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The citizen at the center of health decisions: From shared decision-making to the co-creation of new digital solutions

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ABSTRACT: The 21st century has been seen as the time of citizen-centered care, with efforts by the World Health Organization (WHO) going towards ensuring that health systems reverse the excessive and exclusively biometric orientation of recent decades. This reorganization of the paradigm requires that patient-centered care be a key dimension of quality in health, creating contexts that value cooperation between citizens and systems. In this relationship, the patient can no longer be seen as inactive, but rather as an element that can influence the entire process linked to medical care. In this paper, we explore the relevance of citizen engagement from a broad and integrative perspective. We begin this reflection with a discussion on the assumptions of Shared Decision-Making in Health that are being implemented in Portugal. Given its relevance, we expand this analysis to justify how citizen involvement is also highly relevant for the development of new information technologies. In this last point, we very briefly present PLAY-THE-ODDS, a project to co-create a communication tool between parents and children about hereditary cancer syndromes.

KEYWORDS: health, shared-decision making, ehealth, digital divide, co-creation.

1 INTRODUCTION

Although Patient-Centered Medicine is already a widely accepted reality, its implementation still lacks effective coordination with integrated health systems [1], [2]. This greater articulation is essential to ensure complete coverage of systems and an increase in citizens' quality of life [1]. In the context of current societal challenges in the world, the European Union has debated the need to take concrete action, developing greater research applied to action, with integrated health management models that involve the population [3].

In the same sense, in 2015, the WHO launched a guideline that demonstrates the impact of including individuals in health systems and the functioning of these systems in integration. In this document, the entity proposes the implementation of five strategies that are the basis for greater involvement between different health agents [4].

The first strategy is related to the empowerment and training not only of the citizen, but also of their family and other caregivers. This recommendation relates to the impact of the level of health literacy on the individual's experience as a patient, the cost associated with the use of health services, and the general health status of the citizen [4]. The second strategy is related to strengthening governance and transparency, especially on topics related to community engagement and increasing participation in health. The third strategy proposed by the WHO is related to the reorientation of the health care model. For the entity, local, regional and national health organizations must work together with communities to propose services, and debate how and where these should be distributed. The fourth strategy is related to service coordination. One of the main objectives portrayed here is the delivery of quality services, based on the correct mapping of health organizations, increasing the synergy between them and the citizen. Finally, the last strategy proposed proposes the creation and support of ecosystems that can promote the first four indications, so that there is real integration of health services and citizen involvement [4].

One of the barriers identified for the implementation of these strategies has been the "polymorphic nature" of health care and related institutions, continuing to discuss the definition of Patient-Centered Medicine [4]. Still, the various definitions in the literature seem to find themselves in the need to go beyond the characterization of the epidemiological profiles of the population, integrating holistic perspectives that incorporate individual needs and community proposals [5]. Shaw et al. [6] state that patient-focused healthcare implies the inclusion of citizen perspectives as the center of any decision, influencing the way in which the principles and visions of organizations are founded. Goodwin [5] describes integrated health care as "an approach to strengthening patient-centered health systems by promoting services that are designed to be implemented across the life cycle." Based on WHO strategies, this author also mentions that, at the base of these services, there must be "a coordinated multidisciplinary team to respond in different contexts and levels of care" [5]. Despite the recommendations, health systems and related institutions are among the most complex and interdependent entities in society, so that their full organization is difficult to achieve [7].

Without integration and organization at multiple levels, from primary care to hospital follow-up outside clinical settings, there are several aspects of health care that can compromise the health experience: patients may feel lost; necessary services may be delayed or even fail; patient satisfaction declines; and there may also be a reduction in the cost-benefit ratio [8].

2 THE PATIENT'S PERSPECTIVE AND SHARED DECISION-MAKING IN HEALTHCARE

It is from the Ottawa Charter and the Health Promotion movement [9] that Public Health practices acquired a more robust and assertive theoretical body to work on the "centrality of the citizen". According to the provisions, citizens must assume responsibility for ensuring the defense of their individual and collective health, through access, internalization and translation of important information. This will make it possible to change your less healthy behaviors, creating conditions to manage the onset of the disease.

To operationalize these concepts, the role of the National Health System among citizens has been reinforced in Portugal, through initiatives that seek to increase their participation and promote trust in the health care provided. These participation mechanisms were based on several concrete projects: the creation of an observatory to work on the effective use of health services, offering greater levels of satisfaction with the effective involvement of citizens; doctor-user communication channels were increased, with the creation of direct electronic lines for family doctors; complaints and claims became easier to present with institutionally formalized procedures; several mixed advisory boards were created, which, integrating users, health professionals and politicians, allowed the development of policies to support the management of health centers and hospitals [10]; and, to assess user satisfaction, several studies were carried out at health centers and family health units, contact points close to the population [11], [12].

