

Isolated but not alone: the response to the pandemic in the story of pags: from the italian case history to the global health summit “rome declaration”

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Received date: February 01, 2022; **Accepted date:** february 25, 2022; **Published date:** March 16, 2022

Citation: Mariano Votta, Maira Cardillo and Michaela Papavero. (2022). isolated but not alone: the response to the pandemic in the story of pags: from the italian case history to the global health summit “rome declaration”. J. Clinical Research Notes. 3(3); DOI: [10.31579/2690-8816/057](https://doi.org/10.31579/2690-8816/057)

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Abstract

Struggling with practical problems such as the sudden cancellation of scheduled visits and exams and a sense of abandonment and uncertainty. This is how the “ordinary” patients lived the period of the health emergency in Italy. At the same time, civic and rights protection associations, since the beginning, have been active with a sense of responsibility, creativity, and energy, often revealing themselves to be the only point of reference and the only service available to citizens.

This is the double side of the coin, in the implications of the pandemic on chronic and rare patients, which emerged from the XVIII National Report on Chronic Policies of Cittadinanzattiva, presented on October 13th, 2020, and entitled: “Isolated but not alone: the response to the pandemic in the story of Patients Advocacy Groups (PAGs)” [1]. The Report arised from the story of 34 Italian associations of patients with chronic and rare diseases who adhered to the **National Coalition of Associations for Patients suffering Chronic Diseases (CnAMC)** [2] of Cittadinanzattiva [3].

This experience - thanks to Active Citizenship Network [4] - was first socialized on the occasion of the 15th European Patients' Rights Day held on May 5th & 6th, 2021 [5], and then brought to the attention of the leaders of the G20 and other states, gathered together with the heads of international and regional organizations on the occasion of the Global Health Summit held in Rome on May 21, 2021 [6].

Keywords: *Patients with chronic and rare diseases; Patients Advocacy Groups; Chronic Policies; Italy; European Union; Civic participation; Citizens' engagement; Patients' rights*

Introduction

The XVIII National Report on Chronic Policies was first being talked about by Cittadinanzattiva in the midst of the first Covid-19 lockdown. Lives had just been turned upside down and activities had to be reorganized with the necessity of multiplying the political initiatives to protect citizens, especially the most fragile, and the information interventions that the situation required. In such a vulnerable and unclear context, even a well-established and eagerly awaited event such as the

publication of the National Report on Chronic Policies had to find meaning and sense within the experience of the Covid-19 pandemic.

This is how Cittadinanzattiva chose to make the 2020 CnAMC National Report a collective account of what the Italian associations have experienced, especially during the first phase of the pandemic, which was that of the extension of the containment measures of the “red zones” to the entire country. This collective story aimed at outlining the experiences of those who - with a chronic or rare pathology - were “more isolated”

than others; at highlighting the problems that people with chronic or rare diseases have encountered in their relationship with a health service totally and "heroically" focused on mitigating the health emergency, but which has at the same time clearly revealed the limits that existed even before the pandemic. The story also demonstrated, through the lives of people with chronic and rare diseases during Covid-19, that if the National Plan for Chronic Diseases had been implemented at all levels, much of the suffering could have been avoided. Still, on the positive side, the story showed - in a tangible way - the great reforming force of civic organizations, capable of responding promptly to new needs by organizing services, building alliances, pointing out necessary regulatory or procedural changes, mobilizing resources (human and economic), innovating their own modes of operation, and introducing and/or promoting practices which will be difficult to abandon when it is all over.

In this regard, the title of the 2020 Report underlines how, despite the dramatic experience of isolation lived during the difficult phase of the lockdown, the associations have represented for millions of people affected by chronic and rare diseases an essential point of reference. This was the first time that such a large group of associations - in a convinced and participatory way - used the tool of storytelling to describe a dramatic moment in our lives and traced clear perspectives for the immediate future of policies on chronicity.

Methodology

Below is the list of the 34 Italian associations belonging to the CnAMC that have actively participated, with their own testimony, to the contents of the XVIII National Report on Chronic Policies, which was realized thanks to the unconditional support of MSD.

