
Participatory Design as an Approach for Public Engagement in Health Policymaking in Portugal

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ABSTRACT

Improving public participation in the development of Portuguese health policy requires an approach to enable public to participate in a more equal and reciprocal partnership. Although the Portuguese State highlights the importance of encouraging public participation to address national problems, the National Health Council reports that public participation in health matters is limited. This brings the question of how does the current Portuguese health policymaking process promotes outcomes that address all key stakeholders needs? This paper presents two case studies where design approaches were used to enable a range of people to participate in health and care innovation. The paper discusses the importance of participatory co-design methods to enhance public participation in health innovation in Portugal. It highlights reflections for a collaborative model as an enabler for healthcare innovation.

Keywords: Design for policy redesign, Participatory design, Public participation, Innovation in the public sector

INTRODUCTION

Over the last decade, design has increasingly been engaging a range of stakeholders such as policymakers, citizens, people living with chronic conditions and others to support policymaking and service innovation in the public sector (Bason, 2014). In addition, design research within healthcare context has made considerable efforts to engage people living with chronic conditions and healthcare professionals in processes to address healthcare improvements (Neves et al., 2021). Involving public participation in real matters is specially important when designing for change. This paper is part of a master study whose objective is to enhance public participation in a more equal and reciprocal partnership between health policymakers and citizens in Portugal. This paper discusses two case studies that sought to engage policymakers, people living with chronic conditions, citizens and young people in health and care innovation processes (Lee, 2017; Sonja et al., 2021). In this paper, we discuss the importance of participatory co-design methods to facilitate public participation to happen in health policymaking.

A BRIEF INTRODUCTION TO HEALTH POLICYMAKING IN PORTUGAL

Despite the efforts to legislate public participation in health policymaking process, the ability of Portuguese government to meet this goal has clearly been challenging (Simões et al., 2017; World Health Organization, 2018). Since 1974, Portuguese society has shifted from a dictatorship to a more democratic regime (Português, 2005). The health policymaking process has been the responsibility of the government and the regulation, assessments and audits, planning and management of the National Health Service (NHS) has been the responsibility of Ministry of Health. In other words, the government is responsible for the formulation of health policy and decision-making and the parliament has the role of overseeing it. The Regional Health Administrations (RHA), are responsible for implementing the national health policy at the regional level and coordinating health care (Simões et al., 2017). But there are significant gaps in the linkage and implementation of plans at national, regional and local levels, as well as in their monitoring and evaluation (World Health Organization, 2018). The principles of the Constitution of the Portuguese Republic are based on ensuring and encouraging “the democratic participation of citizens in solving national problems” (República Portuguesa, 1976). In addition to this, the Basic Health Law (Assembleia da República, 2019) also claims that the State should promote people’s participation “in the definition, monitoring and evaluation of health policies.” Despite the fact that the Portuguese law states public participation as a requirement to policy, decision and evaluation-making process, the World Health Organization (WHO) reports that public participation as a National Health plan is still undervalued. Think for example, in the last decade evaluations on the quality of healthcare in Portugal (OECD, 2015) reveal that Portugal must improve relations with patients to involve them in decision-making. Additionally, the Portuguese government published in 2019 the charter for public participation. This is a Law that seeks to promote the participation of people in policy decision-making. Nevertheless, the National Health Council indicates that this Law has never been regulated, and the lack of regulation prevents its application. What this suggests is a need to create tools and mechanisms that promote participation (Conselho Nacional de Saúde, 2020). For this to happen it is necessary to create tools and mechanisms that promote public involvement and facilitate their understanding and means for participation to happen. Policymakers recognize that the issues of public participation in health policymaking need more attention, in particular when people’s participation is considered the driving force in responding to real matters of healthcare concerns. What this shows is the need to learn from public participation to understand how currently policy is developed and implemented and what are the results produced and how they benefit from local populations, and can be replicated at the national level. This paper now presents two case studies to discuss how design might offer a fresh approach to health policymaking process in Portugal.

