

The National Recovery & Resilience Plans According to Citizens' Perspective: will the EU regain its Leadership in Health? From the Italian Case History to the XVI European Patients' Rights Day

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Abstract

Healthcare, well-being, and a healthy lifestyle are vital for all of us. In this regard, the engagement of European citizens is key to improve the health system and it is necessary to provide a leading role to the people, the communities, intermediate bodies such as Patients' Advocacy Groups (PAGs), citizens organizations involved in healthcare issues and, more generally, to all actors that promote health as a common good. European institutions struggle to translate into concrete actions the many times highlighted principle relating to the involvement of actors of the civil society and PAGs in the management of health issues. The need to close the gap between the principles affirmed and the real involvement is even more serious when discussing about the management of serious cross-border threats to health. In line with its standing point, the civic organization Cittadinanzattiva [1], being deeply involved in health issues that promote civic participation in the policy-making activities both at the national level in Italy and, through its EU branch Active Citizenship Network (ACN) [2], also at the EU level, is working – of course not alone – to promote civic participation in the drafting and implementation process of National Recovery and Resilience Plans (NRRPs), with relevant political goals already achieved. As the Conference on the Future of Europe (CoFoE) [3] is approaching, emphasizing the great contribution of civil society to the success of the EU recovery plans is urgent and essential, now more than ever.

Keywords: civic participation; citizens' engagement; patients' rights; national recovery and resilience plans; European union; Italy; patient advocacy groups (pags); civic society organizations

Introduction

According to the European Economic and Social Committee (EESC) Resolution titled "Involvement of Organized Civil Society in the National Recovery and Resilience Plans What works and what does not?" [4], based on consultations done in the 27 Member States and voted on February 2021, "with regard to the involvement of pan-European social partners and civil society organizations (CSOs) in the Next Generation EU Recovery Plan... most of them consider that the level of actual participation is still largely insufficient and that the processes do not allow civil society organizations opinions to have enough of an impact. Social partners and civil society organizations call for these shortcomings to be corrected in the National Recovery and Resilience Plans (NRRPs) implementation and evaluation phases by establishing more formal procedures that facilitate real exchanges".

In a few words, we are facing a lack of coherence between what has been stated and the reality. In fact, it is probably important to remember that the agreement reached by the European Parliament and the Council in December 2020 and drafted in the "Regulation (Eu) 2021/241 of the European Parliament and of the Council of 12 February 2021 establishing the Recovery and Resilience Facility" [5] includes a paragraph on the involvement of the social partners and civil society, among others. Article 18(4) (q) requires NRRPs to set out "a summary of the consultation process, conducted in accordance with the national legal framework of local and regional authorities, social partners, civil society organizations, and other relevant stakeholders, for the preparation and, where available, the implementation of the plan and of how the inputs of the stakeholders are reflected in the plan".

Again, the European Economic and Social Committee denounces that “the preparations to distribute huge amounts of money are taking place, sometimes behind closed doors and even more often with national governments, not including civil society enough. The participation of civil society can greatly contribute to the success of the EU recovery plans. If the EU Recovery Plan is properly implemented, it could turn an obvious political crisis into profound progress for a stronger economy”.

This is the overall situation for each pillar of the Plan, green and digital transitions, including the health sector. About it, Cittadinanzattiva/Active Citizenship Network (ACN) strongly believes that the engagement of European citizens is key to improve the health system: we want to be heard because, as in any reconstruction, the involvement of a large number of active and aware social and civic actors is essential. In this regard, the WHO stresses the “Community and civil society engagement” as a pillar of its “Global Action Plan for Healthy Lives and Well-being for All” [6]. Indeed, it is necessary to guarantee a leading role to the people, the communities, intermediate bodies such as Patients' Advocacy groups (PAGs), citizens organizations involved in healthcare issues and, more generally, to all actors that promote health as a common good. From their testimonies during the pandemic, it emerges the great reforming force of civic organizations, capable of responding promptly to new needs by managing services, building alliances, quickly signaling necessary regulatory or procedural changes, mobilizing resources (both human and economic), innovating their operating mode, and introducing and promoting practices from which it will not be necessary to go back once the health emergency is over [7]. We have discussed it on occasion of the XV Edition of the European Patients' Rights Day (May 2021) [8].

Discussion

Of course, a huge number of national civil society organizations and European umbrella associations underline the same point set forth by the EESC, revealing a strong desire to contribute to the drafting of National Recovery and Resilience Plans (NRRPs). In particular, citizen intermediate bodies ask for concrete tools to monitor the funds that each European country is receiving. We are talking of over EUR 672, 5 billion funds approved, an investment in our future that we cannot make wrongly. In line with the provisions of the regulation for the Next Generation EU fund, we request a public and open tool to track financial data linked to the NRRPs, an open government platform that enhances transparency, and the monitoring of funds allocation.

