



Action Plan for 2018 – 2019

(Last updated: 4th March 2019)

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, being in continuity with them.

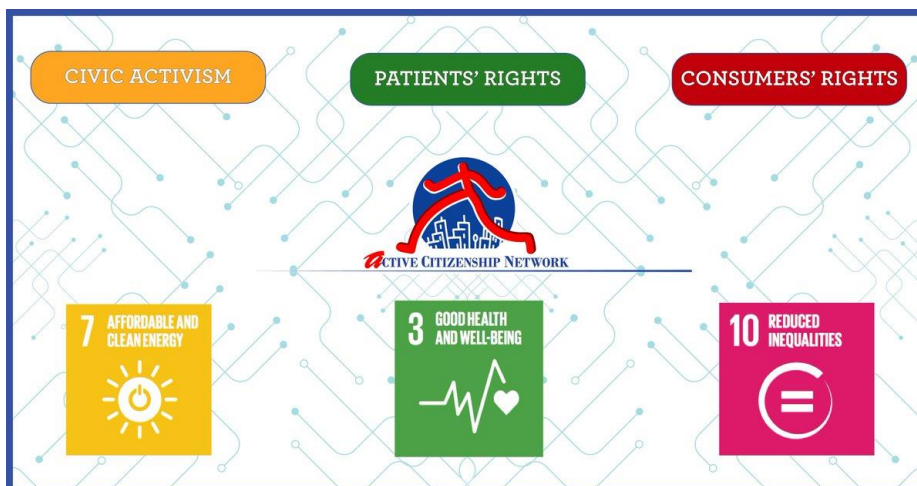
1) Institutional activity at the EU level on citizens' rights with the new EU Parliament and the EU Commission

[Active Citizenship Network](#) (ACN), the European branch of [Cittadinanzattiva Onlus](#), 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.

- **MEPs INTEREST GROUP “EUROPEAN PATIENTS’ RIGHTS & CROSS-BORDER HEALTHCARE”**. In recent years we have contributed to increase the attention of European Institutions on the issue thanks to the [MEPs Interest Group “European Patients’ Rights & Cross-Border Healthcare”](#): civic society and patient organizations together with the Members of the European Parliament to strengthen the protection of patients’ rights in the European Union. We have encouraged the creation and continuation of this interest group since 2015, following the widespread request of more than [80 civic and patient organizations](#) to officially recognize the value of citizens’ initiatives, such as the [European Charter of Patients’ Rights](#), based on the Charter of Fundamental Rights of the European Union, and the [European Patients’ Rights Day](#), which has been organized every year on April 18th since 2007 at the local, national and EU level. During 2019, in occasion of the election of the new EU Parliament and the EU Commission, ACN wants to continue its advocacy work, implementing policies, strengthening alliances, promoting public initiatives to drawing and maintaining the highest level of attention on patients’ rights, also because their reinforcement all over Europe may contribute to strengthen a sense of belonging to a European citizenship. Why the MEPs Interest Group “European Patients' Rights and Cross-border Healthcare”? [Read more](#)



- 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 due 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.
- 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.





2) The European Patients' Rights Day 2019

At the occasion of the XIII European Patients' Rights Day, on the 9th of April, a selection of candidates for the new EU Parliament - to be voted at the end of May 2019 - will be invited to discuss different priority topics linked to healthcare policies at EU level, including health promotion & disease prevention, value of and access to innovation. During the multi-stakeholder conference, titled "Delivering patient value throughout the healthcare system. An electoral debate on citizens' expectations", questions will be provided by experts selected among leaders of patient associations and advocacy groups, key stakeholders, past politicians, journalists, etc. Thanks to an interaction tool, all the attendants – approximately a hundred people coming from different Member States – will have the opportunity to discuss and ask the MEPs about their future commitment on healthcare issues.



3) 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 Prof. Maurizio Scarpa who's 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 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](#)".



4) Build a safer healthcare by increasing the awareness of patient associations & advocacy groups thanks to the following activities:

Activity n. 1: European training seminar

To organize a European training seminar on patient safety, risk management & healthcare-associated infections (HAIs), opened to a selected number (at least 20) of leaders of patient associations and advocacy groups coming from at least 8 EU Member States plus an Extra EU Member State. The initiative aims to improve:

- the overall public and private engagement on the topic;
- the role of innovation on patient safety;
- hygiene in the healthcare sector and the role of civic evaluation of public services;
- new strategies to advocate in this field of action.

Activity n. 2: Event at the EU Parliament

The idea is to realize a multi-stakeholder event at the EU Parliament immediately after the activity n. 1 in order to offer to a selected number of leaders of patient associations and advocacy groups, already involved in the European training seminar, the opportunity to attend an EU debate on the topic.

The topic of the event is linked to one or more patients' rights included in the European Charter of Patients' Rights, such as the patients' right to preventive measures (1st), the patients' right to the observance of quality standards (8th), the patients' right to safety (9th), the patients' right to innovation (10th).

Activity n. 3: Social media communication campaign

As follow-up of the three previous activities, Active Citizenship Network could promote a social media communication campaign with a video-message in several European countries (6 at least) in English as well as in different national languages.



