

# Addressing non-Covid patients' unmet needs to the Global Health Summit: Covid-19 lessons learned for more resilient Health Care Systems. Ten recommendations towards a European Health Union

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## ABSTRACT

The Global Health Summit is an opportunity to share lessons learned from the Covid-19 pandemic, to define a joint commitment to build a healthier, safer, fairer and more sustainable world. Global leaders and high-level experts will discuss how to improve health security, strengthen our health systems and enhance Europe's ability to deal with future crises in a spirit of solidarity.

Their goal is to create a 'Rome Declaration' including principles that can be a powerful guide for a medium/long-term structural change brought about through international cooperation and joint action to prevent future global health crises. These principles will take into account the views of the scientific community and civil society.

During the 15th European Patients' Rights Day conference, recently held by Active Citizenship Network, participants welcomed the European Commission President Ursula von der Leyen's statement, made in her September 2020 "State of the Union" speech, that it is a necessity to create a stronger European Health Union.

From the account of oncological and chronic patients during the pandemic, it emerged how they had been left almost alone for several months, a situation that jeopardized 20 years of prevention.

The 15th European Patients' Rights Day – held on 5 & 6 May 2021 [1] - recognized the key role of Patients' Advocacy Groups, who gave their account of the pandemic. They revealed the reforming force of civic organizations, their capacity to respond promptly to new healthcare needs by managing services and building alliances.

Will political leaders at the Global Health Summit insist on integrating Patients' Advocacy Groups as part of the new strategy? Expectations are high. In this context, Active Citizenship Network [2], the EU branch of the Italian NGO Cittadinanzattiva [3], drafted a Manifesto with ten recommendations – that has been already signed by 50 associations from 18 countries - addressed to the institutions to remark non-Covid patients' unmet needs. Above all, to encourage forms of monitoring as "Follow the Money" to monitor together the funds of Recovery Plans that each European country is receiving and engage European citizens to improve health systems. There is the need to be heard because, as in any reconstruction, the involvement of a large number of active and aware social and civic actors is crucial. The other recommendations are: to monitor Covid-19 impact on non-Covid patients; to urgently secure safe access to diagnostic, immunization, screening and treatments; to secure well-resourced healthcare systems post-Covid-19; to support the Digital Healthcare transition; to affirm a life-course approach for chronic diseases prevention; to strengthen a "One Health approach" to prevent future pandemics; to better protect the rights of patients living with multi co-morbidity; "Health for all EU citizens" must be placed at the heart of the Conference on the Future of Europe. The Manifesto is available on ACN's website [4], and it is still opened for endorsement.

**Keywords:** Patients Advocacy Groups (PAGs), patients' rights, Non-Communicable Diseases (NCDs), chronic patients, European Patients' Rights Day, Covid-19 pandemic

## INTRODUCTION

Covid-19 has threatened all health systems and their sustainability as well as the social stability of all countries during the emergency, but it has especially affected oncological and chronic patients worldwide, challenging their right to health and continuity of care. Across the world, these patients were left behind, and this will have public health consequences, counting not only the deaths caused by Covid-19 but also the number of people who died prematurely because they did not have the chance to access the care they needed. According to Eurobarometer data [5], this justifies why health risks are a primary concern for European citizens of 9 EU countries. During the Covid-19 health emergency, health services were totally and “heroically” focused on stemming the epidemic, but, at the same time, this revealed the limits that existed before the emergency. “Ordinary” patients have struggled with practical issues of postponing or forgoing a wide variety of services, ranging from emergency treatment of acute conditions to routine check-ups, recommended cancer screenings, creating a sense of abandonment and uncertainty.

According to the data collected by the World Health Organization, UNICEF, Gavi, etc. [6], provision of routine immunization services was substantially hindered in at least 68 countries with a significant variation on how the pandemic disrupted access to immunization services even within the same regional territory; very different protocols are in place regarding infection prevention policies, both in facilitating access to vaccines and in conducting screenings.