- A.Fa.D.O.C. Associazione di famiglie di soggetti con deficit Ormone della Crescita e Sindrome di Turner - Association of families of subjects with Growth Hormone Deficiency and Turner's Syndrome [7]
- AIDE – Associazione Italiana Dislipidemie ereditarie - Italian Association of Hereditary Dyslipidemia [8]
- A.L.I.Ce. Italia Associazione per la Lotta all'Ictus Cerebrale - Italian Association for the Fight against Cerebral Stroke [9]
- A.M.R.I. Associazione per le Malattie Reumatiche Infantili - Association for Infantile Rheumatic Diseases [10]
- A.N.I.F. Associazione Nazionale Ipercolesterolemia Familiare - National Association of Familial Hypercholesterolemia [11]
- A.N.I.Ma.S.S. Associazione Nazionale Italiana Malati Sindrome di Sjogren - Italian National Association of Sjogren's Syndrome Patients [12]
- A.P.E. Associazione Progetto Endometriosi - Endometriosis Project Association [13]
- AICH-Roma Associazione Italiana Còrea di Huntington di Roma - Rome Italian Association of Huntington's Chorea [14]
- AICMT Associazione Italiana Charcot – Marie -Tooth Onlus - Italian Association Charcot - Marie -Tooth Onlus [15]
- AIL Associazione Italiana contro le leucemie - linfomi e mieloma - Italian Association against leukemia, lymphoma and myeloma [16]
- AISF Associazione Italiana Sindrome Fibromialgica - Italian Fibromyalgia Syndrome Association [17]
- AISLA Associazione Italiana Sclerosi Laterale Amiotrofica - Italian Association of Amyotrophic Lateral Sclerosis [18]
- AltroDomani Onlus [19]
- Associazione AMICI onlus - Associazione Nazionale per le Malattie Infiammatorie Croniche dell'Intestino - National Association for Chronic Inflammatory Bowel Diseases [20]

- AMIP Associazione Malati di Ipertensione Polmonare - Pulmonary Hypertension Patients Association [21]
- AMOR Associazione Malati in Ossigeno - ventiloterapia e Riabilitazione - Oxygen Sick Association - Ventilotherapy and Rehabilitation [22]
- ANF Neurofibromatosi -ANF Neurofibromatosis [23]
- Anmar Italia Associazione Nazionale Malati Reumatici - Italian National Association of Rheumatic Patients [24]
- ANNA – Associazione Nazionale Nutriti Artificialmente - National Association of Artificially Nourished People [25]
- As.Ma.Ra. Associazione Malattie rare Sclerodermia ed altre malattie rare - Association for Rare Scleroderma and other Rare Diseases [26]
- Associazione Italiana Pazienti BPCO - Italian COPD Patients Association [27]
- CFS/ME Sindrome da stanchezza Cronica – CFS/ME Chronic Fatigue Syndrome [28]
- CFU Italia Comitato Fibromialgici Uniti – CFU Italy United Fibromyalgic Committee [29]
- F.A.I.S. - Federazione Associazioni Incontinenti e Stomizzati ONLUS - Federation of Incontinent and Ostomates Associations ONLUS [30]
- FAND Associazione Italiana Diabetici - FAND Italian Diabetic Association [31]
- Forum Nazionale delle associazioni di nefropatici trapiantati d'organi e volontariato - National Forum of Associations of Transplanted Organs Kidney Patients and Volunteers [32]
- GAT-GRUPPO AIUTO TIROIDE - GAT- Thyroid Aid Group [33]
- LIS - Lega Italiana Sclerosi Sistemica - Italian League of Systemic Sclerosis [34]
- Parent Project - Distrofia di Duchenne e Becker - Parent Project - Duchenne and Becker Dystrophy [35]
- PARKINSON ITALIA - PARKINSON ITALY [36]
- Respiriamo Insieme - Breathing Together [37]
- SIMBA – Associazione Italiana sindrome, malattia di Behçet e Behçet like - Italian Association of Behçet's syndrome, disease and Behçet like [38]
- SOS Alzheimer [39]
- UILDM - Unione Italiana Lotta alla Distrofia Muscolare - Italian Union for the Fight against Muscular Dystrophy [40]

Results, Responses, and Solutions

This section of the article hosts both a summary of the major issues faced by patients but also a set of recommendations put forward by patient associations.

