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Health Reform Monitor

# Institutional reforms to strengthen patient and public involvement in the Czech Republic since 2014<sup>☆</sup>



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## ABSTRACT

Many countries aim to strengthen patient and public involvement (PPI) in healthcare decision-making. This article discusses the institutionalisation of PPI in the Czech Republic from 2014 to the present based on a review of available documents as well as interviews with policymakers and representatives of patients' organisations. Important steps that contributed to the institutionalisation of PPI were the establishment of the Ministry of Health's (MoH) Patients' Council and the MoH's Patients' Rights Support Department. The institutionalisation of PPI was facilitated through the bottom-up engagement of patients, top-down policy developments, transnational pressures, the support of statutory insurance funds and the pharmaceutical industry, and macro-societal developments. Compared to other post-socialist countries, the institutionalisation of patient involvement in policymaking is amongst the most developed. Although the pharmaceutical industry enhanced PPI, its involvement raised ethical concerns. Various stakeholders called for public funding of patients' organisations to provide them with a stable income and more independence. In summary, the role of patients has been strengthened through macro-institutional involvement. Further progress will demonstrate whether these changes at the macro level of policymaking will stimulate more profound transformations at the meso and micro levels and, therefore, contribute to more profound cultural changes in doctor-patient relationships.

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## 1. Introduction

In recent decades, higher patient and public involvement (PPI) has become one of the key directions of healthcare system reform in Western economies (e.g., [1–5]). Different countries have implemented different models for enhancing patient participation in this field, which include improving the legal framework of patient rights (e.g., in the Netherlands or Greece), instituting a healthcare ombudsman (e.g., in Austria, Finland, Hungary, Norway, Greece, or the UK), and enhancing patient involvement in decision-making (e.g., in the UK) [6].

The rationale which extends from the PPI concept manifests in a number of different ways, most frequently combining the term 'patient' with another noun, such as patient empowerment (PE), patient involvement, patient activation, patient engagement, patient enablement, or patient participation, while others emphasise specific aspects of PPI and refer to health literacy, public involvement, or patients' rights (for more, see, for example, [6–10], and [11]). In general, PPI is viewed as a mechanism for fostering the

health literacy of patients [12], a vehicle to increase the accountability of healthcare institutions and policymakers [13], and a tool used to improve healthcare services and outcomes [14].

Thus, efforts to strengthen the role of patients are based on different definitions, and each of them emphasises different aspects [9]. In other words, there are a wide range of instruments, policies, and interventions which seek to systematically improve the patient position in health care. All the definitions refer to activities rejecting or weakening the paternalistic model of healthcare in which the provider is viewed as the only authority in health care provision. In general, they refer to systemic change in healthcare systems, a shift to patient-centred care leading to a 'redistribution of power from physicians towards patients' [10].

The Czech Republic is no exception in this regard. Over the past decade, it has seen efforts to improve PPI in health care organisation, provision, and policymaking. However, the Czech example is specific because the PPI reforms have emerged in a post-socialist era. As part of the socialist legacy, patients' rights were not recognised, and institutional structures to involve patients in decision-making processes were absent. Moreover, the healthcare system suffered from a high degree of medical paternalism and weak communication between patients and doctors [15].

While the fall of the socialist regime in 1989 was followed by a rise in bottom-up initiatives, exemplified by service-driven self-

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help groups as well as advocacy-driven patients' organisations, the formal, top-down institutionalisation of PPI has emerged only recently. Given these circumstances, the PPI institutionalisation reflects previous bottom-up developments and, at the same time, draws upon international experience. Scholarship on PPI in the post-socialist context is quite rare and primarily focused on the patient-doctor relationship. While existing studies indicated general interest in PE in Poland and Slovenia [16,17], they also reported a low degree of institutionalised patient engagement [16] or its limited effectiveness [18]. By focusing on the Czech context, the research here complements these studies by exploring a context with a high degree of PPI institutionalisation in healthcare policymaking at the macro level.

This article maps and explains the institutional reform of PPI in Czech healthcare policymaking from 2014 to the present. We first map the purpose and content of the reforms and then recount the evolution of PPI reform policies in the country. The data which underpins this article is based on a review of available documents (e.g., policy documents, institutional websites, meeting minutes) combined with 60 semi-structured interviews with various stakeholders (41 with representatives of patients' organisations, 19 with MoH officials as well as policymakers, and experts) and observations from several meetings between health policymakers and patients. Empirical evidence was collected following the data saturation principle, and interviews were conducted in order to ensure sample heterogeneity, including organisations of differing size, relations with public authorities, focus, and history.