Cittadinanzattiva/Active Citizenship Network is deeply involved in health issues that promote the civic participation in the policy-making process at all levels (in Italy at local and national level since 1978, and at the EU level since 2001) and the protection of citizens' and patients' rights. In line with its standing point, Cittadinanzattiva/Active Citizenship Network is working – of course not alone – to promote civic participation in the National Recovery and Resilience Plans, starting of course at the national level, but also with initiatives at the EU level.

The Italian Case History: Recommendations & First Achievements

About Italy, the first beneficiary between EU countries, the lack of involvement of civil society organizations, the lack of transparency, and the absence of civic monitoring are the main weaknesses. Not only: “The citizens' perspective did not emerge even through the ordinary modalities of representative democracy, since even the Parliament received the document just 24 hours before its presentation and final approval”. In front of this situation, together with other organizations, Cittadinanzattiva has:

- 1) launched the programme called “Follow the Money” [9], which intends to monitor the quality and inclusiveness of the decision-

making process for the construction of the National Recovery and Resilience Plan.

- 2) implemented a Civic Observatory, [10] with a dedicated website [11], with the aim to build a broader awareness campaign; obtain a public and open tool for the tracking of financial data related to the National Plan; monitor the quality and inclusiveness of the decision-making process of construction of the NRRPs and follow the implementation of projects. The Observatory is promoted by 4 organizations (ActionAid [12], Cittadinanzattiva, Legambiente [13], Slow Food [14]) and more than 30 organizations joined and endorsed the initiative.
- 3) Advanced concrete proposals to the National Institutions [15]: we do not have any information on the criteria used for the allocation of resources provided for the individual missions and components of the Plan nor the list of individual projects that will be financed. We ask this information to be made public and that the NRRP portal [16], the communication tool of the Plan, makes all analytical data available in an open-source format, in order to allow citizens themselves to monitor resources and impacts of each project on their own territories and local communities.
- 4) Carried out the annual “Festival della Partecipazione” [17] - realized in hybrid format last 18 of September 2021 - dedicated to the topic, hosting experiences from other countries.

In Italy, to date, Cittadinanzattiva has achieved that a representative of civil society organizations will be included in the Official Committee led by the National Institutions. In October 2021, the Civic Observatory was invited to enter the Permanent Table for the economic, social, and territorial partnership [18]. For over a year, the Observatory has been working to help make the Plan more inclusive, participatory, and transparent. This appointment represents an important first step, which pushes to a further commitment to be as representative as possible of the demands of civil society. The hope is that the Table will represent a concrete working space to address, based on the demands and needs of communities and territories, the implementation of the NRRP, projects and reforms of which it is composed. The Observatory, which now includes some of the main national organizations with strong experience in the field of transparency and reporting, also intends to open up to other actors with more specific thematic expertise, such as environmental or digital transition areas. The overall aim of the work is to monitor the implementation of the NRRP funded by the Recovery and Resilience Facility in all its different phases [19].

The above-mentioned initiatives testify Cittadinanzattiva's concrete commitment at the national level in Italy. Of course, its commitment does not stop here and, through its EU branch Active Citizenship Network (ACN), Cittadinanzattiva also focuses on other experiences across Europe in order to share ideas and join efforts.

Eu Dimension: Lessons Learned Versus Lost Occasions

The importance that will be given to the concrete civil society participation in the NRRPs will be the key element with which we will evaluate the work of our politicians at all levels.

In this regard, in the framework of the recent “State of the Union” address of the past 15th September 2021 [20], the European Commission President Ursula von der Leyen missed an important opportunity to underline the value of the civil society participation in the Next Generation EU and so in National Recovery and Resilience Plans.

This is neither the first nor the only missed opportunity by European institutions. In fact, civic activism and involvement in support of the institutions and for the benefit of local communities - were also not mentioned, for instance, in the context of the “Proposal for a regulation of the European Parliament and of the Council on serious cross-border threats to health and repealing Decision No 1082/2013/EU” (opened for

a public consultation until last February 2021) [21]. The proposal reveals a serious lack which proves as completely unjustified in light of the lessons that we should have learnt from the pandemic.

This is the context in which civic organizations and PAGs struggle daily. Nonetheless, sometimes, some relevant political goal is achieved. For instance, in 2019, in order to commit to deliver accurate information to the public, to fight myths and exchange best practices, Active Citizenship Network (ACN) has achieved that the Coalition for Vaccination, one of the 20 concrete actions included in the “Proposal for a Council Recommendation on Strengthened Cooperation against Vaccine Preventable Diseases [22]” has been extended also to all the civil society’s representatives engaged on the topic, instead of being opened only to the European associations of healthcare workers and relevant students’ associations in the field, as written in the Council Recommendation of 7 December 2018. And, as a matter of fact, ACN has joined the last General Assembly planned on October 12th, 2021.