**Key message:** *It is not acceptable to respond to the immediate needs of citizens and patients facing the Covid-19 pandemic simply by closing services. Instead, alternative organizational solutions are needed to guarantee continuity and quality of care.*

## METHODS

In organising the 15th edition of the European Patients’ Rights Day, Active Citizenship Network (ACN) has developed an action in 4 steps:

- a) collection of examples, experiences, good practices on citizen & patient organisations’ engagement during the Covid-19 pandemic, by contacting associations throughout Europe with which it is in contact [7]; b) selection of 4 significant experiences, two on the subject of oncology and two on the subject of chronic diseases as testimonials, and their presentation on the occasion of the inaugural day of the European Patients’ Rights Day on May 5th, 2021 (Fig. 1). Rather than recalling the impact of Covid, the aim was to highlight the actions and reactions that have civic & patients’ organisations as protagonists: actions realised despite the pandemic and reactions put in place to mitigate its impact. c) Abstraction from the experiences gathered of the ten main indications to be presented in the form of a Manifesto addressed to the institutions and experts about to meet in Rome on the occasion of the Global Health Summit (Rome, May 21st 2021). d) Request for endorsement for a more incisive action of advocacy. All, of course, keeping in mind what the burden of the Covid-19 pandemic was.

**15<sup>th</sup> European Patients' Rights Day**

**The role of civic society and Patients Advocacy Groups for more resilient Health Care Systems. Lessons learned toward a European Health Union**

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**Figure 1.** Communication material produced by Active Citizenship Network in occasion of the EU conference “The role of civic society and Patients Advocacy Groups for more resilient Health Care Systems. Lessons learned toward a European Health Union” realized on 5 & 6 of May, 2021.

In this regard, evidence collected during the crisis shows that Covid-19 has had a significant impact on non-communicable diseases (NCDs) [8]:

- Many countries postponed elective surgery to free up human resources and hospital beds. This was the case, for example, in Germany and Portugal for all non-urgent elective surgeries [9]. In France, *the Académies de médecine et de chirurgie* estimated that around 1.1 million non-urgent surgical acts were postponed during the pandemic [10].
- There have also been fewer visits to emergency departments. In Germany, the Covid-19 pandemic was associated with a significant decrease in all-cause admissions (30% lower than for the same period in 2019) and admissions due to cardiovascular events in the emergency department (41% lower) [11].
- There has been an approximately 40% drop in cancer diagnoses [12]. In Italy, an estimated 1.4 million fewer screening exams were performed during the first five months of 2020 (Italian National Oncology Association, 2020) [13], and in Spain (Madrid), outpatient visits in oncology departments decreased by 23% between March 9th and April 13th 2020 [14].
- During the pandemic outbreak, and in particular, during the confinement period, far fewer patients than usual have called for help or visited hospital emergency units with heart attacks and strokes: the European Society of Cardiology early in July 2020 denounced that the number of heart attack patients seeking urgent hospital care has dropped by more than 50% during the Covid-19 outbreak [15].

**Key message:** *A situation that jeopardises 20 years of prevention*

### **Results: Civic society & Patients 10 Recommendations**

As a follow up of the XV European Patients' Rights Day, Active Citizenship Network, supported by many PAGs across Europe, launched an appeal to the European Union, national and regional institutions, and decision-makers to work together to find concrete solutions that ensure prompt care of Covid-19 positive patients to effectively manage the pandemic, without doing it at the expense of continuity of care for all other patients. In this context, we have proposed ten concrete recommendations to integrate the lessons learned from the pandemics immediately and to be urgently considered to ensure continuity of care for patients suffering from other diseases than Covid-19:

1. **Monitor Covid-19 impact on non-Covid-19 patients:** It is crucial that authorities continuously monitor the situation at the European and national level on the impact of the pandemic on non-Covid-19 patients and take appropriate actions in close cooperation with patient communities. Joint Communication efforts by healthcare sectors and authorities across Europe are key and need to be

synchronised. It is essential to share best practices, raise awareness, and encourage patients and citizens to take care of their health during Covid-19 times.

1. **Urgently secure safe access to diagnostic, immunisation, screening and treatments:** patients must continue to have access to prevention, diagnostic, screenings, and other treatments without fear, even during a pandemic. It is crucial for authorities to look at alternative options to guarantee those fundamental rights of the people, for example, by simplifying as much as possible the procedures with which chronic and rare disease patients obtain drugs, usually distributed in public facilities and hospitals, and favouring and facilitating home delivery of drugs and health assistance, depending on the functioning of the national health system. In particular, building resilient health and immunisation systems and improving access to routine and new vaccinations becomes essential in Covid-19. To achieve this objective, all possible efforts should be made to affirm the culture of life-course immunisation and to engage all healthcare providers as each of the actors in the vaccines ecosystem contributes to strengthening the resilience of the immunisation system.
2. **Secure well-resourced healthcare systems post Covid-19:** Healthcare systems must be well-resourced to face health crises leaving no one behind. In this context, it will be crucial to abandon the idea of hospitals as exclusive treatment centres and to ensure assistance and patient care in their households, also with the aid of advanced technologies, to reinforce primary and continuity care outside hospitals. At the same time, hospitals should help reduce the impact of the pandemic on non-Covid-19 patients in the future by welcoming patients back into healthcare settings. For instance, the hospital should ensure the separation of Covid-19 and non-Covid-19 areas.
3. **Support the Digital Healthcare transition:** for the future, it is essential to simplify procedures and facilitate access to medical services in order to achieve a significant shift in care delivery by fostering digital technologies and offering digital medical services, including e-appointments and e-prescriptions. It is essential to favour prescriptions by email and telemedicine by investing in homogeneous IT platforms between hospitals and local centres, aimed at ensuring continuity of care - both for checks and consultations - and the management of patients at home. It is important to also look at ways to increase training for patients and healthcare professionals on the digitalisation of healthcare.
4. **Affirm a life-course approach for chronic disease prevention:** Non-Communicable Diseases (NCDs) threaten progress towards the 2030 Agenda for Sustainable Development, which aims at reducing premature deaths from NCDs by one-third by 2030. A life-course perspective

