hypotheses and possible solutions in the community that lives with the consequences of persistent problems, such as health, and that has more risks in solving them (Roberts, Fisher, Trowbridge, & Bent, 2016).

In this chapter, the authors, who come from the field of design, aim to highlight the importance of the participatory methodology of Design Thinking. This methodology originally emerged in their field of study but has increasingly been applied in other contexts. Collaboration and interdisciplinarity are crucial factors to foster a participatory culture, essential for achieving successful solutions. The interaction between specialized knowledge and insights from both experts and non-experts promotes knowledge expansion, innovative solutions, and a sense of integration. Designers play a crucial role in applying Design Thinking to complex fields like health and education. They foster collaboration, embrace diverse perspectives, and conduct iterative tests, contributing significantly to identifying, developing, and delivering services that positively impact population health outcomes.

To do so, a portion of a research conducted by the author (Santos, 2020) within the scope of their doctoral degree is presented. The study analyzes the significance of Information Design for the autonomy of the Portuguese population in the context of healthcare, applying the Design Thinking methodology. The aim of this methodology was to adopt a bottom-up procedure in which people and the community were at the center of the process. It was discussed that Information Design tools are crucial for enhancing individual awareness and autonomy, but active user participation in the design process is vital.

The central issue addressed in this research was the lack of population autonomy concerning their own health and how design could positively contribute to this situation. Presently, despite government measures aimed at a preventive healthcare model, it is often observed that the population still utilizes healthcare services in a consumeristic or reactive manner, not considering their health as a life goal to achieve. This behavior results in various negative consequences, both on a personal level and in terms of the services' ability to respond effectively. Additionally, this research revealed that current health education messages were not tailored to user literacy, neglecting cognitive needs at cultural and social levels, as well as emotional needs.

Following an in-depth literature review involving experts in the field of health, Information Design, and Design Thinking, case studies were analyzed, and workshops were conducted, incorporating observation, interviews, and co-creation methods to identify challenges in accessing and comprehending information. The study focused on the current clinical analysis report model used in the Portuguese National Health Service.

Through co-creation, involving designers, users, and healthcare professionals, the study successfully developed a prototype for a new clinical analysis report, which is showcased here as a successful example. In short, in this paper we will discuss the definition of Design Thinking as a human-centered innovation method which, due to its comprehensive approach, can be applied to any area and to which various actors with different skills contribute, and in which new ideas are transformed into new products or services. Through collaboration, learning, visualization and prototyping, it makes it possible to discover real needs, mediate the creation of knowledge and improve the user experience.

2. DISCUSSION / LITERATURE REVIEW

Several studies, conducting a comparison of different versions of the layout of the clinical analysis document, before and after user collaboration, highlight the importance of user-centered Information Design (Nystrom, Singh, Baldwin, Sittig & Giardina, 2018; Meroni & Sangiorgi, 2011; Zikmund-Fisher, Exe, & Witteman, 2014). Most of them conclude that this collaboration is crucial because patients who are involved in making decisions about their health are more likely to achieve better health outcomes (Hibbard, 2003 cited by McCarron, Arora, Courneya, St-Pierre, & Elmohee, 2019). The most effective methods are those that involve direct intentional experiences that represent reality or as closely as possible, and the more sensory the forms of interaction with the informational object, the greater the probability of learning from it. As argued by Edgar Dale in 1946 (according to Anderson n.d., as cited in Dale, 1969), the amount of information retained and remembered depends on the way it is received. Similarly, we also 'store' more information through what we "do" rather than what we "hear" and "read".

In this sense, it is necessary to use methods that make it possible to integrate citizens into the Information Design process. Design Thinking, being a democratic, holistic, collaborative, integrative and human-centered process allows citizens to be involved from an early stage in the process and not just as passive spectators.