## 2. Purpose and content of the reform

The roots of patient involvement and the first initiatives date back to the nineties, when the first patients' organisations were established. From 1997 to 2006 there were numerous health reform strategy concepts; none mentioned PPI. The key milestone in the strengthening of patients' rights was the adoption of the 2011 Act on Health Services, which defined patients' rights for the first time inside Czech legislation. [19] Still, as part of the socialist legacy, the Czech healthcare system has remained relatively paternalistic in nature. However, the strengthened expression of the patient voice in bottom-up, politicised activities, including lobbying and engagement with the mass media, opened a pathway towards the formal recognition and institutionalisation of PPI in the Czech Republic. Progressively, PE has become an important issue in the country's healthcare system, and recent legislation in healthcare has been aimed at empowering patients [19]. The online ministerial platform currently (as of January 2021) lists 127 active patients' organisations. The development of PPI can be described as a progressive and constant institutional transformation which corresponds with the understanding of the reforms as a combination of long-term, structural and continuous incremental changes [20]. The purpose of the ongoing reforms is to institutionally and legally anchor PPI to the Czech health policy framework. In this regard, the main institutional change which has occurred is the establishment of (1) the Patients' Council, a permanent advisory body to the MoH, and (2) the Patients' Rights Support Department, details of which will follow in the subsections below.

## 3. Policy processes

The emphasis on the PPI process within the country drew inspiration primarily from Germany and France as well as from international organisations such as the European Patients' Forum or the International Alliance of Patients' Organisations [21].

In 2006, the first, tentative establishment of a 'patients' council' was initiated by the association *Koalice pro zdraví* (Coalition for health), a non-governmental organisation which originally acted as

an umbrella association. The council was an independent advisory body to the MoH which stayed outside the MoH structure. By being neither institutionally nor formally recognised, its position was rather weak, and its continuity was undermined by the personnel turnover at the MoH [21]. Another institute with limited policy and political impact was the General Health Insurance Company of the Czech Republic's (VZP) Patients' Council, established in June 2014 by the largest public insurer, with *Koalice pro zdraví* as the key organisation representing patients [22].

In 2014, the deputy health minister confirmed that patients' organisations were one of the pillars of the health system, [23] and, over the next year, the MoH began an effort to formalise patient involvement in health policy. Regular quarterly meetings of MoH representatives with patients' organisations were instituted [24]. The goal was to improve and accelerate the processing of patients' organisation suggestions as well as discuss and anticipate the government's plans. In 2016, the Patients' Rights Support Office was established at the MoH to address any problems faced by patients and patients' organisations [25]. Funded through an informal project, this office was not part of the organisational structure of the MoH.

In 2017, the Patients' Rights Support Department was established by Minister's Decree No. 11/2017 and the MoH Secretary General's Service Regulation No. 17/2017 as a permanent part of the organisational structure of the MoH's Legislation and Law Section (Fig. 1). The department gathers comments from patients and patients' organisations, cooperates with patients' organisations and supports them, organises meetings amongst patients' organisations, informs patients and patients' organisations, and organises the education of patient representatives. The department also regularly updates the MoH's web portal for patients' organisations. [26]

In October 2017, the Patients' Council was established by Minister's Decree No. 15/2017. This new institutional element in healthcare governance emerged as an initiative of the patient meetings. The Patients' Council is a permanent advisory body to the MoH and, in line with its statute, its primary mission is to voice patients' concerns at the MoH; to initiate the preparation of and amendments to laws, regulations, and other rules; to participate in the intra-departmental commenting procedure; and to express opinions on measures under preparation (such as guidelines) - in short, to mediate patient input and perspectives on proposed measures and provide a platform for asserting patient rights. The council meets at least four times a year, and, to date, there have already been 13 regular meetings and two extraordinary ones related to the COVID-19 pandemic [27]. The Patients' Council can pass a resolution to establish a working group (hereinafter 'WG'), while the Patients' Rights Support Department supports administratively the activities of the Patients' Council and its WGs, which are composed of patients [26].

Individuals delegated by patients through their organisations are appointed as members of the Patients' Council [27]. The council's 24 members are selected according to strict criteria, with emphasis on representativeness and balance between patients with different diagnoses. Furthermore, the member organisations must have been operational for more than a year [26].