Patients' discomforts

Starting from the lockdown and continuing with the consequences that are still visible today, the pandemic has caused countless effects on patients with chronic and rare diseases. Above all, the Report has highlighted several major patients' discomforts.

More than two in five patients reported canceled visits, exams, or surgeries; more than one in three had difficulty in keeping in touch with specialists and centers of reference for their pathology; more than one in ten did not have the personal protective equipment or did not find the drugs they needed because, very often, they were used for Covid-19 patients. In addition to the "practical" difficulties, there were psychological discomforts, reported by almost three out of five citizens, including uncertainty, fear, anxiety and sadness, a sense of loneliness, anguish, fatigue, and confusion.

The associations' response

From the forensics lab for growth hormone deficient kids to the online help desk for women with fibromyalgia, from online yoga classes for endometriosis to the game on rare diseases, over 85% of associations have enhanced their activities to stay in contact and support their members, in the most varied ways and fields. 70% increased communication channels to their members; 50% activated psychological support services; 38% carried out socialization services such as workshops, group video chats, collection of testimonies, games, social and educational support; almost 15% organized video lessons of physical activity; and about 9% also activated a legal and work assistance service. Furthermore, one in three associations has collaborated with health professionals to obtain information and online advice for its patients, but also with other associations to carry out information campaigns and put pressure on institutions.

Recommendations

From the pandemic, there are also solutions that must be spread so as not to go back to the

Pre-pandemic situation:

1. **Guarantee more innovation.** According to the 2019 CnAMC Report [41] 27.5% of associations in 2019 declared that they had to go personally to the counter to request the necessary exams and check-ups. During the lockdown period, the associations experimented with innovation especially in the phase of managing the disease, as they themselves had to guarantee telemedicine and remote rehabilitation services in the emergency; but the possibilities offered by technological innovation and digitalization are equally decisive in the prevention phase and for therapeutic adherence. It is, therefore, necessary to start from factors that are as obvious as much as they are neglected: first, the implementation of the electronic health record and the start of simplification procedures to access it; secondly, the increase in telemedicine services for checks and consultations, and the management of patients at home; finally, the networking of pharmacies with other actors who protect public health, with the aim to promote synergies and with particular attention to inland areas where services are scarce, where there is a very high percentage of people with chronic disease also due to demographic reasons, and recourse to hospitalization is often improper due to the lack of reassuring alternatives.
2. **Reduce bureaucracy and give more time for the relationship.** Again in 2019, 42.5% of associations reported the need to have more time and quality in the relationship between patient and healthcare professionals. The time for listening and for the report must be "recovered" by adopting methods of taking charge and managing chronic patients aimed at simplifying and overcoming bureaucratic difficulties, as required by 55.2% of the associations of chronically ill patients. In order to reduce bureaucracy, some important procedures tested during the emergency period must be fully implemented, such as the dematerialized prescription and the automatic renewal of the therapeutic plans. It is also necessary to allow faster access to pain medications, facilitate the pathways to recognize disability, ensure pharmaceutical and prosthetic assistance that is not only effective but also equitable throughout the country.
3. **Guarantee quality hospitals and proximity services.** The 2019 CnAMC Report also highlighted the poor integration between primary and specialist care, the lack of continuity of

care in the transition from hospital to territory, the failure to enhance home care, and the poor personalization of care as critical factors.

Some models of assistance that move certain services from the hospital to the local area or home need to be extended: examples are the administration of drugs for cancer patients outside of hospitals, using the territorial branches of the NHS/Territorial Social Health Authorities (ASST in Italian) or the patient's home; the transition to more easily manageable routes of therapeutic administration, compared to the infusion ones, at local facilities or home, for those drugs that have both routes of administration and with the same authorized therapeutic indication; home delivery in light of particular difficulties in moving the patient, of those pharmacological therapies normally distributed in direct mode (PHT), subject to the authorization of the referring doctor; the administration of vaccines in alternative places to vaccination centers and closer to citizens, such as GPs and PFC, workplaces, pharmacies, schools.