3. INFORMATION DESIGN

Information Design aims to create clear, organized, and visually appealing documents that can be easily understood and used for effective action. This can be challenging in the health field where complex relationships and low health literacy can make it difficult for the audience to access the message (Espanha, 2009). When messages are designed with preconceived assumptions from the person creating them, and without considering the informational needs of the audience, the information can result in inadequate communication and visually uninteresting presentations that are not suitable for the intended target audience. This can cause information to be rejected for being difficult to understand, irrelevant, boring, irritating, or unconvincing. The negative impact of this difficulty can lead to frustration for users who may not know how to act on the information they have received, leading to a dependence on doctors or health professionals for decision-making on health management.

Assumptions of Information Design are fundamental to health communication messages, as they often involve changing behaviors and presenting strategies to incorporate new actions into daily life. By applying the principles and process of Information Design, the audience can be engaged with the message, perceive it, agree with it, think about it, remember it, and have the intention to act on its content (THCU, 2002).

4. DESIGN THINKING

4.1. Concepts and Principles

The increasing complexity and ambiguity of design and its associated problems have highlighted the importance of understanding the design process and methods. This has led to the emergence of the study of the nature of design problems. The Conference on Design Methods held in London in 1962 marked a milestone in the development of design methodology as a field of research (Cross, 2007). In the book "The Science of the

Artificial," Herbert Simon argues that design is a process aimed at transforming existing situations into preferable ones and that design can be carried out by anyone. To address complex challenges, it is often not about finding 'definitive' answers but rather about having the ability to 'transform existing situations into preferable ones,' as suggested by Simon (1999). In line with Rittel (Rittel & Webber, 1973), he argues that there is no definitive solution to design problems, only the creation of other situations that may be more or less satisfactory. In 1973, Horst Rittel and Melvon M. Webber coined the term "wicked problems" to refer to the complex, ambiguous, and unique problems that design faces (Rittel & Webber, 1973). These are problems that are not isolated, and in seeking to solve one, we discover others, requiring a more creative approach than science can offer. An approach to problems informed by design theories and methods places the emphasis on synthesizing information and ideas from various sources in the search for new and unconventional solutions (Roberts & al, 2016).

By placing design at the level of a criminal activity, American designer Victor Papanek argues that, in addition to persuading people to buy what they do not need, with money they do not have, satisfying only fleeting desires, the true needs of humanity are often neglected (Papanek, 1984). He proposes identifying the real needs of people by promoting a social and human-centered approach characteristic of the Design Thinking process. For this to happen, design must move from being done "for" people to being done "with" people (Thackara, 2005). The author goes further by critiquing design education and highlighting the holistic nature of the process. He argues that design education should not be limited to teaching design alone but security, pleasure, affection, understanding, autonomy, meaning, and acceptance are the main human needs (Curedale, 2013). Involving the people for whom design is intended and their experience in the process, human perception (Rittel & Webber, 1973; Manzini, 2015; Tschimmel, 2011 adds human value. The Design Thinking process is a democratic process that anyone can use (Tschimmel, 2011) because every human being is creative (Manzini, 2015).

"Design thinking," initially written in lowercase, denotes the cognitive process of designers, with a primary focus on the attributes of creative design. Since the beginning of the century, the concept of Design Thinking (now capitalized) has expanded to other disciplines and is now recognized as an organizational resource for innovation (Tschimmel, 2018). The origin of Design Thinking, while uncertain, is often attributed to Peter Rowe's book "Design Thinking," gaining momentum with the methodological approach of the renowned American design and innovation company IDEO (IDEO, 2015) and Stanford d. School. It is presented as an innovative process (Brown & Wyatt, 2010; Buchanan, 1992) with a human-centered approach (Cross, 2011; Brown, 2009; Lockwood, 2009), using collaborative design tools and methods. Therefore, some argue that it is unique to design and designers, while other professionals claim that it is a blend of methods borrowed from other practices such as business, marketing, and creative arts (Martin, 2017). Integrating the needs of stakeholders, the methods used create value for users and are capable of developing better solutions for social problems, taking into account what is technologically feasible and viable for the organization's or institution's strategy (Brown, 2009). It provides society with a set of tools that help achieve its goals with less need for investment, helping to create a society in which citizens take control of their lives and decide what matters to them (Blyth & Kimbel, 2011). By including citizens and considering their needs in the process, it has a fundamentally social character. For the process to be truly social and human-centered, there must be a culture characterized by a participatory mindset, in which designers value people as co-designers in the process (Sanders & Stappers, 2008; Manzini,

2016), trust the abilities of non-specialists (Kimbell, 2011), and do not see people merely as passive users or consumers.