Despite the initiatives taken to involve users, the European Observatory on Health Policies and Systems warns that citizen participation in health still "remains confined to the legislative references and intentions announced in the official documents and directives launched" [13]. This is also a problem reported by various Portuguese governments, and highlighted in the 2004-2010 National Health Plan. In fact, although legislation has promoted the activation of formal mechanisms for citizen participation in the SNS, in practice, the implementation of these mechanisms has fallen short of expectations [14].

In 2014, the Calouste Gulbenkian Foundation developed, with the support of the Portuguese Government, the theoretical foundations to implement a vision for healthcare in Portugal over the next 25 years. The report "A Future for Health" describes the relevance of working on the implementation and sustainability of multidisciplinary projects, characterized by citizen empowerment. Based on the active participation of society in cross-cutting aspects of health, seeking continuous improvement in quality and effectiveness, this vision calls for the development of a new pact for health [15]. This vision coincides, in fact, with the purposes of the WHO, which recommends that reforms implemented in the health sector be centered on the needs and expectations of citizens. The design, organization and functioning of health services must echo the voice of citizens, allowing the promotion of a more participatory democracy, as well as increased trust in decision-making and organizational structures related to health [16].

This is a perspective that consolidates health policy as a social policy, and assumes it as one of the rights inherent to the condition of the citizen and his participation [17]. The WHO proposes a complex and delicate construction around the concept of "citizen-centered health", which requires concrete measures to be applied at three levels: institutional, labor and individual. At the institutional level, this involves breaking down barriers in the system and transforming it so that it becomes more open, transparent and receptive to citizens, encouraging proximity and interaction. The work level applies to health professionals and the strengthening of their responsibility in transmitting information and knowledge, as an integral part of their routine functions. The last level, the individual, is completely focused on citizens and the need to have a more proactive and interventionist attitude, in terms of the objectives of maintaining good individual and community health [18].

Some authors draw attention to the difficulty in defining the concept of “patient-centered health care” [19]. This lack of consensus can lead to the implementation of different directives, different forms of organization and management, and weaken the sustainability and implementation of network measures. For this reason, the definition of the International Alliance of Patients’ Organization (IAPO) was chosen by the European Observatory of the World Health Organization to be the definition adopted for European countries. This definition states that patient-centered healthcare is an integrative and patient-conscious approach to multiple dimensions of health. This integration respects the values, preferences and needs expressed by the citizen regarding integration in care, access to information, communication and support for education. It is also important for physical comfort, help and emotional support, creating points for the involvement of family and friends, and support in the transition and continuity of health [20].

One of the bases for enabling citizen involvement in health, and enabling care to be centered on their needs, is through decision-making related to prevention, treatment and management in relation to a disease [21]. According to Elwyn [21] and O’Connor et al. [22], the sharing of health decisions between doctors and users, as opposed to clinical decision-making made solely by the health professional for his/her patient, is gaining great importance in the way health is regulated. The development of strategies to increase clinical dialogue between physician and patient has had an impact on the literature published in the health field [23]. Within this, Shared Decision Making in Health has figured as a pillar of patient-centered healthcare. Thus, patient participation in decision-making, programming, planning and execution of care has been identified as an added value for health outcomes, increasing the effectiveness of the procedures involved [24], [25].

Florin [26] states that looking at the patient as an integral part of the team has allowed for an increase in the window of opportunities related to the valorization of health, and that Shared Decision Making in Health can be an indicator of excellence for the quality of care provided. A systematic review that studied more than eight dozen randomized studies points to the success of Shared Decision Making in Health in terms of patients’ health knowledge, confidence in their decisions, as well as the level of patient commitment. The study also showed that more informed patients choose more conservative treatment options [27].

3 CITIZEN INVOLVEMENT IN THE CO-CREATION OF NEW TECHNOLOGICAL TOOLS FOR HEALTH

Adaptation to meet the strategies launched by the WHO has guaranteed new models of action, such as co-creation or co-production models in health [28]. In this type of model, the individual is recognized as an active element in the process of developing health activities, co-producing action plans that promote better care, but also enhance their learning and self-management mechanisms [29].

The use of clinical information systems, such as Electronic Health Records, has allowed for greater organization and easier implementation of these co-creation models. With the evolution of the characteristics of these records, and the implementation of personalized record systems, such as Personal Health Information Systems, the inclusion of people as an integral part of the decision-making process will be easier, as shown in the following figure. Respect for individual autonomy and ensuring that the patient’s needs are heard require mechanisms that facilitate communication between the different agents, including the patient. The so-called Individual Care Plans, which are recent information management tools built by the patient and their medical team, can become important platforms for the implementation of co-creation models in a real context [30].