enables the identification of a high-risk phenotype and markers of risk early, supporting current efforts for primary prevention of NCDs by providing timely interventions in early life.

5. **Strengthen a ‘One Health approach’ to prevent future pandemics:** NCDs, also known as chronic diseases, tend to be of long duration and result from a combination of genetic, physiological, environmental and behavioural factors [16]. We can only prevent future pandemics through an integrated ‘One Health approach’ to public health, animal health and the environment we share. It is time that the concept of One Health – where multiple sectors communicate and work together to achieve better public health outcomes – is also translated into local-level systems [17].
6. **Develop a Manifesto for the rights of patients living with multi co-morbidity:** Patients with multi co-morbidity have complex health needs but, due to the current traditional disease-oriented approach, they face a highly fragmented form of care that leads to inefficient, ineffective, and possibly harmful clinical interventions. This situation increases the risk of negative outcomes, and it is no longer acceptable: a joint effort with the involvement of the Institutions in favour of multi-disciplinary healthcare professionals’ (HCPs) teams is needed as well as clear health pathways.
7. **“Follow the Money” to monitor together with the funds of the Recovery Plan:** we want the tools to monitor the funds from the National Recovery and Resilience Plan (PNRR) 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 National Recovery and Resilience Plan (PNRR), an open government platform that enhances transparency and the monitoring of funds allocation [18].
8. **Engage European citizens 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. 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” [19]. Indeed, it is necessary to guarantee a leading role to the people, the communities, intermediate bodies such as Patients’ Advocacy groups (PAGs), citizens organisations involved in healthcare issues and, more generally, all actors that promote health as a common good. From their testimonies during the pandemic, it emerges the great reforming force of civic organisations, capable of responding promptly to new needs by managing services, building alliances, quickly signalling necessary regulatory or procedural changes, mobilising 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.

9. **“Health for all EU citizens” must be placed at the heart of the Conference on the Future of Europe:** Beyond the emergency setting in which we have been living in recent months, the public health condition and its ongoing reform towards a real EU Health Union can only be addressed in a pan-European coordinated way, creating synergies between institutions at all levels, operators and citizens/patients. Only in this way, we will be able to ensure sustainability, predictability, reduced health inequalities, and guarantee access to care to all patients. In the framework of the Conference on the Future of Europe as well as the Global Health Summit 2021, we urge authorities at the EU and national level to prioritise health with the relevant resources needed, as well as to set up a dialogue at the national level with all relevant stakeholders to address current issues of non-Covid-19 patients and implement concrete solutions.

*Key message: Health is more than being Covid-19 free, and this situation needs immediate actions*

## DISCUSSION

On May 21st, 2021, in Rome, the European Commission will co-host the Global Health Summit in cooperation with the Italian G20 Presidency [20]. The Summit is an opportunity to share lessons learned from the Covid-19 pandemic, to define a joint commitment to build a healthier, safer, fairer and more sustainable world. Global leaders and high-level experts will discuss how to improve health security, strengthen our health systems and enhance the ability to deal with future crises in a spirit of solidarity. Their goal is to create a ‘Rome Declaration’ including principles that can be a powerful guide for medium to long-term structural change through international cooperation and joint action to prevent future global health crises. These principles will take into account the views of the scientific community and civil society. For these reasons, Active Citizenship Network has decided to point out what emerged in the 15th edition of the European Patients’ Rights Day, starting from a Manifesto with ten recommendations, produced thanks to the contribution of 50 associations from 18 countries. The main message is that in the role of needed changes towards more resilient healthcare systems, even in the context of the global crisis, it is necessary to recognize also the key role of Patients’ Advocacy groups (PAGs), citizens’ organizations involved in healthcare issues and, more generally, of all actors that promote health as a common good. The hope is that political leaders and high-level experts involved in the Global Health Summit will be able to consider the civic & patients’ perspective.