Higher levels of interdisciplinarity are associated with a broader field of knowledge, skills, and abilities (West et al, 2003), promoting a higher level of cognitive stimulation within the group. The integrative approach of the process, combining contributions from various specialties with those of the public (Chasanidou, Gasparini, & Lee, 2015), provides the foundation for generating new ideas and better outcomes, creating a strong sense of ownership of the ideas resulting from the integrative and collaborative process (Szebeko & Tan, 2010). This characteristic of an integrative process transforms the role of the designer into that of a mediator (Manzini & Rizzo 2011; Buchanan, 1992), or even a "provocateur" (Manzini & Rizzo, 2011) who may be more promising in making new initiatives happen. Their way of thinking and decision-making, according to Nigel Cross, sets them apart from other professionals (Cross, 2011).

New spaces are emerging in response to people's constant need for creativity (Sanders & Stappers, 2008). Design Thinking not only helps create solutions but also shapes these creativity spaces and existing problems, making them visible and more understandable through new ways of creating change. The center of these complex problems, such as health, poverty, and education, embedded in complex systems themselves, where information is confusing, there are many stakeholders with different interests, and boundaries are non-existent or blurred, makes these spaces complex as well. Complexity is a defining characteristic of the Design Thinking process (Buchanan, 1992; Jones, 2014), and complex environments lead to changes in the process to adapt to the new context, giving it an adaptive character. Therefore, the focus should be on the process and not just the problem.

Design is not limited to the creation of new physical products but includes new process forms, services, entertainment, and new ways of communicating and collaborating (Brown, 2009). According to Brown, the growing interest in design is a consequence of the shift of economic activity in the world from industrial manufacturing to knowledge creation and service delivery. For this author, the Design Thinking process is exploratory, with many unexpected discoveries and disruptions, and it would be unwise not to attempt to discover where the paths lead. He believes that design cannot happen without constraints; to improve, it is necessary to make mistakes and accept them as part of the process (Brown, 2009; Cross, 2011; Curedale, 2013; Tschimmel, 2012). This approach reinforces the importance of self-reflection in the design process, advocated by Donald Schön, in which "doing" and "thinking" are complementary, one feeds the other (Schön, 1983). Through different methods (testing, actions, and surveys), doing extends thinking, and in turn, reflection feeds action and its results.

Understanding the social, cultural, and economic context that encompasses the problem is essential for its proper framing. Design Thinking has methods that offer a holistic view of the problem, rather than an individual one. We can compare Design Thinking to the value constellation model, different from the Fordist model of value creation in a chain. In Design Thinking, there are multiple sources of knowledge from an open and large-scale system (Freire & Sangiorgi, 2010), leading to a new and multifaceted approach. The participatory nature of the Design Thinking process questions "power" and reformulates the role of stakeholders. The design professional or researcher contributes to the process with expertise in methods and theories, while the community contributes insights from practice, its needs, and its implicit understanding of social and cultural dynamics. In this paradigm, the designer is seen as a facilitator, not a creator as in the industrial model or as a communicator (Buchanan, 1992) seeking to discover compelling

arguments through a new combination of words and images. The mediator or facilitator designer must simultaneously consider human needs, available resources, and the constraints and opportunities of the service or business, in other words, the designer must be both empathetic and analytical; rational and emotional; methodical and intuitive (Tschimmel, 2012). The designer should guide the project without becoming the center, without hierarchizing the process, and without bringing preconceived ideas or biases to the research process, using systemic thinking to consciously work across different areas and domains of design knowledge (Friedman, 2000). There is still no consensus on recognizing the key elements of the Design Thinker mindset; however, Dosi, Rosatti, and Vignoli (2018) propose a table defining a set of elements that are common to most of the authors studied.

