

Active Citizenship Network

Action Plan 2020 – 2021

(Updated on 6th December 2019)

Preamble

Active Citizenship Network (ACN) is one of the most widespread and flexible European citizen network. Established in 2001, it is the European branch of Cittadinanzattiva, the Italian non-profit organization founded in 1978, independent from any political affiliation, trade unions, private companies and public institutions.

The main objectives of ACN are the promotion of civic activism and participation in the political arena, and the protection of citizens' rights, which are both the strength and the uniqueness of ACN.

In the last few years, ACN was able to involve in its initiatives 206 civic, patients and user organizations coming from 34 Countries, plus 21 European/Global network/umbrella organizations.

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This document is in line with our multi annual plan that is based on the following 4 pillars: rights & duty, sustainability, empowerment, cross-border related issues. The majority of the following activities represent the follow up of some initiatives already developed in 2018/2019, being in continuity with them.

1) Institutional activity at the EU level on citizens' rights with the new EU Parliament and the EU Commission

ACN is deeply involved and active in the European and national debate on citizens' rights and it has a concrete interest in improving their protection across Europe, as showed by its long-lasting commitment on the topic.



a) **MEPs INTEREST GROUP “EUROPEAN PATIENTS’ RIGHTS & CROSS-BORDER HEALTHCARE” SECOND TERM (2019-2024)**. Promoted by Active Citizenship Network and endorsed by almost 100 associations across Europe, the Interest Group renews its commitment to be a place of dialogue for the development of the policy making process at the EU level. In line with the commitments taken during the first mandate, the objective is to increase - in a multi stakeholder perspective – the cooperation among EU Institutions, citizens & patients organizations. It will be focused on the one hand, to the patients’ rights for the reduction of health inequalities, and on the other hand, on the priorities underlined by the new EU Health Commissioner. Why the MEPs Interest Group “European Patients’ Rights and Cross-border Healthcare”? [Read more](#)

b) **TRAINING DIALOGUE ON WELLNESS & HEALTH WITH MEPs**. With specific reference to the issue of health and well-being, Active Citizenship Network intends to promote a cycle of institutional meetings at the European Parliament targeting the new MEPs and their staff. Both the members of the new Environment, Public Health and Food Safety (ENVI) Committee and those who will be involved in other relevant parliamentary committees will be invited to the seminars. The initiative will receive the significant contribution of several experts (scholars, [members of the Expert Panel / scientists appointed by the Director-General for Health and Food Safety of the European Commission](#), etc.), and it will contribute to improving the level of knowledge of those main themes that specifically deal with the health and well-being of European citizens. The aim is to: a) provide MEPs with scientific evidences and proofs of civic awareness serving to the taking of future political decisions on themes of general interest; b) open a constructive dialogue with regard for the roles and responsibilities of the different stakeholders involved in healthcare issues; c) present to the institutions the activity and the impact of civic associations, patient advocacy groups and NGOs, in order to avoid any inaccurate evaluation which disregards the activism of thousands of European citizens constantly committed to the protection of public health as an ultimate common good.

c) **INTER-INSTITUTIONAL GROUP “SDGs FOR WELL-BEING AND CONSUMERS’ PROTECTION”**. Citizens at the global level are united by a common language, that of the Sustainable Development Goals (SDGs), which should shift from being a simple language to being a shared “culture of doing”. In line with Cittadinanzattiva's commitment on the topic, in the immediate aftermath of the European elections, Active Citizenship Network will promote, together with other actors, a political initiative that aims at the creation of an Inter-Institutional Group composed of some members of the new European Parliament and some members of the European Economic and Social Committee. This Group will be called "SDGs for well-being and consumer protection" and it will try to approach at least some of the 17 Sustainable Development Goals in order to highlight the connection between the European dimension and the protection of the citizens as users and consumers. This Group will enable us to maintain a certain focus on the effectiveness and the level of protection granted by consumers policies in order to benefit European citizens. [Read more](#).



2) European Patients' Rights Day 2020

In 2020, the global challenge of the Antimicrobial resistance (AMR) will be addressed from a citizen perspective and in One Health approach. Read more about ACN [commitment on the topic](#) and our role as stakeholder of the European Joint Action on Antimicrobial Resistance and HealthCare-Associated Infections (EU-JAMRAI). Inaction is projected to cause millions of deaths globally: it has been [estimated that AMR might cause more deaths than cancer by 2050](#).

