

EU4Health Civil Society Alliance Joint Position Paper

Towards meaningful engagement of health civil society organisations in EU public health policymaking

Building on [the call by Civil Society Europe for an EU Civil Society Strategy](#) signed by more than 300 civil society organisations, and following the publication of the conclusions of the Conference on the Future of Europe (CoFoE), this EU4Health Civil Society Alliance joint position paper supports the case for a **more meaningful and systematic engagement of health civil society organisations (CSOs)** in EU policymaking processes. Notably, this should not only restrict to EU health policymaking, but span across all relevant policy areas of key impact on public health.

The meaningful engagement of CSOs will strengthen democratic processes by improving participation and representation of citizens' and professionals' voices and interests in health (and relevant) policy debates at the European level. It will support the EU in achieving key goals such as **promoting health and preventing diseases across all Member States, improving access to affordable healthcare, integrating health systems, reducing health inequalities, protecting public health from commercial interests, and ensuring that no one is left behind**¹. This could be achieved through the development and implementation of a concrete civil society strategy that enables and institutionalises greater dialogue and establishes a level playing field for CSOs to participate on equal terms with the other stakeholders involved in the democratic and policy processes at the EU level.

I. The case for more meaningful engagement of health CSOs

Despite the pivotal role played by CSOs during the COVID-19 pandemic, different obstacles have increasingly affected their ability to carry out their activities either in full or in an independent manner, such as facing restrictions of their activities, attacks, or being prevented from carrying out their monitoring role in some sectors². Both the European Civic Forum report and the European Commission's rule of law report³ have shown gaps in European measures to support CSOs facing such challenges. **It is paramount for the European Commission to support CSOs in overcoming these barriers.**

A shrinking civic space has also affected CSOs, impacting their resources and capacity to engage and support European democracy.⁴ The European Civic Forum report highlighted the need to **build a vibrant and thriving European civic space** with the support from the European institutions. Despite an increased emphasis on the need to strengthen health policies following the COVID-19 pandemic, CSOs in the health area have faced the prospects of losing public EU funding to support their operations, with the potential phasing out of the OPGs in 2022 and 2023. This adds to recurrent and long-lasting

¹ Leave no one behind is Principle Two from the United Nations' 2030 agenda for Sustainable Development Goals. More information: <https://unsdg.un.org/2030-agenda/universal-values/leave-no-one-behind>

² European Civic Forum, Civic Space Watch (2022). Towards vibrant European civic and democratic space. Available at: <https://civic-forum.eu/wp-content/uploads/2022/06/European-civil-society-strategy-2022-Factsheet.pdf>

³ European Commission (2022), Rule of Law Report, available at: https://eur-lex.europa.eu/resource.html?uri=cellar:2e95c008-037b-11ed-acce-01aa75ed71a1.0001.02/DOC_1&format=PDF

⁴ European Civic Forum, Civic Space Watch (2022). Towards vibrant European civic and democratic space. Available at: <https://civic-forum.eu/wp-content/uploads/2022/06/European-civil-society-strategy-2022-Factsheet.pdf>

requests for **meaningful civil dialogue and for the provision of consistent support to civil society, especially through funding⁵ and recognition**, across different policy fields.

The conclusions of the CoFoE, published in May 2022, further support this call for an enhanced role for and engagement of CSOs, particularly those that are health-focused⁶. If well implemented, the conclusions could allow health CSOs to play an even bigger role in future and better European policymaking, acting as a bridge between EU institutions and citizens, including the most vulnerable, most affected, and otherwise underrepresented.

Building on these conclusions, **Civil Society Europe, supported by more than 300 organisations including the EU4Health Civil Society Alliance, has called for the European Commission to develop a Strategy dedicated to support CSOs active in the European Union**. This demand has been supported by the European Parliament's Resolution on the shrinking space for civil society which passed a majority vote on 8 March 2022 and was later on adopted at the CoFoE on 9 May 2022⁷. If established and implemented, the strategy for civil society would help CSOs implement and develop their advocacy activities, particularly in reaching out to citizens and carrying their voices at the European level. Furthermore, it would enable CSOs to work towards and find innovative ways for a more meaningful engagement of civil society in health policy and other fields at the EU level. The strategy could do so by institutionalising participatory mechanisms, ensuring civil society a permanent seat at the decision-making table, providing a status to CSOs, and stable funding opportunities.

Civil Society Europe calls for a **proactive Civil Society Strategy, recognising the essential role of CSOs, creating an open civic space, and building resilience for civil society, particularly important in a multicrisis context**. This Strategy should fill in the support and protection gaps identified by the European Commission's rule of law report and by the European Civil Forum, and should provide ways for civil society to engage more meaningfully in EU policy making.