Towards The Xvi Edition of the European Patients’ Rights Day

The overall message is that European citizens must be considered protagonists and not passive observers of the decisions that affect our and the next generation’s future. Also for this reason, Active Citizenship Network has decided— at the EU level – to promote, starting from May 2021, a cycle of EU Webinars titled “Health at the heart of the future of Europe” held to feed the debate of the Conference on the Future of Europe (CoFoE). The main idea was to highlight the priority of health as a common good in the debate of our and of the next generation, prescribing a healthier future for Europeans. The cycle of initiatives organized by ACN (II° half 2021 – I° half 2022) with the direct involvement of MEPs, high level experts, leaders of civic organizations and PAGs, and citizens aims to contribute to providing a multi-stakeholder vision for a Healthier European Union. The overall key message is that by voicing your opinions, hopes and concerns, you can influence the way healthcare is provided in Europe. Each EU Webinar led by ACN is realized in the framework of the MEPs Interest Group on “European Patients’ Rights & Cross-Border Healthcare” (2019-2024 Term) [23] and hosted by the multilingual digital platform for the Conference on the Future of Europe [24], created to enable citizens across the Union to share and exchange ideas and opinions through online

events. Next 17 of December is planned our fourth initiative, after the ones realized in June [25], July [26] and September [27] 2021. As an output of the cycle, the recommendations will be forwarded to the European Institutions as a contribution to the Conference on the Future of Europe on the discussed topics in the context of the XVI European Patients’ Rights Day (EPRD), titled “*Conference on The Future of a Healthy Europe: Taking part in the decision-making process on health priorities*” and planned next 20 & 21 of April 2022 [28].

In particular, the annual EU celebration of the XVI European Patients’ Rights Day (EPRD) will be organized by ACN with its traditional format of a big multi-stakeholder conference focused on the role played by key actors in the decision-making process on health priorities. Just before the end of the Conference on the Future of Europe (22-24 April 2022), the expectations and requests of citizens and PAGs addressed to the institutions will be analysed. What has been discussed? Why only a small percentage of the initiatives did promoted within the CoFoE concern health issues? How to ensure that the priorities defined in the context of CoFoE will be incorporated in the implementation of the National Recovery and Resilience Plans? What is the level of involvement of citizens and patients’ associations in defining the implementation process of the priorities that have been identified in the health sector? The 2022 conference will have a twofold structure: a first day, dedicated to the presentation to the EU Institutions of the outputs of the themes that emerged from health-related initiatives organized in the framework of the Conference on the Future of Europe; and a second day, focused on analysing the actual level of citizen involvement by the Member States close to the approval by the European Commission of most of the NRRPs and their implementation at the national level. The sixteenth edition will aim at finding answers also to the above-mentioned questions thanks to the following preliminary actions:

- The recognition of the main themes that emerged from the health-related initiatives hosted by the official portal “FuturEU platform”.
- A European civic survey on the level of involvement of civic and patient associations in the definition of priorities in the health sector starting from those indicated in the National Recovery and Resilience Plans.

Vytenis Andriukaitis, former EU Commissioner for Health and Food Safety attending the 10th European Patients’ Rights Day



Logo of the 2022 Edition of the European Patients’ Rights Day

Figure 1: Vytenis Andriukaitis, former EU Commissioner for Health and Food Safety attending the 10th European Patients’ Rights Day.



Figure 2: Logo of the 2022 Edition of the European Patients' Rights Day.

Conclusion

Civic participation in healthcare policies should be considered not only as a praiseworthy civic act, but also as a strategic source to safeguard the public healthcare system. A principle theorized forty years ago by the World Health Organization in the Declaration of Alma-Ata [29], and then repeatedly affirmed internationally over the years. And twenty years ago, in the process of defining the European Charter of Patients' Rights [30] drafted by Active Citizenship Network together with organizations from 15 EU countries, the right to participate in policymaking in the area of health [31] was emphasized as a right of active citizenship.

Citizen participation is a right, stated in theory but often denied in practice. Thus, we have to join efforts to affirm the enforceability of these rights.

Our hope is that the active involvement of citizens, "out the door" and never contemplated in the definition of the Plans, could come back "through the window", in the process of implementing the Plans. From the importance that will be given to the concrete civil society participation to the health-related topics in this European political framework we will understand if "the necessity to create a stronger European Health Union" as underlined by the European Commission President Ursula von der Leyen in her "State of the Union" statement – is merely a claim or the actual direction taken by the European institutions, and the key element with which we'll evaluate their work.

Declarations

Each of the authors confirms that this manuscript has not been previously published by another international peer-review journal and is not under consideration by any other journal. Additionally, all of the authors have approved the contents of this paper and have agreed to the Clinical Research and Clinical Trials' submission policies.

Authors' contribution

Each named author has substantially contributed to conducting the underlying research and drafting this manuscript. Additionally, to the best of our knowledge, the named authors have no conflict of interest, financial or otherwise.

Conflict of interest

The authors listed on the first page declare that they do not have any conflict of interest.

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