Apart from the human suffering caused by this development, AMR also pushes up the cost of treatment and diminishes the productivity of the workforce due to illnesses.

In the EU alone, it is estimated that AMR costs EUR 1.5 billion annually in healthcare costs and productivity losses. AMR also threatens the achievement of several of the United Nations' Sustainable Development Goals, particularly the targets for [good health and well-being](#) (goal 3).

Against this background, there exists a huge discrepancy between the severity of the situation and the low level of awareness of European citizens and this is unacceptable. Considering that this phenomenon causes more deaths than car accidents, why are most people unaware of it? What are we doing to increase controls in healthcare facilities, to adopt innovative solutions, and to improve the behavior of healthcare workers as well as patients and their families? How can we make sure that this issue will be included in the next European political agenda for the coming years? How can we favor a better cooperation among the actors involved in order to guarantee higher patients' safety standards?

We are confident that the European Patients' Rights Day (EPRD) will continue to be in the next years one of the main Forum where to discuss the future of European healthcare and patients' rights.

For the coming years, the EPRD will address - in a multi-stakeholder perspective - the drivers to reduce health inequalities, in line with the "[Position Paper on prevention, innovation and a new health governance for the new EU Institutions](#)" drafted by ACN with the endorsement of 18 associations as follow up of the EPRD 2019. In the coming editions of the EPRD, the drivers to reduce health inequalities will be identified by ACN in a specific angle, for instance: the role of digital health, the role of innovations (drugs, therapies, Car-T), the role of the personalized medicines, etc. This format will be useful for helping the different stakeholders to answer the following questions: under what conditions, and to what extent, can these factors reduce health inequalities? How to avoid first class and second class patients in the access to care? What role should be recognized to civic and patient associations in the whole cycle of the public health policy? How to guarantee to the advocacy groups an efficient and effective civic participation, both in the event that it arises as a spontaneous/autonomous initiative, and in the event that it instead arises from a specific request coming from the Institutions/stakeholders? How to address the health inequalities? How to disseminate the successful experiences across Europe? How to measure the outcomes of the various initiatives?



3) Vaccination policies

As a member of the Technical Advisory Group committed to increase vaccine coverage, led by the [European Centre for Disease Prevention and Control](#) (ECDC), we are very dedicated on the topic, both at the national level and at the EU level, as you can [read](#).

In coming years, our commitment will be focused to continue strengthening the informal network of civic and patients' associations, advocacy groups, think tanks, etc. able to unite and valorize the actors that promote vaccination, recognizing its fundamental importance, struggling against the climate of vaccine hesitancy, encouraging the exchange of information and the collection of data, and ensuring greater coordination in joint advocacy activities at the European level. To do so, we'll work in the following three directions:

- a) **a social media communication campaign across Europe** will be launched to contribute to the promotion of the core message of the European Immunization Week (EIW): immunization is vital to prevent diseases and protect life. A widespread social media communication campaign in at least 6 European countries can support this core message.
- b) **Official stakeholder & partner of the following European initiatives:**
 - [EU-JAV - European Joint Action on Vaccination](#),
 - [Coalition for Vaccination](#)
 - [VAC4EU](#) a follow up of the [IMI ADVANCE Project](#).

Our role in these initiatives is to bring our national and international experience and to engage and involve our network of associations to continuing to:

- gather insights to feed EU initiatives, providing – from a civic point of view – institutional and healthcare stakeholders with the elements or specificities that may affect the level of vaccines coverage, hesitancy, etc. in different countries, with particular attention to the more disadvantaged or inland areas;
- guarantee efficient knowledge transfer and constant updates among our partners, stakeholders, and the general public through the dissemination of the main outputs (tools, guidelines, recommendations, etc.) and outcomes (best practices, lessons learned, etc.) of the JA, the Coalition, and VAC4EU. For instance, we produce a special thematic ACN-newsletters to spread information, materials, contents and proposals among over than 17.000 subscribers. Moreover, we ensure a coordinated presence on social media such as Facebook, Twitter, LinkedIn, etc.
- underline that it is our duty as active citizens to prevent illnesses, save lives, and to enhance economic and social productivity by deciding to vaccinate.

c) **Advocacy work to involve, motivate and inform the new MEPs:**

in the framework of our interaction with the new European Parliament, and thank to our advocacy work to involve, motivate and inform the MEPs, we have received the attention of parliamentarians so much that the first meeting (Official launch 2019-2024 term) of the “MEPs Interest Group “European Patients' Rights and Cross-border Healthcare” will be a public event focused on vaccine hesitancy and uptake. This event will take place on the 28th of January 2020.