Following these calls the European Commission Work Programme for 2023 included a legislative initiative on a statute for European cross-border associations and the development of a defence of democracy package, including the development of a civic space and of citizen participation. However, the Work Programme does not provide details on the implementation of such objectives.

Civil Society Europe has welcomed these developments⁸ and recommended expanding the mandate of the Commission Vice Presidents responsible for values, transparency and dialogue with civil society; democracy; and of the Commissioner for Justice, to ensure a more structured dialogue with CSOs. Additionally, it also advocated for: (1) the development of an action programme for civil society and rights defenders, which would push for more capacity building, (2) monitoring the participation of civil society to ensure that this is not limited to consultations and other tick-box exercises, (3) ensuring that the meaningful involvement of CSOs in different policy areas is structured in line with the normal steps

⁵ European Civic Forum, Civic Space Watch (2022). Towards vibrant European civic and democratic space. Available at: https://civic-forum.eu/wp-content/uploads/2022/06/European-civil-society-strategy-2022_Factsheet.pdf

⁶ See Annex 1 for an analysis of the conclusions.

⁷ European Parliament (2022). European Parliament resolution of 8 March 2022 on the shrinking space for civil society in Europe. Available at: https://www.europarl.europa.eu/doceo/document/TA-9-2022-0056_EN.html ; EU4Health Civil Society Alliance (2022). The EU4Health Civil Society Alliance joins the call to the European Commission for a EU Civil Society Strategy. Available at: <https://eu4health.eu/the-eu4health-civil-society-alliance-joins-the-call-to-the-european-commission-for-a-eu-civil-society-strategy/>

⁸ Civil Society Europe (2022). The Defence of Democracy Package Building a Resilient Democracy and a strong and vibrant civic space - Preliminary Proposals from Civil Society. Available at : <http://civilsocietyeurope.eu/wp-content/uploads/2022/10/The-Defence-of-Democracy-Package-Proposals-from-Civil-Society-1.pdf>

of policymaking, and (4) ensuring access to funding for CSOs (i.e., via Operating Grants and other instruments, such as Action Grants).

Other organisations have worked on improving dialogue with health civil society, therefore presenting good practice examples that could inspire the European institutions. The **World Health Organisation (WHO)** has, for instance, done just this through implementation of their **Framework of Engagement with Non-State Actors (FENSA)** with plans to follow this up through the launch of the WHO Civil Society Commission in mid-2023 coinciding with the next World Health Assembly⁹. The Organisation for Economic Co-operation and Development (OECD) also increasingly collaborates with civil society, for instance via the PaRIS project where a dialogue was set between policymakers, health care providers and patients to support more people-centred health systems. The EU should follow similar initiatives and be in the front row of institutions engaging with CSOs, together with the WHO and the OECD.

II. The contribution of health CSOs

Health CSOs play a significant role at the EU, national and local levels. Their crucial role in responding rapidly to crises and supporting resilience has been recently recognised during the COVID-19 pandemic and following the invasion of Ukraine. **CSOs are essential in intervening in times of crisis, and in defending democracy and the rule of law.** These crises worsen the different vulnerabilities people are already confronted with.¹⁰ Hence, supporting CSOs in delivering their work in such circumstances is paramount.

The activities of health CSOs also contribute to implementing European values and delivering **EU policy objectives, such as Green Deal, the United Nations' Sustainable Development Goals (SDGs) and leaving no one behind.** Indeed, CSOs can provide the necessary expertise on health issues to better inform the drafting and implementation of EU public health policies, in addition to bringing an independent voice to the debates.

Health CSOs are taking an active part in the **delivery of the EU4Health Programme policy objectives.** More specifically, health CSOs:

- Develop advocacy, create campaigns and share expertise on the different health priorities of the programme. This has had an impact on the Europe's Beating Cancer Plan, the Pharmaceutical Strategy, digital health and building resilience to cross-border health threats.¹¹
- Play an important part in raising awareness of key health issues such as communicable and non-communicable diseases (NCDs) prevention, rare diseases, and antimicrobial resistance (AMR).
- Address health determinants, promoting public health and improved access to affordable medicine and healthcare¹².

