

EU Health Coalition Terms of Reference

31 May 2021

1. Denomination

Building on the cooperation that led to, and on the success of, the first ever multi-stakeholders' EU Health Summit, which took place in Brussels on the 29th of November 2018, 42 organisations from within and across the health community came together to establish the "EU Health Coalition". The intention is to collaborate with other initiatives that share the same goals, as appropriate.

2. Partners

The partners of the Coalition are:

- 1) Active Citizenship Network
- 2) All.Can International
- 3) Alliance for Safe Online Pharmacy in the EU (ASOP EU)
- 4) Association of the European Self-Care Industry (AESGP)
- 5) BBMRI-ERIC
- 6) Biomedical Alliance in Europe
- 7) COCIR
- 8) Consorzio per Valutazioni Biologiche e Farmacologiche (CVBF)
- 9) Digestive Cancers Europe (DICE)
- 10) Digital Health Society (DHS)
- 11) EuropaBio
- 12) European Alliances for Access of Safe Medicines (EAASM)
- 13) European Association for the Study of Obesity (EASO)
- 14) European Brain Council (EBC)
- 15) European Biosafety Network (EBN)
- 16) European Cancer Patient Coalition (ECPC)
- 17) European Confederation of Pharmaceutical Entrepreneurs (Eucope)
- 18) European Connected Health Alliance (ECHA)
- 19) European Diabetes Forum (EUDF)
- 20) European Federation of Internal Medicine (EFIM)
- 21) European Federation of National Organisations Working with the Homeless (FEANTSA)
- 22) European Federation of Neurological Associations (EFNA)
- 23) European Federation of Pharmaceutical Industries and Associations (EFPIA)
- 24) European Health Futures Forum (EHFF)
- 25) European Health Management Association (EHMA)
- 26) European Healthcare Distribution Association (GIRP)
- 27) European Infrastructure for Translational Medicine (EATRIS)
- 28) European Medicinal Cannabis Association (EUMCA)
- 29) European Multiple Sclerosis Platform (EMSP)
- 30) European Patients' Forum (EPF)
- 31) European Regional and Local Health Authorities (EUREGHA)
- 32) European Union of Private Hospitals (UEHP)
- 33) International Diabetes Federation Europe (IDF Europe)
- 34) International Patient Organisation for Primary Immunodeficiencies (IPOPI)
- 35) Mental Health and Social Exclusion – Europa (SMES-Europa)
- 36) Plasma Protein Therapeutics Association (PPTA)
- 37) Rare Diseases Europe (EURORDIS)

- 38) Self-care Initiative Europe (SCiE)
- 39) Senior International Health Association (SIHA)
- 40) Wellcome
- 41) World Federation of Incontinence Patients (WFIPP)
- 42) Youth Cancer Europe (YCE)

3. Language

The operational language of the Coalition is English.

4. Purpose and objectives

The Coalition is formed to promote a shared vision of health in Europe, based on jointly developed recommendations. The purpose is to raise health high on the political agenda and bring the necessary changes to address the unprecedented challenges and opportunities driven by an ageing population and increased prevalence of chronic diseases that healthcare systems and citizens across Europe are facing.

The objectives of the Coalition are:

- To seek implementation of these recommendations by EU, national and regional policy makers and other appropriate organisations
- To monitor the implementation of any joint recommendation
- To support this by sharing best practices and organising joint advocacy meetings and outreach initiatives

The Coalition is not formally registered as an association in Brussels, but it serves the purpose of a forum to discuss how Europe could develop, and take the lead in areas such as research and innovation, health data and digital health, healthcare systems, and policies for health. The Coalition must undertake everything to achieve its objectives in accordance and compliance with the laws in the EU.

5. Activities

Any activities, in addition to the periodically organised EU Health Summit, need to be presented to and agreed by all partners.

6. Partnership requirements and the inclusion of new partners

Every European association, whose main mission and objectives actively contribute to a positive future for European health and are ready to commit to the Coalition's objectives and recommendations, can join the partnership.

Additional requirements are as follows:

- Commitment to the agreed plans and their implementation
- Commitment to actively take part in meetings and assist with the activities of the Coalition

Requests to join the Coalition must be addressed in writing to at least one of the Coalition's partners. All Coalition partners will have to approve it unanimously in writing.

7. Withdrawal and exclusion

Any partner may give notice of its withdrawal to the Coalition in writing. Withdrawal shall take effect two weeks after its receipt by at least one of the Coalition's partners. In the event of a breach of these Terms of Reference, the Coalition, having consulted the partner concerned, can exclude such a partner by a 75% vote of all partners.

8. Governance

All Coalition partners meet regularly either in person or via call, and at least twice a year, to discuss the status of current initiatives and approve the future strategy. More than one representative per organisation can participate in these meetings. However, every partner organisation has only the right to one vote. Decisions are taken by consensus, unless otherwise specified. These meetings are convened by volunteering partners.

The Coalition is also composed of four policy groups, a planning group and a communication task force. The planning group steers the strategic direction and defines the agenda of the EU Health Summit, periodically organised by the Coalition. The communication task force takes care of internal and external communication. The policy groups propose priority topics to all partners, namely in the areas of:

1. Research and innovation
2. Health data and digital health
3. Healthcare systems
4. Policies for health

Partners can propose to focus on additional topics and/or substitute some of the existing ones. Decisions will be taken unanimously by all partners. Partners can also bring up additional issues for discussion in the Coalition, for example relating to a current topic on the Brussels health agenda. Partners will decide by unanimity if the Coalition should develop a joint view on the topic and if necessary set up a temporary working group to work on the issue.