Delivered by the new European Parliament, these commitments may represent a clear message to European citizens and patients that the European Institutions are closer to their needs and ready to protect their health rights.



4) Build a safer healthcare by increasing the awareness of patient associations & advocacy groups on healthcare-associated infections (HAIs) and Antimicrobial Resistance (AMR)

At the national level, we are in the technical group of coordination of the Ministry of Health for the implementation of the National Plan against antimicrobial resistance.

At the EU level, in 2002, ACN drafted the European Charter of Patients' Rights together with other patient associations from 15 different countries. The Charter underlines, among others, the Patients' Right to preventive measures, the Patients' Right to the observance of quality standards, the Patients' Right to safety, the Patients' Right to Innovation.

To encourage the implementation of the abovementioned patients' rights, we have developed activities in different fields of action, as you can read in [our website](#).

Our commitment on the topic allowed us to signed a MoU with INSERM, the coordinator of the EU JAMRAI, which recognized ACN as official collaborating stakeholder to the Joint Action.

On AMR, in 2019 ACN has strengthened a partnership with EFPIA and FEAM - the Federation of European Academies of Medicine, and - in collaboration with sixteen citizens' organizations - drafted an open letter to the Members of the European Parliament, urging them to bring antimicrobial resistance (AMR) to the forefront of EU inter-institutional discussions.

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In the 2020/2021, ACN commitment on the topic will be focused:

- a) to organize training seminar on patient safety, risk management & healthcare-associated infections (HAIs), Antimicrobial Resistance (AMR) opened to a selected number of leaders of patient associations and advocacy groups coming from EU Member States plus some Extra EU Member State.
- b) To encourage our constituency to be more active on the topic. To do so, we have decided to dedicate the 2020 Edition of the European Patients' Rights Day to the global challenge of the Antimicrobial resistance (AMR), to be addressed from a citizen perspective and in One Health approach.
- c) to continue to gather good practices and possible solutions also with regards to patient safety in order to guarantee a balance between the sustainability of health systems and a concrete access to quality & safety of care for all EU citizens. In this context, a better control of the pathogen contamination is a key aspect, also taking into account that healthcare-associated infections affect up to 15% of hospitalized patients: persistent microbial contamination of hospital surfaces and growing drug resistance of pathogens are among the main causes. To bring healthcare into the future, there is an urgent need for effective, alternative and sustainable ways to reduce the pathogens.



5) Pain management

With regards to the patients' right to avoid pain, for many years we have been very active at the national (Italy) and the EU level, as you can read on [our website](#).

In the last years, we have launched the [first European Prize of Good Practices in the fight against pain](#) (I° and II° Edition), gathered over 100 good practices from 2014 to date, become official partners of one of the most important multi-stakeholder initiatives ([SIP-Societal Impact of Pain](#), Editions 2016, 2017, 2019) and won an [international Award](#).

Above all, we have contributed to increase the attention and the commitment of the European institutions on the issue: chronic pain is mentioned in the recent [Conclusions of the Council of the European Union](#); the European Union has recently allocated more funds for research dedicated to the topic; [DG-Santè has opened its EU Health Policy Platform to a group of experts on the subject](#); the European Parliament hosts an Interest Group and [initiatives](#) on the subject; etc.

Our objectives for 2020/2021:

