Popularizing Terminology Using Social Networks: Keeping Citizens Informed About Value in Health Care (Short Paper)

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Abstract

In the context of the creation of the first Portuguese Atlas of Health Variation (PAHV), we associate a linguistic resource to the Atlas in the form of a terminological glossary. In this article, we will present the interdisciplinary contours of this project, in which the fields of Terminology, Literacy, and Health Economics meet to design a collaborative product with two components. One is geared toward experts in the field of Value-Based Health Care. The other is an approach that considers the low literacy level of citizens who are not experts in this field and therefore leads to thinking about adapting terminology content for popularization and dissemination through social networks.

Keywords

Concept, terminology, popularization, health literacy, health economics.

1. Introduction

In this article, we will present the interdisciplinary contours of the project PAHV, the first Portuguese Atlas of Health Variation, in progress, in which the fields of Terminology, Literacy, and Health Economics meet to design a collaborative product. The PAHV is aimed at a diverse user community ranging from experts to non-experts in the field. It may be consulted on a digital platform by economists, managers, health professionals, students, or any citizen wishing to obtain more information on variation in Health Care in Portugal.

In this paper, we enact how we apply terminological and literacy strategies to the domain of health economics in practice to empower citizens and promote their informed participation in society. The importance of more citizen engagement [1] has been recognized and strengthened in the Lisbon Treaty with the European citizens' Initiative and several documents and political declarations, such as the Commission's contribution to the Sibiu Declaration[2] for a new strategic agenda for the EU 2019-2024.

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[2] https://www.consilium.europa.eu/en/press/press-releases/2019/05/09/the-sibiu-declaration/

Citizen engagement values the right of citizens to have an informed say in the decisions that affect their lives and emphasizes the sharing of power, information, and mutual respect between government and citizens. "Citizen science and science engagement, more generally, is an ideal means to democratize science, build trust in science, and leverage the vast societal intelligence and capabilities to conduct excellent research and innovation" [1] (p.5). Developing the PAHV aims to help increase the value of the used healthcare resources. Contributing to optimizing value for the whole population, i.e., ensuring that the tight people reach the right service [2].

In this context, we decided to associate a linguistic resource to the Atlas as a terminological glossary. *Waste*, *variation, unwarranted variation, overuse,* or *value* are some terms used in Value-based Health Care. A linguistic resource with two components is proposed to ensure that all types of users can understand the terminology associated with the PAHV. One is geared toward experts in the field, with a scientific approach to the definition of terms. The other approach considers the lower literacy level of non-experts' citizens in this field. This last component is developed to popularize the terminology, using discursive strategies to simplify the language and contextualize the use of terms. This component will be disseminated through social networks to keep citizens informed about the value in Health Care.

In general, this project aims to develop a culture of responsible and transparent health care, using different types of terminological definitions to access health economics concepts.

2. Portuguese Atlas of Healthcare Variation (PAHV)

The broader framework of this work is to develop a data-driven platform to monitor geographical variation in healthcare in Portugal. This project gathers a group of researchers that are already collaborating, in partnership with Oxford Triple Value Institute (United Kingdom (UK)) and Academia VBHC (Brazil), to estimate and discuss the impact of unwarranted geographical variation in the Portuguese National Health Service (NHS). The fundamental question we are trying to address is, "Does the place of residence influence the use of healthcare services?". Answering this question will allow the development of health policies that address specific population needs.

Aligned with worldwide initiatives, with over a decade, that have developed data-driven atlases that inform unwarranted variations in healthcare provision and outcomes [3]. Value for Health CoLAB led the initiative to gather a group of national and international experts in Health Economics, Public Health, Medicine, and Data Science to potentiate earlier efforts from Portuguese researchers to study variation in healthcare.

The vision is to connect Portugal to a worldwide community of researchers and decision-makers by developing intelligent monitoring tools for geographical variation in healthcare based on national health data (in England [4], Australia [5], or Spain [6]). Their work is highly supported by research activity, academic teaching, and communication. Such tools allow a human-driven evaluation and reflection of health policies and services that reflect on better outcomes, regional equity, and sustainability, incentivizing policymaking based on evidence. Moreover, we aim to involve citizens, pushing for a culture of transparency, participation, and responsibility.

This project includes identifying and developing methodologies and tools that link to the European and international research and sustainability policy framework, such as EU Citizen Science policies and the UN Sustainable Development Goals (UNG 3, 4, 9, 10). We reflect on ways to support decision-making processes and make established information flows efficient, especially considering the opportunities and challenges of digital transformations, to facilitate the dissemination of citizen science-based approaches.

3. Terminology resource supporting the PAHV

This resource will be presented as a terminological glossary describing the terms used in the framework of the PAHV. The objective is to create a linguistic resource whose relevance lies in being an instrument that facilitates communication [7] in European Portuguese within the scope of value in health. We will maintain linguistic diversity, including the Brazilian Portuguese variant, whenever the

term differs from European Portuguese. To make this terminological resource a multilingual communication tool, we will include the equivalent terms in English, French, and Spanish.