Every group can be co-chaired by up to two partners, who set up meetings and/or teleconferences, define the agenda and steer the discussions. Every partner organisation can put forward its application for co-chairmanship at the beginning of the year. Elections will take place during the first meeting of the group; the co-chairs are voted by simple majority of the groups' members. In case of a tie vote, a second round will be organised when only top three candidates contest.

The list of partners active in each group can be found in Annex I, while Annex II defines the organigram of the Coalition. Membership in the groups is revisited at the beginning of every year, but partners can, at any time and in writing, show their interest in joining another group, and they will be automatically be admitted.

9. Rights and obligations of partners

A. Rights

Each partner has the right to:

- Have access to all internal and external information gathered by the Coalition

- Actively participate in meetings and events organised by the Coalition, including foster its visibility by providing its logo
- Use the documents adopted by the Coalition, media and website provided that the name of the Coalition is used as a reference
- Express one vote in every all partners meeting
- All partners have the same voting rights, without distinction between in cash and in-kind contributors.

B. Obligations

Each partner has the obligation to:

- Adhere to the objectives and purpose of the Coalition and collectively work towards their realisation
- Positively contribute to the Coalition's activities. This could include chairing meetings, providing the venue, drafting the agenda, and taking the minutes. Partners with limited meeting venue facilities might ask support from other partners to offer venue.

10. Budget

The costs incurred by the Coalition for the organisation of the EU Health Summit are shared between any willing partner. In cash contributions will be agreed by the interested partners. Other partners, unless they request otherwise in writing, contribute in-kind. The list of in cash and in-kind contributors can be found in Annex III. In cash contributions will be made transparent and be published in the Coalition's website.

Banking arrangements, and the accounting process, will be agreed unanimously between the partners.

The budgetary/accounting year will cover the period from January to December. In the event that there is a leftover balance at the end of the mandate of the Coalition, the remaining amount will be divided and redistributed between the partners, in proportion to their budgetary contribution.

Both in case of withdrawal or exclusion in the course of the financial year, the contribution for the current year, if applicable, will be due.

11. Legal effect

These Terms of Reference do not grant any authority for any individual partner to legally bind any other partner, or partners, or the Coalition.

Have agreed to the EU Health Coalition Terms of Reference dated 1 September 2019 on behalf of their respective Associations:

Michel Ballieu
Biomedical Alliance in Europe Executive Director

Nick Batey
European Regional and Local Health Authorities Chair



Simone Boselli
Rare Diseases Europe Director of Public Affairs

Antonella Cardone
European Cancer Patient Coalition Director

Nicole Denjoy
COCIR Secretary General

Monika Derecque-Pois
European Healthcare Distribution Association Director
General

Frédéric Destrebecq
European Brain Council Executive Director

Elisabeth Dupont
International Diabetes Federation Europe Regional Director

Bianca Ferraiolo
Active Citizenship Network Head of EU Office

Francesco Florindi
Strategy and Partnership Manager BBMRI-ERIC

Ilaria Giannico
European Union of Private Hospitals Secretary General

Stefan Gijssels
Digestive Cancers Europe Executive Director

Bernard Grimm
EuropaBio Director for Healthcare Biotechnology

Catherine Guinard
Wellcome Policy & Advocacy Manager (UK & EU)

Kaisa Immonen
European Patients' Forum Director of Policy

Mike Isles
Alliance for Safe Online Pharmacy in the EU Executive
Director

Mike Isles
European Alliance for Access to Safe Medicines
Director

Elisabeth Kasilingam
European Multiple Sclerosis Platform Managing Director



Federico Lega
European Health Management Association President

Luigi Leonori
SMES-Europa President

Penny Lukats
European Medicinal Cannabis Association Communications
Director

Roberto Messina
Senior International Health Association President

Nathalie Moll
European Federation of Pharmaceutical Industries and
Associations Director General

Nicola Montano
European Federation of Internal Medicine President

Lars Münter
Self-care Initiative Europe Communications Lead

Brian O'Connor
European Connected Health Alliance Chair

Karl Petrovsky
Plasma Protein Therapeutics Association Director Health Policy

Eduardo Pisani
All.Can International Chief Executive Officer

Johan Prevot
International Patient Organisation for Primary Immunodeficiencies
Executive Director

Bleddyn Rees
Digital Health Society Chair

Katie Rizvi
Youth Cancer Europe CEO

Freek Spinnewijn
European Federation of National Organisations Working with the
Homeless Director

Oliver Sude
European Confederation of Pharmaceutical Entrepreneurs Deputy
Director General



Santé Mentale et Exclusion Sociale
Mental Health and Social Exclusion





Jurate Svarcaite
Association of the European Self-Care Industry

Bart Torbeyns
European Diabetes Forum Executive Director

Mary Lynne Van Poelgeest-Pomfret
World Federation of Incontinence Patients President

Donna Walsh
European Federation of Neurological Associations Executive Director

Euan Woodward
European Association for the Study of Obesity Executive Director

Ian Lindsley
European Biosafety Network

Anne-Charlotte Fauvel
European Infrastructure for Translational Medicine

David Somekh
European Health Futures Forum

Donato Bonifazi
CVBF Chief Executive Officer and EPTRI Coordinator