- a) To encourage a better cooperation with the European Commission, in order to:
 - a) value the good practices collected during the different editions of the "European Civic Prize on Chronic Pain: Collecting Good Practices" by hosting them within the [EU Best Practice Portal](#) promoted by EU Commission.
 - b) consider a potential expansion of the "Area/Topic of interest" search list on the EU Best Practices Portal by adding a new specific subject area: Pain/Chronic Pain (Cancer and non-cancer related).
- b) Taking into account that the 4 winning practices of the II° Edition of the Prize are all digital solutions, more precisely mobile apps, we intend to deepen the connection between digital health & pain not only by using the most recent innovations, but also considering what is the level of empowerment that is required from pain patients to be able to take full advantage of these devices.
- c) To launch & carry out the third Edition of the "European Civic Prize on Chronic Pain: Collecting Good Practices".
- d) As [official members of the SIP](#) platform, our commitment is to continue supporting the political initiative Societal Impact of Pain at the European level and across Europe: [Joint statement](#), [SIP at the national level](#), etc.
- e) As board members of [Pain Alliance Europe](#) (PAE), we aim to promote coordinated activities to better advocate on the topic of pain.
- f) "Pain policy advisory board": as an official member of this multidisciplinary expert group comprised of patient advocacy organizations and clinicians, we will contribute to identify core policy issues and solutions for the optimal management of chronic pain in general & chronic low back pain in particular at the European level.
- g) To realize, together with [Sine Dolore - European Pain Foundation](#), the annual meeting of the Pain Euro-Mediterranean Coalition: the first civic hub-incubator of best practices against pain across Europe. This community is an informal network of manager & operators of best practices to facilitate the exchange of knowledge that every year is enriched by the participation of the winners of the Award. Here you can read the Annual Meeting realized in [2018](#) and [2019](#) in Spain.
- h) To promote common initiatives with our European and international partners, the [European Network of Fibromyalgia Associations](#) (ENFA) and the [World Federation of Incontinence and Pelvic Pain](#) (WFIP), with whom we have signed different agreements of cooperation throughout 2018.
- i) To open a dialogue on the topic of pain and to exchange experiences with Extra-EU representatives (including US representatives), as we are actually starting to collect good practices from outside the EU.

6) Increasing consciousness and access to treatment, reducing the burden of cardiovascular diseases across Europe.

In order to reduce the number of deaths due to cardiovascular diseases, in 2013 European Member States signed the Health for Growth Programme, the third multi-annual programme of EU action in the field of health for the period 2014-2020. The aim is to identify, spread and promote the adoption of validated good practices for efficient and sustainable prevention measures, facing the main risk factors related to cardiovascular diseases, fighting tobacco use, alcohol dependence, obesity and promoting good lifestyles. In this context, over the last 15 years, Cittadinanzattiva-Active Citizenship Network has been increasing its contributions for the prevention of cardiovascular and cerebrovascular diseases, as you can read on our website ([EN](#) – [IT](#)).

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Starting from 2019, we intend to increase the awareness of a growing number of patients' rights associations on the importance of the prevention and management of pathologies correlated to cardiovascular protection, as well as on the new available therapeutic options that exist today.

Active Citizenship Network proposes to realize the following 4 initiatives:

- A cycle of training seminars addressed to the leaders of civic and patients' associations from different European countries, which are not yet particularly focused on the theme of cardiovascular protection. This would offer them an update, enabling them to better answer to the demands of information and protection that citizens and patients may request in the context in which they operate.
- A European and national awareness campaign on proper lifestyles and on the prevention of the risks linked to cardiovascular disorders and pathologies. The same associations that would take part to the training seminars mentioned above would carry out such campaign.
- The third initiative consists in the promotion of a partnership between the associations involved in the cycle of training seminars (point 1) and those associations that are specifically devoted to the theme of cardiovascular protection. The objective is to create an informal network of relationships among associations, to promote the sharing of good practices, and to integrate and to strengthen initiatives on the theme, with a view to cross-border healthcare cooperation.
- A public event at the European Parliament, hosted by the Interest Group "[European Patients' Rights & CrossBorder Healthcare](#)," to share good practices and political views to subject to the attention of the new European institutions. This public initiative would involve associations and experts that have taken part to the previous activities (points: 1;2;3).



7) Cross-border healthcare, ERNs, e-Health & m-Health

The commitment of Active Citizenship Network on the topic started many years ago and it is linked to EU healthcare policy goals, underlined during the Maltese Presidency of the Council of the European Union, and stated on 16 June 2017 in the Council Conclusions on "[Encouraging Member States-driven Voluntary Cooperation of Health Systems](#)".