Its function will be:

- provide access to the Value-Based Health Care (VBHC) terms that underpin the atlas creation;
- facilitate the understanding of the concepts using the methodology of terminological popularization;
- promote the usability of the terms among citizens through clear language, contextualized examples and without conceptual ambiguity.

This resource will be disseminated in several ways: through the printed-based PAHV; through the project platform linked to the PAHV; through social networks aimed at the general public; through the multidisciplinary and collaborative platform for health literacy UNLOCK (ENSP-NOVA).

3.1. Terminological data analysis

After having previously analyzed the information needs of potential users, we organized the structural requirements of the resource. Then, following the methodological principles of Terminology science [8], [9] we identify the terms to be included in the glossary. As a relatively new specialty area, the fundamental concepts of Value-based Health Care are estimated to be around fifty. This is the first terminology work developed for European Portuguese in this field.

For this task, we use other similar materials in foreign languages that present a collection of terms and their respective descriptions as a basis for comparison. In particular, we have consulted works sources in English, French, and Spanish. This comparative work allowed us to define the basic nomenclature of our terminology resource. The next step was establishing a table of equivalents based on English, French and Spanish terms to identify the terms used in European Portuguese.

From here, we describe the concepts [10], creating a version of the definitions aimed at specialists in this field, supported by reference sources[3]. The result is to propose two versions of the same definition: one is a standard terminological definition, and the other is a concise definition aimed at a clear perception of the concept, supported by additional contextual information, as well as by concrete examples to increase the global comprehension and the use of the terms.

3.2. Popularization of terms

Knowledge units, concepts are not grasped by everyone in the same way due to each person's knowledge level. So, we will use the terminological popularization [11] strategy, which consists of simplifying the descriptions of concepts [12], [13] and using plain language [14] techniques, to make them understandable to everyone, including those citizens with a lower literacy level.

To support and make the popularization process effective, we will associate each concept with an example that helps contextualize the term's use. This sociocultural contextualization component has an illustrative function that promotes greater understanding, removes ambiguities, and allows adherence to reality. In this way, we improve access to understanding and enable the appropriate terminology in the health economics domain related to the Portuguese Atlas of Health Variation.

Starting from the work of popularizing the terms, we used literacy techniques to recreate a conversation scenario that simulates a chat whose group members naturally dialogue about health economics concepts. This idea supports the achievement of the goal of increasing health economics literacy.

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4. Increase literacy on health economics

Health literacy is recognized as a key determinant of public health. It has become a key issue for public health at the level of international health policies (WHO, UN, EU) and at the national level in member states (DGS Portugal). Health literacy involves "an individual's knowledge, skills, motivation and ability to identify, understand, evaluate and use health information when making decisions in the contexts of health care, disease prevention and health promotion to maintain or improve quality of life over the life course" [15].

The last study to evaluate the health literacy of the Portuguese population was carried out within the scope of the Action Plan for Health Literacy 2019-2021, and framed in the European consortium Action Network on Measuring Population and Organizational Health Literacy (M-POHL), between 2019 and 2021 [16]. This assessment was obtained by applying the HLS19 population survey. It was organized by the M-POHL consortium and carried out in fifteen Member States of the European Region of the World Health Organization [17].

Results from the HLS19 application in mainland Portugal show that 3 out of 10 people have low levels of health literacy [16]. The results suggest that the tasks of "navigating" the health system are the most challenging when it comes to developing people's health literacy skills. The study points to the need for the design and practical development of health literacy interventions focused on groups of individuals, such as women, the elderly, the unemployed, people with lower economic capacity, and people with lower levels of education. The results recommend a strategic focus on actions to improve health literacy for health promotion, disease prevention, health care, and health system navigation.

Moving in this direction, we think that by having the knowledge, skills, and confidence to understand and evaluate the many different ways of thinking about health-related economics concepts, citizens can better develop independent ideas, make decisions, and participate in issues related to value in health [18]. They also become better able to understand common economic topics and use terms to help them participate in conversations with economic content.

To do this, we applied a methodology of popularizing the terms to facilitate understanding the respective concepts. This literacy action will have an impact on improving communication, thus contributing to good health and well-being (UNG 3), on health education (UNG 4), empowering citizens to self-manage their health process with informed decision-making, and on health rights, promoting equity (UNG 10).

5. Conclusion

The purpose of this article is to describe how to promote better understanding and communication between the different stakeholders working in value in Health, whether they are specialists, non-specialists, or simply ordinary citizens. We do not intend to create an extensive resource but instead a concise compilation of terms and their corresponding concepts useful to public and private decision-makers, students, researchers of health economics and related fields, and academics in other fields. Nor is it intended to be prescriptive or limiting, but rather to stimulate discussion and debate where differences remain.

With this work, we have also proven that combining interdisciplinary methodologies can result in an interesting new research perspective. We combine the methodologies of Terminology with those of Health Literacy to create linguistic resources adapted to various audiences within the framework of the PAHV.

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