The Patients' Council may set up its own WGs on various topics. To increase the representativeness of the patient voice, WGs include not only members of the Patients' Council but also members of patients' organisations which are not represented on the council. The Patients' Council has currently established five permanent WGs (Fig. 1). Moreover, patients' organisations are represented in another 15 ad hoc and interdepartmental WGs, advisory bodies, and committees of the MoH. [27]

In 2018, these processes of strengthening the patient role were also reflected in the Policy Statement of the Government of the

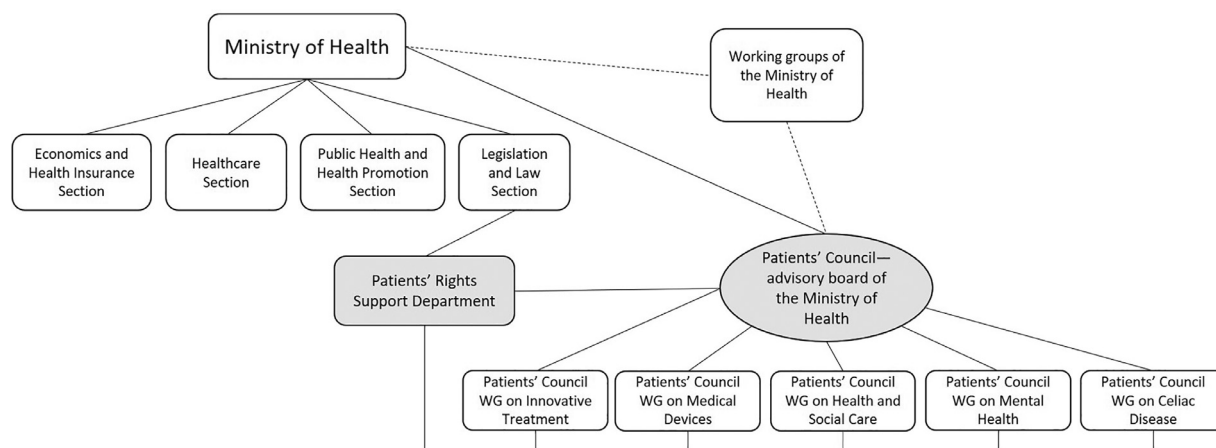


Fig. 1. The Patients' Council within the MoH structure Source: Authors according to the Ministry of Health 2017 [26].

Czech Republic, which explicitly defined a goal for health policy to 'reinforce the status of patients throughout the healthcare system' [28]. Moreover, one of the objectives of the new Strategic Framework for the Development of Health Care in the Czech Republic until 2030 is dedicated to 'strengthening the segment of patient organisations and organisations focused on helping patients. Both the Patients' Council and the Patients' Rights Support Department are currently involved in the development of an implementation plan.' [29]

The institutionalisation of PPI was further reinforced thanks to the creation of an ombudsman position, recommended in 2018 by the health minister to all hospitals managed directly by the MoH. Currently, the institution exists in almost 40% of them [30]. One of seven Czech insurance funds has instituted its own ombudsman too.

In 2018 and 2019, the MoH's Patients' Rights Support Department joined the Association of Innovative Pharmaceutical Industry (AIFP) to implement a series of intensive education courses for members of patients' organisations focusing on soft skills and health-related issues [27]. The AIFP has been involved in patient education since 2012 when it launched a development project for patients' organisations, the Academy of Patient Organizations (APO). The academy is supported by bodies of healthcare professionals who actively collaborate with the MoH through its umbrella organisation, the Czech Medical Association of J. E. Purkyně [31,32]. These forums, in which patients, doctors, and healthcare authorities gather, also provide informal platforms for negotiation and lobbying.

#### 4. Outcomes

The PPI institutionalisation processes instigated several outcomes, although given their relatively recent introduction, we should understand them from a short-term perspective. The impact of the Czech PPI reforms is reflected in the Euro Health Consumer Index, which provides a comparison of healthcare system performance, including indicators such as 'patient rights and information' or 'patient groups' involvement in decision making'. While, in the PPI area, the Czech Republic was amongst the worst performing out of 35 countries, its ranking increased significantly in the period following the institutionalisation of PPI, scoring above average [33,34].

The institutionalisation of the Patients' Rights Support Department has helped to protect PE from the influence of political volatility. In addition to cultural and institutional changes, the outcomes of PPI institutionalisation are also legislative, economic, and related to research and development initiatives.

As regards legislative changes, from its establishment until the end of 2019, the Patients' Council commented on 71 documents and draft legislations, with a total of 300 comments, many of which were accepted [35,36]. A significant success of the Patients' Council and its WGs is, for example, the acceptance of their comments on a draft amendment to the Health Insurance Act (No 48/1997, Coll.) which simplifies the process and increases the transparency of orphan drugs entering the public health insurance reimbursement system. The amendment includes, for the first time, patients in decisions on the reimbursement of orphan drugs [37].

Another notable step in the area of PPI is the draft amendment to Act No. 372/2011 Coll. on health services, which provided a hitherto absent legal framework for patients' organisations to specify a definition of subjects entitled to represent patients [27].

Last but not least, PPI has seen increasing, although still rather marginal, participation of patients in health care research, such as in the area of mental health care [38].