The core message of the campaign will be co-defined. In particular, a factsheet produced by Active Citizenship Network with key messages will be customized for each country. Aims of the initiative:

- To present the topic to the wide public in a smart way;
- To



provide some source of information in the national languages;

- To increase the constituency of actors involved in the topic.

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 2 years, we have launched the [first European Prize of Good Practices in the fight against pain \(in 2018-2019 is ongoing the Second Edition\)](#), 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](#), Edition 2016 and 2017) 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 2019:

1. 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](#), and SIP Symposium 2019.
2. Second Edition of the “[European Civic Prize on Chronic Pain: Collecting Good Practices](#)”: as we have finished collecting the candidate good practices, we are now committed to select the winners of the Prize, to write and publish the final report, and to reward the four winners of the Second Edition during an award ceremony that will take place during the autumn of 2019.



3. To cooperate with the European Commission in order to 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 [Best Practice Portal](#) and introducing a new specific subject area: “pain”.
4. “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.
5. 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 is an informal network of manager & operators of best practices to facilitate the exchange of knowledge. Here you can read the Annual Meeting realized last May 2018 in Spain.
6. 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.
7. To organize an initiative on chronic pain related to fibromyalgia with the direct involvement of the European Network of Fibromyalgia Associates (ENFA), that signed a Memorandum of Understanding with Active Citizenship Network in May 2018 in Malta.
8. As board members of [Pain Alliance Europe](#) (PAE), we aim to promote coordinated activities to better advocate on the topic of pain.
9. To open a dialogue on the topic of pain with US representatives.

6) Collection of good practices in terms of therapeutic adherence in different therapeutic areas



Active Citizenship Network celebrated the 12th European Patients' Rights Day on the 23rd of May 2018 at the European Parliament as an occasion to foster communication among different partners/actors in the healing and caring process in order to improve adherence to treatments and take commitments. Starting from concrete experiences, the conference provided patient associations, health-care professionals, scientists, pharmacists, industries and representatives of national and European Institutions with the opportunity to work together to identify the main changes that are necessary to face non-adherence to treatment plans.



As a follow-up of the initiative, Active Citizenship Network has promoted a social media communication campaign in the second part of 2018 and, in 2019, ACN intends to organize a public event in the framework of the [MEPs Interest Group "European Patients' Rights & Cross-Border Healthcare"](#):

1. to explore recent achievements and share good practices at EU and national level about therapeutic adherence in different therapeutic areas;
2. to demonstrate what this community can offer in terms of raising awareness about the phenomenon, enhancing the body of knowledge of positive cases and successful experiences, and strengthening commitment to this topic;
3. 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 so as to enable people to easily find initiatives connected to this topic.

7) 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 the [initiative on the 28th of February 2018 at EU Parliament can testify](#). We are inviting more EU umbrella organizations to develop a multi-annual activity with the aim of increasing the commitment of civic society and advocacy groups on the topic. On the 6th and 7th of November 2018, we have organized a 2-days initiative "[European active citizen to advocate on the value of vaccination](#)".

In 2019, as a follow-up of the previous initiatives, we would like to promote:

A civic evaluation

To realize a civic monitoring of citizens' needs to improve vaccination coverage across Europe with the cooperation of national citizens' organizations in at least 6 European countries.

Taking into consideration the specific data of each country, provided by official sources (National Health System, ECDC, WHO, etc.), in-depth interviews with key people will be carried out. In particular, leaders and representatives of civic and patients' associations as well as health professionals will be involved. The aim is to underline the strengths & weaknesses of national vaccination policies for each selected country, looking for recommendations as well good practices.

A social media communication campaign

Cittadinanzattiva, through its EU Branch Active Citizenship Network, is deeply committed 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.



In particular, the factsheet produced by Active Citizenship Network in occasion of the initiative promoted at the European Parliament and entitled [“The challenges of life-course vaccination to enhance public health protection in Europe: a multi-stakeholder approach”](#) was customized for each country.

8) 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 third multi-annual in the field of health. The aim is to identify, adoption of validated efficient and measures, facing the to cardiovascular use, alcohol promoting good over the last 15 years, Citizenship Network contributions for the cardiovascular and as you can read on our

Growth Programme, the programme of EU action for the period 2014-2020. spread and promote the good practices for sustainable prevention main risk factors related diseases, fighting tobacco dependence, obesity and lifestyles. In this context, Cittadinanzattiva-Active has been increasing its prevention of cerebrovascular diseases, website ([EN](#) – [IT](#)).

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



Active Citizenship Network proposes to realize the following 4 initiatives:

- 1) 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 vascular 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.
- 2) An European and national awareness campaign on proper lifestyles and on the prevention of the risks linked to cerebral and cardiovascular disorders and pathologies. The same associations that would take part to the training seminars mentioned above would carry out such campaign.
- 3) The third initiative consists in the promotion of a partnership between the associations described in point 1 and those associations that are specifically devoted to the theme of vascular 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.
- 4) 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 (point 1;2;3).