DESIGN FOR HEALTH POLICYMAKING

Governments are under a tremendous pressure to create more effective ways of delivering healthcare services. Improving the effectiveness of policymaking has been discussed as a way to address the concrete social needs (Conselho Nacional de Saúde, 2020). In Europe, policy reforms shows the importance of decentralizing which is the transfer of powers and responsibilities from central government to regional and local level as an effective way to improve service delivery. In doing so, governments are involving public participation in decision-making. Although the Portuguese National Health Service (PNHS) follow this view of decentralizing and has autonomy to manage health organizations, the regulation, control, monitoring and financing of the public health system appears to be the responsibility of the central administration (Simões et al., 2017). This situation brings delay in the effectiveness and efficiency of the management of resources and services provided, which should be created through proximity between citizens and local entities, allowing for a more effective evaluation and decision, responding to local specificities.

According with Bason (2014) design for policy has been considered an important resource for government by engaging design tools for public sector reform and service innovation. Design is providing a range of research tools to probing and rapid prototyping as well as visualizing a range of complex data in powerful ways that are helping policymakers to better understand where the problematic issues are located. In doing so, the policy process is changing, and design can be seen as a useful approach to improve policymaking and for public sector reform (Bason, 2017). In the following section, we will show how design as an approach has been working in practice on Case Study 1 – looking how to involve citizens in health policy and in Case Study 2 – looking how to engage citizens and practitioners to understand what are the difficulties that young people face when back to work after they had an accident.

DESIGN WITHIN INNOVATION LABS

In 2013, the European Commission developed an action plan for design-led innovation, which views design as an approach for creating innovation within the policy process. This plan reported that “a more systematic use of design as a tool for user-centered and market-driven innovation in all sectors of the economy would improve European competitiveness” (European Commission, 2013). Following this, several countries in Europe have been using design within innovation labs as a public space to discuss issues of real concern to their governments. Although the labs have been working at national and regional context, design practice has become more actively involved to identify and tackle local issues in order to make change (Bason, 2014). This brings the question of how designers have been working in the context of health policymaking? The figure below (see Table 1) provides details about the two Case Studies involving design methods for health sector improvement.

Table 1. Design within innovation labs: two case studies.

	Project	Ethnographic	Workshops	Prototype	Validation	Findings
Nesta	Case Study 1		Co-creation	Issues and recommendations	Workshop	Implement 12 recommendations
MindLab	Case Study 2	Interviews		Issues and recommendations	Interviewed	Adjustment of administrative procedures

Case Study 1: Looking How to Involve Citizens in Health Policy in Scotland

Nesta is an independent UK government funded innovation agency to create long-term innovation in England and Wales. Recently created the Health Lab to explore how the health system can be better designed by providing greater social support and enabling people to live with conditions for a longer period (Nesta, 2022).

Our Voice Citizen's Jury on Shared decision-making, Scotland project uses innovative participatory approaches to public engagement to be used by the Scottish government by engaging participants with the purpose of identifying good practice, innovation, identifying barriers, risks and challenges to participation. The first stage was the selection of the public to participate: those best suited; at what stage of policy making do they participate; and what are their limitations. They are a small number of people who participate for a short period addressing issues such as, improving health and social care through involvement and participation. Citizens' juries were created for the purpose of generating a set of recommendations. The group met to define the questions that were then developed in workshops where stakeholders were involved. Facilitation methods were used in these workshops that included conversational and visual tools, with the intention of promoting reflection and aiding deliberation. Participants had access to brief presentations from experts and asked questions, after which issues and recommendations were identified to be shared with policymakers, who committed to implement 12 of the 13 recommendations presented (Sonja et al., 2021).

Case Study 2: Looking How to Engage Citizens and Practitioners to Understand What Difficulties do Young People Have When Back to Work After They Had an Accident

MindLab, established in 2002 in Denmark is an intergovernmental innovation lab, its goal is to create innovation within government by creating new and better solutions for citizens. They are dedicated to working on societal challenges of a complex nature, through relationship building by sharing the power of decision-making with stakeholders, and through experimentation, giving relevance to the ongoing process by taking into account that change and failure are inevitable (Prehn, 2015). MindLab is not dedicated to developing policy, but rather uses design methodologies to coordinate project teams, which include ethnographers, designers and policy experts. Helping to

contour barriers of complex policy systems by directly engaging the needs of users through co-design methodologies. Prototype to produce workable solutions and communicate them to policy-makers for them to decide whether to implement (Council, 2013).