New models have attempted to incorporate information technologies used by citizens into the health care implementation strategy. This attempt to centralize information, creating bridges between the individual’s various sources, is highly complex, but has been identified as the most effective way to ensure good health results and citizen empowerment [31], [32]. For this reason, it is crucial to understand the relationship between the population and the health information technologies they use.

3.1 E-HEALTH: AN OPPORTUNITY TO PROMOTE KNOWLEDGE

According to the literature, e-Health, e-Health or “online health” – “practice of using the Internet and technology associated with telecommunications to provide health information and services” [33] – is presented as a very effective strategy to increase the exposure of a topic such as health to audiences with little contact with the area, increasing the accessibility of information [34]. This concept, according to Espanha [35], is more than the search for information, and may include research into second medical opinions, alternative treatments, and different sources of information. It is an important area in which the entire set of services applied to communication and information technologies intervenes in the health sector [36]. This expands the scope of e-Health to more than just the use of the Internet, and, quoting Gil and Amaro (2010), "the inclusion of tools for authorities and professionals in the area" of health, for patients and for citizens" [37].

Given the potential of digital tools, this topic becomes closely related to the concept of "informed patient" – as an individual who is aware of his or her health condition, due to extensive research and information sharing on the Internet – used by Shilling [38] and by Henwood et al [39]. Based on an architecture of complementarity, e-Health tools form a cooperation network, allowing to ensure transversal information from different sources, and guaranteeing the development of services that are indispensable for primary health care and current hospital care. From hospital management tools, such as electronic records, to remote medical services, the incorporation of this technology has ensured innovation in products, processes and greater convenience for human beings [40].

As Espanha (2009) also points out, the main role of Health Communication can be divided into three levels: 1. Improving the provision of health services in acute and chronic cases. 2. Promote equity and greater socioeconomic balance between peoples, races, ethnicities and people with different disease histories. 3. Finally, improve Health Prevention and Promotion policies. The aim, as corroborated by Raeve [41], is to allow the storage and analysis of information produced in the health area, anticipating behaviors and improving the effectiveness of indicators for citizens [42]. Evidence shows that the context has and relies on mobile technologies to access the Internet, such as smartphones [43]. Searching for health topics is a common activity among those who have these means of communication. A recent Pew Research Center survey suggested that 62% of individuals who use smartphones have used them to acquire information about a health condition or topic [44].

3.2 E-HEALTH PLATFORMS: MOBILE APPLICATIONS

The rapid adoption of mobile phones and smartphones among populations more likely to have low health literacy is therefore an opportunity to improve access to information tools that can increase health knowledge [45]. e-Health interventions have the potential to be integrative rather than exclusive [46], in that they can simultaneously meet the needs of users with lower levels of literacy and be broadly acceptable to users with adequate levels of literacy in health [47].

Given this opportunity, new health information tools have become widely available, with the exponential development of mobile applications (apps) aimed at, among others, self-management of different diseases, nutrition or physical activity monitoring. Eng & Lee's research is an example of this: 240 results applicable to the Android platform and close to 600 applications for use on the iPhone were found when entering the term "diabetes" in their respective search engines [44]. Recent reports from the technology industry indicate that the use of mobile fitness and nutrition apps continues to grow in popularity, with more and more people willing to use these tools to help manage their health [49]. Many of these virtual tools are relatively affordable and are compatible with a variety of devices, including tablets, computers, and wearable technology. In this new concept that highlights the potential of communication and information technologies, m-Health is presented as an innovative concept designed for the search for information, and with capabilities to increase access to health services [50].

Many of these virtual tools are relatively affordable and are compatible with a variety of devices, including tablets, computers, and wearable technology. In this new concept that highlights the potential of communication and information technologies, m-Health is presented as an innovative concept designed for the search for information, and with capabilities to increase access to health services [50]. The growth of this market over the past 5 years suggests that health information tools are now available to a wider market, and that they seek to increase citizens' ability to easily manage health information [48], [51], [52], [53], [54].

3.3 A NEW THREAT OF DIGITAL EXCLUSION

The successful and sustainable transfer of intervention programs into citizens' personal routines and clinical practice has been inconsistent [55]. The creation of effective interventions of this nature is an opportunity that can easily be lost if the development of these technological tools does not include a strategy to incorporate the needs and preferences of target audiences with lower levels of health literacy [56].