4. **Go back to take care of us.** In 2019, 82% of people with chronic or rare disease recorded a delay in diagnosis due to various factors including the underestimation of symptoms, the lack of specialized personnel in the area, waiting lists (CnAMC 2019 Report).

The pandemic has exacerbated these problems. However, as the Ministry of Health itself states on its website, "People with chronic diseases must resume treatment as soon as possible if postponed in the emergency phase of the pandemic". "Let's get back to taking care of ourselves", as the information campaign just launched by Cittadinanzattiva says [42]. To do this, it is necessary to plan ad hoc paths and procedures for all fragile subjects and for the family members or caregivers who support them; it is necessary to offer uniformity and equal opportunities for access to services, regardless of the place of residence; it is necessary to invest in the role of the caregiver through adequate training and above all through the simplification of the path of recognition of the qualification of caregiver.

5. **Encourage civic participation.** 43.1% of the associations replied that they had not been involved at all, in any Region, in the implementation of the Chronicity Plan and 25.6% did not know if, concerning the reference pathology, the data relating to patients were included in regional or national registers (CnAMC 2019 Report). Regarding health promotion, prevention, and early diagnosis, 82.3% of the programs for the change of lifestyles and the fight against risk factors were promoted by the associations themselves, and only 4.3% by Regions, doctors, and public universities.

Even outside of the crucial phase of the health emergency, the condition of public health and its reform can only be addressed from the perspective of community leadership and synergy between institutions, operators, and citizens. And, of course, this is true not only at the national level. For this reason, Active Citizenship Network, the EU branch of the Italian NGO Cittadinanzattiva, within the context of the 15th European Patients' Rights Day (EPRD), held on May 5th & 6th, 2021, has participated in the Global Health Summit held in Rome on May 21st, 2021 by sending a video message and 10 concrete proposals to the institutions called upon to discuss how to prevent future global health crises [43].

From a national to a EU perspective: the Global Health Summit's "Rome Declaration" and Active Citizenship Network's valuable contribution

In the role of needed changes towards more resilient healthcare systems, it is necessary to recognize 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. This is the message that came to light during the European conference of the 15th European Patients' Rights Day, promoted by Active Citizenship Network. The event was realized thanks to the unconditional support of F. Hoffmann-La Roche LTD, Teva Europe, Boehringer Ingelheim International GmbH and Viartis and it involved more than 150 civic society representatives from across Europe, members of the European Institutions and key stakeholders. The focus of the 2021 edition of the European Patients' Rights Day was on the effects of the recent pandemic on national health systems and on how patient organizations faced it, offering answers to people and actions that should be put in place in order to have more resilient healthcare systems, starting from the 14 rights stated in the *European Charter of Patients' Rights* [44]. The lessons learned by the Covid-19 pandemic demonstrated how all countries need to better work together to improve global health security and why Patient Advocacy Groups must have a greater voice at the table.

The Global Health Summit, co-organized by the European Commission and Italy as chair of the G20, has been an opportunity to share the lessons learned from the pandemic and to define a joint commitment to build a healthier, safer, fairer and more sustainable world. Global leaders and high-level experts also discussed on how to improve health security, strengthen EU health systems, and enhance Europe's ability to deal with future crises in a spirit of solidarity. Their goal was to create a 'Rome Declaration' [45] including principles which can be a powerful guide for medium to long-term structural change, brought about through international cooperation and joint action to increase global health security. Active Citizenship Network has also contributed to the discussion, creating both a video message addressed to the political leaders and experts gathered together in the Global Health Summit, and drafting 10 concrete proposals to the institutions called upon to discuss how to prevent future global health crises.

Priority attention to non-Covid patients, especially oncological and chronic, in order not to lose the progress achieved in the last 20 years in terms of prevention and treatment. Ease of access to health services and

medicines to reduce inequalities and "leave no one behind". Investments to have more resilient health services and to support research for more equitable access to care and to address unmet health needs. Strong reference to the sense of responsibility at all institutional levels in order to transform into acts the spirit of solidarity between countries which is a precondition for dealing with crises worldwide. These, in summary, were the main messages hosted in the video [46].