The emotional conditions under which Design Thinking can thrive include tolerance for uncertainty and comfort with ambiguity, holistic vision, accepting and learning from mistakes, human-centered, empathetic, learning-oriented, abductive thinking, interdisciplinary, experimental thinking, and creative confidence. There are other characteristics not as commonly mentioned but equally important: risk acceptance, optimism, teamwork spirit, and openness to other perspectives. Given the variety of contexts and situations in which Design Thinking can be applied and the variability of its complexity, the relevance of these attitudes may vary from one situation to another. Researchers recognise the complexity inherent in the practice of design and the change from the paradigm that answered the question "what do we solve?" to the paradigm that seeks to answer the question "how do we solve it?", highlighting the Design Thinking process as a cognitive style (Kimbell, 2011) and in order to achieve success in the design process.

The Design Thinking process promotes innovative ideas, yet human beings have an involuntary resistance to the new, a consequence of the way they have been trained to see the world through analysis. When there is no analytical proof of the effectiveness of something innovative, or at least a track record that provides data for this analysis and the necessary emotional comfort we need, it becomes difficult to adopt "innovation". The methods used in the Design Thinking process, through an intervention that pays attention to both logic and emotions, favour this emotional comfort (logic) that we need to commit to something new, increasing the likelihood of commitment from the different players in the process and the success of the results (Martin, 2017). The great levels of complexity that exist in the context of problems such as health or education, while expanding the potential for opportunities and directions for design, also imply difficulties. The Design Thinking process, in addition to the risk of the process, requires the limited acceptance of results and development (Sangiorgi, Patricio, & Fisk, 2017), the ability to deal with different domains and specialities (Friedman, 2000), and the vast network of interactions that implies that when one suffers it affects the others unfavourably.

The characteristics of traditional object-orientated design (products, services or systems), seen as a specialist activity (Manzini, 2016) that designs objects for industrial production, do not fit into this reality. The focus has shifted from "objects" to "ways of doing and thinking", to the process of designing solutions to complex and intractable problems (Manzini, 2016; Cross, 2007; Brown, 2009). Through the application of Design Thinking, we sought to move away from the traditional design process and bring the citizen into the process, analysing, observing, involving, exemplifying, and in this case testing clinical analysis documents in order to provide an efficient response to the problem that meets the needs of the users.

5. DATA SURVEY AND ANALYSIS

5.1. 1st Step: Visual Analysis

In a first approach of our survey, visual analysis of the sample of reports was carried out. We aimed, at first identify visual factors that could affect users with low literacy and second, to establish guidelines for the design of health communication supports. For this study, 30 reports selected from the main laboratories from Porto (Portugal) district, were analyzed regarding design elements as: support, structure, and organization. The relevant issues found, including the absence of graphics and images, the use of technical language, and the presence of unrecognized symbols, act as barriers to the understanding of the information.

5.2. 2nd Step: Perform Tasks_Co-Creation Method (Workshop)

After analyzing clinical analysis reports, two workshops, each lasting three hours, were developed. The workshops consisted of five phases where participants, selected through a random sample of 12 participants each, in which we sought to integrate different genders, ages and literacy levels, were asked to perform tasks such as reading and locating information, brainwriting/sketching, organizing information spatially, and evaluating final results. This document, in which the participants had to carry out the requested tasks, simulated the presentation of clinical results of a fictional patient, where the values were intentionally outside the reference parameters, and patients were asked to suggest preventive measures to avoid the onset of the disease.