Häyrinen et al argue that as the development of these platforms continues to evolve, the needs and demands of different users must be taken into account [57]. Similarly, Bickmore and PaascheOrlow argue that if organizations, researchers and companies work to reduce barriers related to access and use of this technology, when promoting the development of health information tools they should always have as a "point of reference " the person with the least health knowledge [58].

The struggle to make democratic technological development a reality, increasing the adoption of health information tools by people with disparate self-management capabilities, will make it possible to combat the emergence of a potential "digital divide". The development of mobile applications or web portals for inserting or consulting health data has another important implication, as it puts citizens' information at risk [58].

The literature indicates that this problem can occur mainly in two ways. First, citizens, by self-perceiving a high ability to access and update their health information, may share information without knowing it or share personal information that they would prefer to keep private. On the other hand, some individuals may be reluctant to admit that they have difficulty using these tools and, not wanting to ask for help, end up making mistakes that can compromise their personal information or choose not to use these tools [58].

Privacy and protection of personal health information vary across information sharing platforms, something that, according to some studies, is not known to most citizens [59]. For example, Electronic Health Records, usually belonging to the national health systems of each country, comply with specific laws implemented in their respective countries. An example often discussed in the literature is the HIPAA Privacy Act of the United States of America, which stipulates "safeguards" and specific rules on how a user's health information is treated and disclosed through specific electronic platforms. These measures help ensure that a patient's health information is not shared indiscriminately to third parties that do not share an agreement with a healthcare organization. These measures were developed to increase the trust and security of these platforms, so that the exchange of information can be carried out by all segments of the population, without any additional problems (Charles et al., 2015). Current regulations have expanded privacy coverage so that some companies are actually responsible for maintaining the privacy of each person's health information. However, we are talking about policies that are limited only to Electronic Health Records managed by health systems. As such, other health information tools, such as the aforementioned mobile applications, are excluded.

Trust is, according to some studies, an important factor in the adoption of new technologies [60]. However, existing security policies may be misinterpreted by citizens, especially those with inadequate health literacy, with a strong possibility of assuming that all health information systems have similar privacy rules and regulations [46].

The degree to which a citizen exhibits trust in institutions that may develop various health information technologies, such as health care organizations, government, information technology companies, and media outlets, may influence the likelihood of adoption of these technologies and may be associated with their level of health literacy [59].

In one of the first studies on the subject, published in late 2016, Mackert et al. showed that US citizens with low health literacy were less likely to use health information tools, such as mobile apps and web portals, or to perceive their usefulness or usability, understanding that what is disclosed on these platforms remains private and confidential. security [46].

4 CITIZEN INVOLVEMENT IN THE CO-CREATION OF NEW TECHNOLOGICAL TOOLS FOR HEALTH: THE PLAY-ODDS PROJECT

About 10% of all cancers may be caused by inherited genetic changes. Hereditary cancer syndromes in families can be identified by genetic testing. A positive test result means that a family member has a higher than average risk of developing certain types of cancer over their lifetime (National Cancer Institute, 2022).

Maintaining open communication over time about Hereditary Cancer Risk (HCR) is crucial for the psychological adjustment of families affected by this condition. However, families have difficulties regarding how, when and what to communicate to their children regarding the genetic risk of cancer. The literature recommends disclosure appropriate to the child's developmental stage by an emotionally stable adult parent in possession of the genetic information in order to be able to answer any questions that may arise (Metcalfe et al., 2008). However, parents face difficulties during the process and ask for support and guidance in family communication. The roles of genetic health professionals vary in terms of providing guidance to these parents, depending on legislation and differences in syndrome specialties (Young et al., 2020).

Researcher Werner-Lin (2018) highlights the importance of individual emotional stability, the relationship between the parental dyad and communication with health professionals as determinants for a good disclosure of syndromes to children. However, families and genetic counselors reported the need for materials to support them in this process. In the absence of available resources to facilitate parent education or empowerment for open and developmentally appropriate communication with their children, both healthcare providers and parents are calling for robust supplemental tools to assist them in this process.

PLAY-THE-ODDS is part of a line of research at the Psychology Center of the University of Porto and funded by the Foundation for Science and Technology in Portugal, and aims to meet this need. Based on scientific research and using participatory methodologies, PLAY-THE-ODDS brings together people with hereditary cancer syndromes and their families, genetic counseling specialists, psychologists, communication designers and gamification experts to, together, co- create solutions that promote greater involvement of end users in communicating about these syndromes with their children.

In this sense, this project conceptualized 4 co-creation workshops. Over the course of four workshops, participants were divided into four groups, each dedicated to a specific dimension according to the determinants listed by Werner-Lin (2018): a) emotional self-management; b) parental dyad; c) patient-professional communication; d) parent-child communication.