Also, starting from the concrete experiences made during the pandemic, 50 associations from 18 countries signed a Manifesto [47] with 10 Recommendations addressed to European institutions, to remark the unmet needs of non-Covid patients, drafted by Active Citizenship Network and launched on the occasion of the recent European Patients' Rights Day.

Among these recommendations there is the one to encourage forms of monitoring such as the Italian one promoted by the Civic Observatory on NRRP "Follow the Money" – to involve citizens, in every country, in the use of funds in order to improve the healthcare system. Secondly, as in any reconstruction, the involvement of a large number of active and attentive civic and social actors is essential in order to improve European healthcare systems.

The other eight recommendations are: to monitor Covid-19 impact on non-Covid-19 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 pandemic; to develop a Manifesto for 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 (CoFoE) [48].

The Global Health Summit was a significant opportunity to strengthen cooperation and solidarity, and to renew mutual commitments to reform, transform and invest in global health. It was also a space to define new models of action and powerful synergies able to immediately ensure essential vaccines and medicines to citizens of all countries of the world, fighting inequity and inequality.



Figure 1: global health summit conference, May 21, 2021, rome.

President of the European Commission Ursula von der Leyen together with Italy's Prime Minister Mario Draghi at the Global Health Summit Conference held in Rome on May 21st, 2021.

The 2022 European Patients' Rights Day

The celebration of the European Patients' Rights Day [49] has become a regular annual event on the European and national political agendas to inform, discuss and take commitments to improve patients' rights in Europe and in each Member State. Every year, also thanks to the more than one hundred patient and civic associations of our network, the EPRD is celebrated in hundreds of cities and ways all around Europe [50], allowing civil society to fully enter policy making processes and achieve important objectives.

In this view, the European celebration of the 2022 XVI European Patients' Rights Day, to be held next 20th and 21st April 2022, will be organized by Active Citizenship Network 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. In particular, just before the end of the Conference on the Future of Europe (22-24 April 2022 tbc), 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 (NRRPs)? 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. The first day will be 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. The second will instead focus 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. This will be done thanks the following preliminary actions:

1. The recognition of the main themes that emerged from the health-related initiatives hosted by the official portal "FuturEU platform";
2. 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 (NRRPs).

Given the current situation of uncertainty, the XVI European Patients' Rights Day will be organized in a digital format, with the hope that it can be transformed into a hybrid event, with onsite & online attendance. Regardless of its format, the main objectives of the 2022 EPRD are:

- To collect ideas to fuel EU initiatives, exchange and discuss different experiences, best practices and more effective solutions - from a civic point of view - to overcome the challenges for global health of this historic moment.
- To provide the leaders of civic associations and patient advocacy groups the opportunity to participate in an EU debate and keep them updated on the decision-making process on health priorities.
- To ensure community leadership and the participation of society as a whole: involve all stakeholders, especially civil society, to achieve ambitions for a European health union.

The question now, is, as the EPRD is approaching, 'will political leaders at the Global Health Summit insist on the integration of Patients' Advocacy Groups as part of the new strategy?' Expectations are high.

Europe has just begun to overcome the Covid-19 crisis and there is a brighter horizon ahead. However, Europe is still facing widespread public health crises, which, will not be defeated without a health union, that allows for an efficient use of our resources and for preventing unnecessary suffering to patients. Patients' Advocacy Groups are the voice that needs to be heard, to ensure fair and equal access to healthcare. In this regard, the Rome Declaration is an opportunity to shape a public policy which citizens will understand and welcome. It's time to act as one, together we are stronger - together, we are healthier.



Logo of the 2022 Edition of the European Patients' Rights Day.

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

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.

Conflict of interest

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

Acknowledgments

The authors would like to thank the CnAMC colleagues, starting from Tiziana Nicoletti, Coordinator of the Chronicity Policies of Cittadinanzattiva.

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38. SIMBA – Associazione Italiana sindrome, malattia di Behçet e Behçet like (IT language).
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