⁹ WHO (2022). WHO Director-General's opening remarks at the Civil Society Townhall, World Health Summit. Available at: <https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks--world-health-summit--civil-society-townhall---16-october-2022>

¹⁰ Civil Society Europe (2022). Letter to Ms. von der Leyen. European Commission work programme 2023: the need to include the development of a European Civil Society Strategy. Available at: <https://epha.org/wp-content/uploads/2022/06/letter-to-ms-ursula-von-der-leyen-220621.pdf>

¹¹ HaDEA (2022). EU's health priorities. Available at: https://hadea.ec.europa.eu/programmes/eus-health-priorities_en

¹² HaDEA (2022). About the EU4Health Programme. Available at: https://hadea.ec.europa.eu/programmes/eu4health/about_en

- Contribute to the delivery of the Programme's objectives through the **exchange of good practices at different levels of governance**, through their networks and through capacity building.
- Make a valuable contribution when it comes to **tackling health inequalities and supporting the strengthening of health systems**.¹³
- Play an indispensable role in acting as multipliers, connecting the dots between fragmented and siloed policies at the EU level, by building bridges and integrating policy areas and topics that are not traditionally considered health-relevant.

In other policy fields, such as education, social policy, or environmental policy, CSOs have taken part in activities such as:

- Coalitions and working groups on dedicated topics, including interest groups in partnership with members of the European Parliament, where CSOs can play their vital role as a watchdog;
- Co-creative processes linked to better policymaking;
- The design of activities to help establish a civil dialogue.

Strengthening the role of health CSOs will further contribute to better delivery of these activities.

III. Meaningful engagement of health CSOs in EU policymaking: our proposal

The European Commission can encourage CSOs to contribute by developing meaningful ways for them to be involved in the decision-making processes. In essence, this means promoting a **thriving civic space at the EU and national level**. This encouragement, including through financial means, is crucial to strengthening the role of health CSOs in supporting EU health objectives.

What is a "thriving civic space"?

According to the report on the shrinking space for civil society by the European Parliament, the "*civic space refers to the legal and political framework in which people and groups can meaningfully participate in the political, economic, social and cultural life of their societies, exercising the right to express views, the right to information, and the right to assemble, associate and engage in dialogue with one another and with authorities*".¹⁴

A thriving civic space implies that CSOs participate to policymaking, are supported in tackling the challenges they face, and in carrying out their activities. It also suggests that democracy is healthy and well-functioning, and the voices of citizens are heard in democratic processes, in particular through the involvement of CSOs. The European Parliament report stresses that "*for CSOs to thrive, civic space must be an enabling and safe environment free from undue interference, intimidation, harassment and chilling effects by both state and non-state actors (...)*".¹⁵

Health CSOs have called for DG SANTE to **reinstate operating grants through a multi-annual framework going beyond the annual calls of 2022 and 2023**. This would provide health CSOs with more certainty and would also create a more efficient process for the European Commission. Along with financial means, it is essential **to guarantee a level playing field for health CSOs in decision-making processes**. This is especially important when commercial determinants of health need to be

¹³ EU4Health Civil Society Alliance (2021). A missed opportunity in the EU Work Programme to support European health NGOs to play their key role in the COVID-19 pandemic and beyond. Available at : <https://eu4health.eu/a-missed-opportunity-in-the-eu-work-programme-to-support-european-health-ngos-to-play-their-key-role-in-the-covid-19-pandemic-and-beyond/>

¹⁴ European Parliament (2022). Report on the shrinking space for civil society in Europe. Available at : https://www.europarl.europa.eu/doceo/document/A-9-2022-0032_EN.html

¹⁵ European Parliament (2022). Report on the shrinking space for civil society in Europe. Available at : https://www.europarl.europa.eu/doceo/document/A-9-2022-0032_EN.html

addressed and to give civil society an equal voice among players representing other sectors and interests that could clash with the public interest and public health.

Considering the upcoming health policy initiatives to be discussed and adopted, the increased involvement of health CSOs would bring **significant added value and expertise**. The strong involvement and quality input of CSOs at the European level is needed, not just in the delivery of the EU4Health Programme objectives, but also in other key initiatives, such as the new EU Global Health Strategy, a comprehensive approach to mental health in the EU, addressing health inequities, social and commercial determinants of health, and many more. The health policy issues to be addressed during the current and upcoming Council presidencies, such as the European Health Data Space or the revision of the pharmaceutical legislation, would also strongly benefit from increased European health civil society input and participation. CSOs contribute to concretising and grounding the building blocks of the European Health Union. It is key for CSOs to be enabled and encouraged to take part in these discussions that will have a central impact on the lives of EU citizens.