These sessions were prepared with Design Thinking tools and agile methods to best collect the positions, opinions, comments and results of the collaboration of all participating voices. Given that decisions would need to be made on the designed solutions, digital voting software was used so that the group could move forward with the decisions that received the most votes.

The results of this project are being published in different scientific articles, but we can indicate that, in concrete terms, the following steps were taken:

1st Session: Identification of needs related to each of the groups under analysis

In this session, each group received information about evidence published in the literature in scenario format. This scenario characterized a persona, i.e., a fictional representation based on real data, and was the starting point for the group to discuss the main difficulties experienced in each of the points mentioned by Werner-Lin.

After reading these scenarios, each group filled out an empathy map that could best characterize each of these personas. An empathy map or empathy map is a Design Thinking tool that allows us to put ourselves in someone else’s shoes, and imagine the context in which a person lives, what they think, what they feel and what they say in relation to a given topic. It also allows us to reflect on the main pains and anxieties of a group of people.

A list of needs felt by the persona was added to the empathy map. Each group presented their list to the assembly made up of the 4 groups. Everyone, without exception, used digital software to vote on the needs they considered most important to resolve.

2nd session: Ideation

The second session was dedicated to the development of ideas. After identifying the priority needs to be resolved in each of the groups, participants were encouraged to think of solutions to solve the problem with the most votes on each of the lists in each group.

For the ideation exercise, the “Crazy 8s” tool was used, which we call the Idea Generator. This exercise puts participants on a fast, agile and individual journey, in which each one has to think of 8 different ideas in 8 minutes. Ideas can be simple, complex, easy to implement or difficult to achieve. The exercise involves thinking about different innovations without barriers or conditions.

After this exercise, the members of each group had time to present their solutions internally. The objective was to identify 4 solutions that could respond more effectively to the priority need identified in session 1.

At the end of this discussion, each group presented the 4 chosen solutions, and the assembly voted electronically on the solution that should proceed to the next session.

3rd session: Development of solution functionalities

This session was dedicated to characterizing each of the solutions that had received the most votes in the previous session. The “Mind Map” was the tool used to map and describe the priority functionalities that each solution should have.

4th session: Integrating solutions into a single response

Given that we wanted to respond to the 4 elements announced by Werner-Lin, it would be pertinent to integrate the solutions that the groups thought of individually.

In this session, it was decided to discuss which solution would allow the remaining solutions to be integrated more easily. From there, each group adapted their solution to be integrated into this more comprehensive solution.

Figures 1, 2 and 3 describe some of the steps if this process.

Fig. 1. Participants of the Play-The-Odds project working in a multidisciplinary context

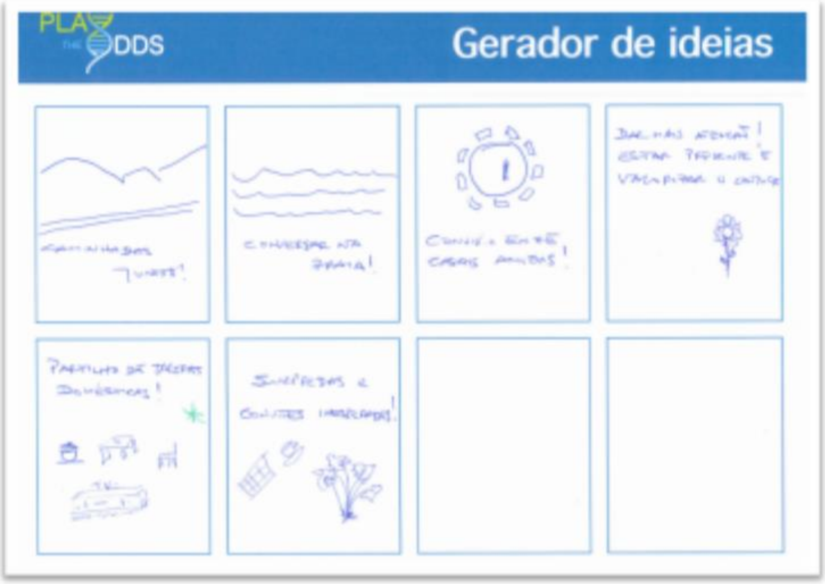

Fig. 2. Example of the "Crazy 8s" template, called Idea Generator in our project, for identifying solutions

Fig. 3. Example of a template used to map solutions on a single platform

This was a project that gave a voice to citizens, families with syndromes, geneticists, researchers and other members of civil society. Despite being logistically demanding, every participatory experience ensures the motivation of researchers and end users, allowing the creation of more and better evidence.

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