#### 5. Assessment

The institutionalisation of patient involvement in the Czech Republic was facilitated by five simultaneous factors: the bottom-up civic engagement of patients, political interest and top-down policy developments, transnational influences, financial support provided by insurance funds and the pharmaceutical industry, and macro-societal developments. These five factors not only determined the very emergence of PPI institutionalisation but also how it was implemented.

First, the PE process would never have occurred without the growing bottom-up civic engagement of patients. The number of patients' organisations has particularly increased as of the new millennium, and their initiatives have progressively intensified.

Second, PE was further facilitated by existing political opportunities. Institutional pathways for PE opened thanks to the interest of politicians and health policymakers. This was due to the engagement of the last two ministers of health, who repeatedly emphasised the need to strengthen the voice of patients in decision-making processes. Furthermore, PE was declared as a goal in key strategic healthcare documents, including the country's 2030 Strategic Health Framework [39].

Third, the institutionalisation reflected transnational processes stressed by the OECD [40] and the WHO [41]. Hence, the introduction of PPI in the Czech Republic was also legitimised by references to transnational policy and can be viewed as an expression of institutional isomorphism.

Fourth, PPI in the Czech Republic would have hardly taken place without the symbolic and material support of key stakeholders, such as insurance funds and the bodies of healthcare professionals as well as pharmaceutical companies, who represent an important donor and driving force behind patient engagement in policymaking.

Finally, PPI in policymaking was facilitated by macro-societal transformations. Digital technologies have increasingly been used as tools for communication. Patients' organisations also provide reactions to misleading and incorrect health-related information posted online. Furthermore, the neoliberal context enhances the vision of patients as informed citizens and consumers [42,43].

While the institutionalisation of patient involvement in policymaking is amongst the most developed in the post-socialist area, PPI institutionalisation has still been undermined by several barriers. Further, PPI policies will face the need to secure inclusive participation in order to avoid the exclusion of patients or citizens with a lower socioeconomic status. Moreover, the Czech implementation of PPI is not free from the risks previously identified in different countries, in particular those of tokenism or medical paternalism—that is, a tendency amongst doctors to control patient engagement [42,44,45]. The acknowledgement of potential barriers inhibiting PPI helps to mitigate several risks. Therefore, the introduction of a WG serves to increase the representativeness of the patient voice. Additionally, the requirement for patients' organisations to be operational for more than one year prevents the instrumental ad-hoc creation of organisations.

What is more, the reliance on funding provided by the pharmaceutical industry inevitably raises ethical concerns related to potential conflicts of interest and the misuse of patients for lobbying interests (e.g., see [46]). These concerns are partly prevented by codes of conduct and a patients' code approved by the AIFP. These have been only recently publicly debated as part of discussions related to the financing of patients' organisations [43]. In this context, the representatives of both the Patients' Council and the MoH have called for legislative changes to increase the public funding of patients' organisations to ensure them a stable income, prevent the overreliance of patients' organisations on the pharmaceutical industry, and increase transparency concerning financial flows [47].

Lastly, and particularly during the COVID-19 pandemic, both MoH's Patients' Rights Support Department as well as the Patients' Council proved to work as important communication platforms, ready to switch from offline to online modes of functioning. This operational readiness confirms that PPI institutionalisation contributed to the establishment of an effective system of interaction between patients and healthcare authorities which could be acted in moments of urgency and crisis.

## 6. Conclusions

This paper provided an account of institutional reforms to patient involvement in Czech healthcare policymaking from 2014 to the present. The introduction of the MoH's Patients' Rights Support Department and the MoH's Patients' Council are understood as two key institutional steps favoured by the long-term developments and bottom-up initiatives of patients' organisations.

Our analysis of preliminary outcomes suggests that patient involvement in policymaking has been strengthened. However, we concur that PE cannot be overestimated. The impact of the patient voice on decision-making is still limited due to tokenism and persisting medical paternalism. Only further developments will demonstrate whether the institutional changes at the macro level of policymaking will stimulate more profound transformations at the meso and micro levels and, therefore, contribute to a more equal relationship between health care providers and medical doctors and patients. Their achievement will be determined by fu-

ture developments, political context, and level of financial independence that the patients' organisations will gain. In this regard, the recently discussed financial reliance on the pharmaceutical industry poses a potential conflict of interest and will be subject to further regulations. Our conclusions could be relevant to explore PPI developments in similar post-socialist contexts and countries with significant medical paternalism, in particular, as regards the importance given to PPI in the context of a broader health policy agenda, the overall degree of PPI institutionalisation, and the measures to regulate the role of the pharmaceutical industry in the support of patients' organisations.

## Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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