Our vision for the more meaningful engagement of health CSOs includes the following recommendations:

1. We, call on the European Commission to develop, in cooperation with civil society, a **dedicated and overarching Strategy for Civil Society** as a proactive step towards meaningful **civil society engagement**.
2. We advocate for the Strategy to promote and strengthen a **civil and social dialogue and establish a dedicated civic space** on health policy, strengthening and going beyond the EU Health Policy Platform, and avoiding the shrinking space for CSOs. The involvement of health CSOs should grow beyond their inclusion in consultations and expand to programme development, policy debates and agenda-setting for EU strategic priorities¹⁶. On the model of the European Development Days¹⁷, further engagement with CSOs could consist of European Health Days discussing and **shaping the future of public health policy in the EU**. Similarly, the EU could organise a European Year of Civil Society.
3. The Strategy should recognise health CSOs for their **crucial role in times of crisis**, in building the European identity, and in democratic processes, being the intermediaries between citizens and policy makers. We call on the Commission to involve **health CSOs in crisis management discussions and other debates, following the WHO model of engaging with CSOs**. This could be done by more clearly defining the engagement of civil society in HERA (the EU's Health Emergency Preparedness and Response Authority) activities within its Civil Society Advisory Forum¹⁸.
4. The Strategy should provide a clear framework for cooperation with civil society at the EU level, ensuring stability and long-term planning. **Key commitments on the protection, financial support and level of independence of CSOs** should address the aforementioned gaps in the protection of democracy. Providing accessible means and dedicated and flexible funding

¹⁶ European Civic Forum, Civic Space Watch (2022). Towards vibrant European civic and democratic space. Available at: <https://civic-forum.eu/wp-content/uploads/2022/06/European-civil-society-strategy-2022-Factsheet.pdf>

¹⁷ More information on European Development Days: <https://eudevdays.eu/>

¹⁸ Active engagement of civil society actors could be based on the experience of the European Medicines Agency Patients and Consumers' Working Party: <https://www.ema.europa.eu/en/committees/working-parties-other-groups/chmp/patients-consumers-working-party>

through different EU programmes¹⁹ will help CSOs have an equal role with other stakeholders in health policy processes and ensure the fair representation of citizens.

5. Funding frameworks organised by the European Commission should be transparent, multiannual and aligned across the different DGs to avoid any discrepancies between sectors.²⁰ Secure frameworks for the funding of CSOs would also relieve them from seeking other sources of funding that could compromise their independence. Additionally, capacity building elements should be included in the Civil Society Strategy to support these organisations. In addition, and considering the persistent inequalities across EU countries and regions, due support should be provided to close existing gaps in the development of CSOs across the EU.

These recommendations should also be reflected in the mid-term review of the Multiannual Financial Framework for 2021-2027. The European Commission must **maintain the momentum on (public) health as a priority** within the political agenda over the coming years. The contribution of health CSOs will be crucial to ensure that health receives the attention it deserves rather than fading from the political agenda.

IV. Signatories

- Alzheimer Europe
- Association of European Coeliac Societies (AOECS)
- EuroHealthNet, a European partnership for improving health, equity, and well-being
- European AIDS Treatment Group (EATG)
- European Alcohol Policy Alliance (Eurocare)
- European Federation of Allergy and Airways Diseases Patients' Associations (EFA)
- European Federation of Neurological Associations (EFNA)
- European Health Management Association (EHMA)
- European Heart Network (EHN)
- European Kidney Health Alliance (EKHA)
- European Network for Smoking and Tobacco Prevention (ENSP)
- European Patients' Forum (EPF)
- European Public Health Alliance (EPHA)
- European Public Health Association (EUPHA)
- EURORDIS-Rare Diseases Europe
- Health Action International (HAI)
- International Diabetes Federation (Europe)
- International Sport and Culture Association (ISCA)
- Psychedelic Access and Research European Alliance (PAREA)
- Smoke Free Partnership

¹⁹ European Civic Forum, Civic Space Watch (2022). Towards vibrant European civic and democratic space (report). Available at : https://civic-forum.eu/wp-content/uploads/2022/05/European-civil-society-strategy-report-2022_European-Civic-Forum.pdf

²⁰ In December 2022, several CSOs representing healthcare professional and patients published a letter to the European Commission on the issue of the co-funding mechanism. For more information on this letter: <https://www.europeancancer.org/co-funding-model-concern>



Annex 1 – Conclusions from the CoFoE: analysis

Conference on the Future of Europe – Conclusions relevant to public health CSOs and the role they can play