Europe has begun to overcome the Covid-19 crisis, and there is a brighter horizon ahead. However, Europe is still facing widespread public health crises with cancer care, diabetes, and obesity.

Without a health union, our resources are inefficiently used, and our citizens suffer unnecessarily. Without a health union, widespread health inequality will remain.



Patients' Advocacy Groups are the voice that needs to be heard to ensure fair and equal access to healthcare. The Rome Declaration is an opportunity to shape a public policy which citizens will understand and welcome. It is time to act as one; together, we are stronger and healthier.

The Manifesto drafted by Active Citizenship Network will also be promoted in the Conference of the Future of Europe to contribute to putting health-related issues at the heart of the debate.

This is the list of the endorsing organizations:

1. Italy: Cittadinanzattiva/Active Citizenship Network (promoter)
2. EU: International Council of The Patient Ombudsman
3. EU: International Alliance of Patients Organisations (IAPO)
4. EU: European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA)
5. EU: European Society of Radiology's Patient Advisory Group (ESR-PAG)
6. EU: Dystonia Europe
7. EU: European Heart Network
8. EU: ThinkYoung
9. EU: Stroke Alliance for Europe
10. EU: European Union of Private Hospitals (UEHP)
11. EU: European Federation of Nurses Associations (EFN)
12. EU: ADHD-Europe
13. EU: TEDDY Network - European Network of Excellence for Paediatric Research
14. Albania: "Together for Life"
15. Austria: Lower Austrian Patient and Nursing Advocacy
16. Bulgaria: Bulgarian Association for Patients' Defence (BAPD)
17. Bulgaria: Alliance of Transplanted and Operated ATO "Future for All"
18. Bulgaria: Association of Reproductive Health, Pregnancy and Childcare "Smile"
19. Bulgaria: Association of Patients with Cardiovascular Diseases
20. Bulgaria: Patients' Organizations With you
21. Croatia: Croatian Association for Patients' Rights
22. Cyprus: Thalassaemia International Federation
23. France: INDECOSA
24. Hungary: Civilians for Vaccination Association (VÉDEM)
25. Ireland: Irish Patients' Association
26. Italy: Federation of Italian Associations for Anticoagulated Patients (Feder-A.I.P.A.)
27. Lithuania: Council of Representatives of Patients Organisations of Lithuania
28. Malta: Association for Consumer Rights (ACR)
29. Malta: Malta Health Network
30. Malta: National Patients' Organisation (NPO)
31. Malta: Europa Donna Malta
32. Netherlands: EPECS Foundation
33. Poland: WE Patients Foundation
34. Poland: Institute of Patients' Rights and Health Education
35. Portugal: ANSIC - Associação Nacional de Síndrome de Intestino Curto
36. Portugal: Associação de Doentes de Dor Crónica dos Açores (ADDCA)
37. Portugal: Associação MOG Movimento Cancro do Ovário e outros Cancros Ginecológicos
38. Portugal: APN - Portuguese Association of Neuromuscular
39. Portugal: The Portuguese Multiple Sclerosis Society
40. Slovenia: ZDRUŽENJE ZA PRAVIČNOST IN NADZOR
41. Slovenia: SIBAHE - SLOVENSKA BANKA HRANE / SIBAHE - SLOVENIAN FOODBANK
42. Slovenia: DRUŠTVO KULTLAB CELJE/ KULTLAB CELJE SOCIETY
43. Spain: ASPERGA - ASOCIACION GALEGA DE ASPERGER
44. Spain: Asociacion Española Contra La Meningitis
45. Spain: Foro Español De Pacientes
46. Spain: Plataforma de Organizaciones de Pacientes
47. Switzerland: IAPO Patients for Patient Safety Observatory
48. UK: Breast Density Matters UK
49. UK: Pelvic Pain Support Network
50. UK: Excellence in Pediatrics Institute

**Key message:** *From the importance that will be given to 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" address [21] – is merely a claim or the actual direction taken by the European institutions, and the key point with which the civic & patients' organizations we will evaluate their work.*

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during the pandemic outbreak, provided suggestions for the Manifesto and endorsed it.

## 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 Epidemiology and Public Health Research Journal's 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.

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## CONFLICT OF INTEREST

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

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