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EXTENDED ABSTRACT

# P1

# Value-based healthcare: How can data be used by the Portuguese healthcare sector to foster clinical trials?

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## Introduction

Due to challenges in the healthcare sector, the value-based healthcare (VBH) approach emerges has an alternative to the traditional health systems. Also, the way the participation of patients and other involved in the healthcare ecosystem in clinical trials is in need for more understanding [1,2].

So, there is the need to consider how health data is being managed in Portugal and Europe. Therefore, in European Union, the management of health data through a common health data strategy to all the EU members is being discussed [3]. As VBH aims to shift the focus to be more patient-centred, the implementation of such a strategy ideal since it aims to "make it possible for citizens to exercise their right to access their health data across the EU" [4].

This study aims to analyse how the entities involved in the healthcare ecosystem are collecting and managing data from patients to implement a national VBH strategy, while promoting the involvement of patients in clinical trials.

## Methods

Literature search using SCOPUS and ISI Web of Knowledge. Semi-structured interviews with people involved in the development and implementation of VBH' strategies in Portugal were undertaken.

## Results

First, VBH is a new management formula that is important for Portugal. It can be said that Portugal is not in the leadership in terms of VBH projects but is giving significant steps to the development of projects of this nature.

Second, there is a huge difficulty to efficiently collect data from patients and other elements involved in the healthcare ecosystem [5]. The results also confirm that patients still fear what the data is used for. There is a lack of investment to foster the collection and use of data as well to promote participation in clinical trials. Also, it is difficult to coordinate processes and create a general strategy to collect, manage and use data between different stakeholders of the ecosystem [6]. Lastly, the participation in clinical trials in Portugal is rising, but, while comparing to other European countries the number is still low [7].

## Discussion and conclusion

Currently, data is not being used properly to foster clinical trials, placing the patients as the centre of service provision. Although a national platform for the registration of clinical trials has been created [8] its use is not user-friendly and has associated troublesome processes. Actors involved in the healthcare ecosystem need to align goals to develop a VBH strategy that includes collection and share of data (processes and outcomes) from clinical trials [9,10].

There is the need to develop new ways to collect and manage data from the stakeholders and find ways to share the information among the actors to foster innovation and patient participation, What is known is that, in Portugal, patients still fear to engage in clinical trials, because there is the stigma that clinical trials will not succeed and can harm those involved [11]. Furthermore, the path towards VBH has the need for a commitment by all participants, a robust ethical and legal framework and a culture of innovation and collaboration where all participants are able to reuse high quality data in all aspects of healthcare, from planning to clinical trials, as well as in clinical decision making and in primary care [12].

**Keywords:**
alue-based healthcare, clinical trials, data management in healthcare

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In terms of social implications, it was possible to conclude there the is the opportunity to develop a system where the information from patients can be collected and used to foster research and innovation in the healthcare sector. In terms of research implications, this work can serve as basis for future research to reformulate health information systems, from the collection until how data is shared among different actors of the healthcare sector.

In terms of limitations a limited number of interviews was carried out and it does not include any patient association representative. The qualitative nature of the study can also be considered a limitation.

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