1. Educating people about **healthy habits from an early age**, and encouraging them to make safe and healthy choices, through taxation of non-healthy processed food and by **making information on the health properties of food readily available** (...).
Role of CSOs in health and other sectors: advocacy, sharing of best practices, provision of expertise
2. The creation of a **European Health Data Space**, which would facilitate exchange of health data; individual medical records could be made available – on a voluntary basis – through an EU individual electronic health passport, in compliance with data protection rules.
Role of public health CSOs: advocacy and provision of expertise
3. Issuing strong recommendations to the Member States to **invest in effective, accessible, affordable, high-quality and resilient health systems**, notably in the context of the European Semester. The impact of the war in Ukraine on public health demonstrates the need to further develop resilient health systems and solidarity mechanisms.
Role of public health CSOs: sharing of best practices, advocacy, provision of expertise, exchange of experience in crisis responsiveness
4. Improve **understanding of mental health issues** and ways of addressing them, including from early childhood and early diagnostics, building on good practices developed throughout the EU, which should be made readily accessible through the **Public Health Best Practice Portal**. To raise awareness, EU institutions and relevant stakeholders should organise best practices exchange events and help their members disseminate them in their own constituencies. An **EU Action Plan on mental health** should be developed, that would provide **long term Mental Health Strategy**, including on research and also tackle the issue of availability of professionals, including for minors and the setting up in the near future of a dedicated **European Year of Mental Health**.
Role of public health CSOs: advocacy, provision of expertise, sharing of best practices, network building
5. **Expanding the health week initiative**, which would take place across the entire EU in the same week, when all health issues would be covered and discussed. Also consider health year initiatives, starting with the year on mental health.
Role of public health CSOs: advocacy, disseminating campaigns through their networks, provision of expertise
6. **Fight health poverty** by encouraging free of charge dental care for children, low-income groups and other vulnerable groups, such as for instance the disabled. Also consider the impact of poor-quality housing on health.
Role of public health CSOs: advocacy and provision of expertise
7. Recognising the need to take full account of **the principle of subsidiarity** and the key role of local, regional and national players in health matters, ensure there is the ability to act at EU level when the right to health is best addressed there. To allow faster and stronger decision-making on key subjects and to **improve the effectiveness of European governance towards the development of the European Health Union** (such as, for example, in the event of a pandemic or for rare diseases).
Role of public health CSOs: advocacy, provision of expertise
8. **Strengthening links with citizens** and local institutions to **improve transparency**, reach the citizens and communicate and consult better with them about concrete EU initiatives and at the international level.
Role of CSOs in public health and other sectors: developing initiatives and disseminating campaigns through their networks
9. Full support by all relevant stakeholders to citizens who choose to get involved in organised **civil society organisations**, as they did with COVID-19 and Ukraine.
Role of CSOs in public health and other sectors: exchange of experience in crisis responsiveness
10. **Making European values tangible for EU citizens**, especially through more interactive and direct involvement (...).
Role of CSOs in public health and other sectors: disseminating campaigns, dissemination of information, networks
11. **Include organised civil society and regional and local authorities and existing structures** such as the European Economic and Social Committee (EESC) and the Committee of the Regions (CoR) in the citizens' participation process.

Role of CSOs in public health and other sectors: participation, network building

12. **Developing EU-wide measures to guarantee the safety and health of all migrants**, in particular pregnant women, children, unaccompanied minors and all vulnerable people.

Role of public health CSOs: expertise, disseminating campaigns through their networks, experience of crisis responsiveness

13. Promote **European exchanges** in different fields, both physically and digitally, including educational exchanges, twinning, travel and professional mobility (...).

Role of CSOs in public health other sectors: expertise, disseminating campaigns through their networks, sharing of best practices

Conclusions impacting CSOs

14. Provide **enhanced structural support**, financial and otherwise, **for civil society**, especially for youth civil society and support local authorities in setting up local youth councils; this could be achieved through a specific pillar in the **European Democracy Action Plan** for involvement of civil society and social partners, and a dedicated civil society strategy.
15. Strengthening **cooperation between EU legislators and civil society organisations** to utilise the link between decision-makers and citizens which civil society organisations constitute.
16. Ensure proper **civil and social dialogue mechanisms and processes** at every step of the EU decision-making process, from impact assessment to policy design and implementation.
17. Reform the way the European Union works by **better involving social partners and organised civil society**. Strengthening the existing structures in order to better reflect the needs and expectations of EU citizens in the decision-making process, given their importance in the European democratic life. Within this framework, enhance the institutional role of the EESC and empower it as facilitator and guarantor of participatory democracy activities like structured dialogue with civil society organisations and Citizens' panels. **A lively civil society is crucial for the democratic life of the European Union.**