In Denmark's MindLab project: involving citizens and business in problem-solving, the objective was to understand the difficulty of young victims of work accidents in reinserting themselves in the labour market. The first phase was ethnographic research to understand the issue. In the second phase the MindLab team, together with members of the Danish National Board of Industrial Injuries (NBII), visited young people who had suffered work-related accidents, and with the results obtained from the interviews, ideas were generated that were later adjusted in other meetings with the young people. From this project resulted, the need to adjust administrative procedures and the need to improve communication. MindLab contributed with this project to the strategy of reducing the administrative burden in Denmark (Lee, 2017).

THE ROLE OF PARTICIPATORY DESIGN

Participatory design values are based on the social and rational idea of democracy which advocates that those affected by design changes should have a say (Ehn, 2008). Within the context of Portuguese health policymaking, there has been a lack of clarity about how to better support public participation to make a more equitable contribution to the policy process. Based on the analyse developed on the two Case Studies, it became clear to us that Portuguese health policymaking requires particular attention to public participation as not been just those who are better suited but those who have experience such as patients, health professionals, municipality officials and policymakers. Approaches to participation seems to offer opportunities to generate ideas and develop prototypes as a way to develop more useful and desirable policies. Improving the quality of healthcare, creating policies with citizens by sharing responsibilities and increasing transparency, cohesion and equity (Conselho Nacional de Saúde, 2020).

The most common form of participation in Portugal is government elections in every 4 years. However, this is no longer enough. Improving health policymaking in Portugal requires understanding the real problems from a diversity of perspectives, this only happens if citizens are included in the policy decisions that concern them, taking into account their knowledge and experience. It is consensual that citizens need to be involved in the decisions that affect them, the best way to do this is still undecided (Enserink and Monnikhof, 2003). Although there are some public participation tools, such as digital ones where citizens can give input on issues that are under public discussion (República Portuguesa, 2018), however, participation in Portugal is very low and in the health sector it is even lower, in addition, the existing participation is not available for other people to see, nor is their evaluation to check if the contributions were taken into account by policy makers, in that there also exist inquiries done to patients on issues related to their health, but also of these there are no published results. Design can be

seen as a facilitator in helping to understand technical data that are complex to understand. Think for example, Case Study 2 where young people did not understand the content presented to them and were asked to respond, but also in making policy more transparent by demonstrating the outcomes achieved from processes as well as identifying the difficulty of bureaucratic processes and exploring processes to simplify them and as a means to involve stakeholders.

In Europe, design is already used to create solutions with people and not just for people with the intention of involving stakeholders in the policy making process in order to bring legitimacy (Enserink, 2000), to create qualitative evidence to help policymakers create more useful and desirable policy, thus creating more democratic systems (Kimbell and Bailey, 2017). It is also relevant to realize that these case studies are not only implemented at the national level, many of them happen at the regional and local level, this is fundamental to understand the problem from a bottom up perspective, that is, to understand the implementation of policy from the bottom up and not only from the top down, allowing to include in the decision-making process the citizens to whom the policy is addressed, to hear in the first person and through their voice what they think and feel and with this to elaborate insights that can influence the policy makers.

Starting from the experience of other countries it is important to understand how design can through its methodologies and tools explore new ways of promoting public participation in health beyond those that already exist and do not produce results, it is thus important to reflect on whether design might help improving health policymaking process in Portugal.

WHAT NEXT?

This article aims to reflect on the approaches used by European innovation laboratories developing projects in the health policy sector with the intention of inspiring public participation in health policymaking process in Portugal. By replicating the design processes already developed and implemented that resulted in concrete proposals. The central ambition of this master study is to bring a participatory design approach to the context of health policymaking in Portugal to engage people (e.g. citizens, policymakers, healthcare professionals) in a design research process to obtain a better understanding of the current situation of creating health policymaking in Portugal. Overall it aims to use a range of methods such as ethnography, informal interviews and workshops to capture a range of information.

The next stage will be to identify and include stakeholders in the implementation of public health policy and citizen representatives at regional and local levels of the Portuguese health system will be identified and included, to understand how public participation and political system phase happens, having as options the creation of policies, their implementation, monitoring and evaluation of policies and consequently doing their mapping. Also understand if there is difficulty in understanding the technical documents (laws and plans) that are made available for the implementation of policy, map which projects developed at the local level resulted in the creation of policies at

the national level after the pilot project, and finally gather gaps that make it possible to create a strategy for improvement.

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