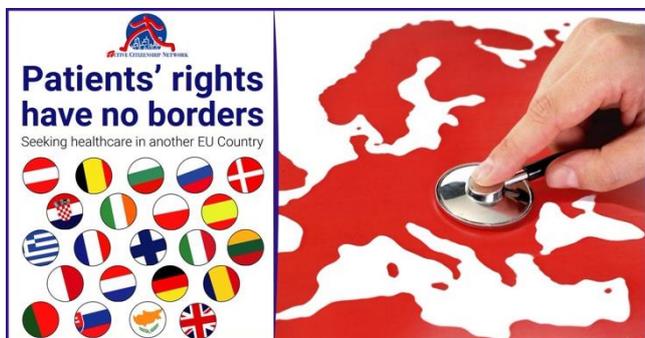
The Health Ministers have recognised that [European Reference Networks \(ERNs\)](#), when fully developed, represent an opportunity for building capacity throughout Europe in the provision of specialised health services, in particular in the field of rare diseases, so as to ensure quality of care, dissemination of knowledge and innovative practices. Thus, the Council has invited the Member States and the Commission to encourage the ERNs to attain their intended objectives of providing better access to patients requiring highly specialised healthcare.

We strongly believe that these goals could be reached also thanks to a more active role of a broader constituency of advocacy groups and patients associations, in terms of raising awareness among European citizens, facilitating the dialogue, the exchange of experiences, the collection of data & of good practices, and removing barriers & obstacles.

In particular, in occasion of the event "[Cross-border healthcare and centers of excellence to enhance patients' rights: access, information and innovation](#)", organized by ACN at the EU Parliament last 27th February 2018, ACN put forward to the EU Institutions and other relevant stakeholders the concrete proposal of **encouraging, for each ERN, the establishment of a multi-stakeholder group of interest**, opened to all the actors already involved in cross-border healthcare and in the implementation of Directive 2011/24/EU. The proposal has been welcomed by the ERNs' coordinators - starting from the Chair of the ERN Coordinators Working Group - and can be developed in the coming years.

We aim to build a network of patients/healthcare users' organizations all around Europe, so as to provide information and collect data on cross-border healthcare, improving citizens' and patients' awareness on the topic. Many public and private actors among associations, healthcare providers, companies and institutional bodies at the European level have already expressed their interest for this initiative.

Our multi-annual EU proposal is in line with [our commitment](#) to implement patients' rights in cross-border healthcare, testified by many initiatives such as the MEPs Interest Group "[European Patients' Rights & Cross Border Healthcare](#)" and the widespread Communication Campaign "[Patients' rights have no borders](#)".



8) The value of therapeutic adherence for patients and the healthcare sustainability

ACN's EU communication campaign titled "[From Therapeutic Adherence to Therapeutic Alliance](#)" was realized in 2018 with the direct involvement of 11 national advocacy groups & patients associations leaders, as well as two umbrella organizations. The same message was disseminated in the national languages of the associations involved; you can find the video in [Bulgarian](#) language (by ACN national partner in Bulgaria "Patients Organizations With You"), [Italian](#) (by our organization, Cittadinanzattiva-Tribunal for Patient's Rights), [Cypriot](#) (by ACN national partner in Cyprus "Cyprus League Against Rheumatism"), [Turkish](#) (by ACN national partner in Turkish Cyprus "Universal Patients' Rights Association"), [English](#) (by ACN national partner in Ireland "Irish Patients' Association"), in [Greek](#) (by ACN national partner in Greece "IISO"), in [Hungarian](#) (by ACN national partner in Hungary "Hungarian Federation of People with Rare of Congenial Diseases Network"), [Maltese](#) (by ACN national partner in Malta "Malta Health Network"), in [Spanish](#) (by ACN national partner in Spain "Asociation Ciudadana Afectados Cistitis Interstitial Sindrome Dolor Vescical"), in Croatian (by ACN national partner in Croatia "Croatian Association for Patients' rights").

As a follow up, ACN is interested to develop the following initiatives:

- a) To expand the abovementioned communication campaign across Europe.
- b) To carry out a tailored initiative in several EU Countries: for instance, a "Civic Consultation on the National Plan on chronicity", where groups of experts will analyze links and barriers between chronic conditions and therapeutic adherence. The goal is to compare the situation between countries and find together proposals and gather impressions, suggestions and advices on that aspect.
- c) To share recent achievements and collect good practices at EU and national level regarding therapeutic adherence in different therapeutic areas.
- d) to demonstrate what the advocacy groups community and the citizen & patients' associations can offer in terms of raising awareness regarding this phenomenon. This will enhance the knowledge of positive cases and successful experiences, strengthening the general commitment to this topic.
- e) to contribute to enrich the [EU Best Practice Portal](#) with the initiatives that we have gathered so far and to include "therapeutic adherence" as a key word of the Portal to enable people to easily find initiatives connected to this topic.