5.3. 3rd Step: Analyzing the Results

The concept tests, in which a document containing 3 intentionally altered values for this experiment was used, yielded the following results: of the twelve participants, only one was able to identify the three altered values; seven participants correctly identified the Total Cholesterol result (Particular emphasis was placed on cholesterol because this research accompanied a study by the Dr Ricardo Jorge National Health Institute on the prevalence of cardiovascular risk factors in the Portuguese population, for which cholesterol is one of the most important analyses); three participants misinterpreted results that were normal; two participants mentioned confusing the symbols ">" and "<", revealing to be a barrier to correctly read the results;

After this participation phase, the participants were asked some more incisive questions in order to gather more detailed information about their perceptions. When asked: "what should you do to prevent your Cholesterol value from rising?" five participants did not know what to suggest.

It was also observed that participants had difficulty keeping their gaze on the same line because there was no orientation in the text lines and mentioned being confused by the existence of two units of measurement for all outcomes. This was later validated by health professionals, who pointed out that the presence of two units of measurement, as well as not adding anything new, led to confusion and misreading on the part of both the public and the health professionals themselves.

5.4. 4th Step: Developing a New Prototype

Based on the findings, a prototype (figure 1) was developed to address reading difficulties and incorporate user responses into graphical elements. Specifically, the results were presented with guiding lines for horizontal reading, highlighting results outside the reference parameters with a gray background. Icons representing right and wrong, chosen by participants, were added at the end of each line. Information on health promotion was included, irrelevant units of measurement were removed to reduce result interpretation ambiguity, and text regarding the sample's nature (e.g., blood, serum) was adjusted to prevent confusion with analysis names. A legend was included to aid symbol comprehension.

*Figure 1.
New prototype detail.*

Resultado	Valores de referência	Status
51 mmol/mol	20 - 42	X
150 mg/dL	70 - 110	X
0,83 mg/dL	0,70 - 1,20	✓
281 mg/dL	>90 - <190	X
56 mg/dL	>40	✓
199 mg/dL	<115	✓

5.5. 5th Step: Testing a Second Concept Prototype (Increasing the Challenge)

The prototype underwent testing with users and health professionals, involving tasks similar to those performed with the 'original' report. At this stage it was considered important to include health professionals in analyses of the layout of the new document in order to validate the holistic and integrative nature of the methodology, which includes all those involved in the process. As a way to increase the difficulty and accuracy in verifying the participants' literacy, seven values outside the reference intervals were placed in this new report.

As a conclusion, all participants correctly identified all the values, except one participant who had doubts about one result, indicating a comprehensive understanding of the document. Some identified issues and improvement suggestions include: confusion caused by added health promotion information, potential anxiety caused by the presence of symbology according to health professionals, removal of irrelevant sample nature information, and inclusion of explanatory notes for interpreting "normal results".

This results and the evidence gathered allow us, in the context of this article, to validate the importance of adopting Design thinking methodologies. This study in particular and the data obtained could have a broader scope, if it weren't for the impediment of Covid at the time, which prevented the continuation of the project with a clinical analyses' unit.

6. CONCLUSIONS

This study allowed us to comprehend the crucial role of Information Design and Design Thinking methodologies as valuable tools in this specific context, thanks to their integrative nature. By co-constructing messages that fostered a strong sense of ownership and commitment, individual awareness and autonomy were enhanced, ultimately promoting informed decision-making regarding their health.

This study has confirmed that in order to enhance outcomes and develop effective health-related educational content, it is essential to work in collaboration with the public for whom the communication project is intended. To do this, it is necessary to bear in mind that a project of this nature cannot be based on isolated decisions, or decisions identified only by the designer or institution. Accessing people's direct experience and all the stakeholders in the process is a fundamental source of knowledge if the designer is to be able to respond successfully to the various day-to-day problems faced by ordinary users. In this increasingly aware scenario, it is imperative to re-evaluate the traditional design paradigm. Instead of viewing users as passive recipients of assumed content, they should be recognised as active participants in the co-creation process of health messages. Lastly, we emphasise that participatory methodologies that involve collaboration between users and designers result in integrated, retained, and memorable information, crucial factors in the educational environment.

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