<u>Disclaimer</u>: information contained in this document has been provided by the non-State actors themselves, and its accuracy and completeness is the sole responsibility of the non-State actors, not WHO.



Accreditation of regional non-State actors not in official relations with WHO to attend meetings of the WHO Regional Committee for Europe

Non-State Actors' profiles 2019

Introduction

This document provides information about the non-State actors as required in Framework of Engagement with non-State Actors (FENSA), paragraph 39 and the procedure to accredit NSAs to the Regional Committee for Europe¹

WHO's interaction with non-State actors is managed transparently through the WHO Register of non-State actors, and the below information will be made public via the Register when it is fully operational.

All accredited Non-State Actors have signed the required WHO Tobacco and Arms Disclosure form The WHO does not engage with the tobacco industry or non-State actors that work to further the interests of the tobacco industry. WHO also does not engage with the arms industry

¹ http://www.euro.who.int/en/about-us/partners/non-state-actors/procedure-for-accreditation-of-regional-non-state-actors-not-in-official-relations-with-who-to-attend-meetings-of-the-who-regional-committee-for-europe

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AFEW International

General information

Official name:	AFEW International
Short self-description/Aims /Objectives	AFEW's vision: All people in Eastern Europe and Central Asia participate fully and confidently concerning their health and rights, in an inclusive and just society.
	AFEW is there for all people in EECA that face barriers regarding access to health, justice and/or voice and prioritizing those who are more at risk, more stigmatized, and are facing more severe barriers.
	AFEW works in the 4 dimensions:
	 access to good quality health services: Good quality health services need to include prevention, medical treatment, (consultations /social) care and support, early detection, rehabilitation and psychological support. Access implies not only that it is available within suitable parameters, but also that it is experienced as being accessible - inclusive and non-judgemental, and affordable. Good quality health services need to be responsive to the needs of specific communities, including needs related to SRHR, and within a context of high levels of HIV, TB and viral Hepatitis. legal and social justice: Legal and social justice includes equality before the law, and protections against human rights violations, for all. Social justice also includes access to a certain range of services that help people to maintain at least a minimum standard of living, for example welfare services, shelter, and education. power to voice, participate and decide: To ensure full participation in society, people need information, skills, and the ability to organize themselves autonomously.^[1] People need platforms where they can voice their experience and their needs and experience dialogue, including (but not restricted to) in political spaces. Their power in the dialogue needs to be recognized and actively sought in decision-making processes. appreciation of diversity: Appreciation of difference is a global challenge; people tend to be comfortable with what looks and feels familiar and suspicious or fearful of what seems different. A real shift is needed in the EECA region to move from the current situation, to a celebration of difference as something that has value and adds richness to society.
Website:	http://www.afew.org/

Governance

Legal status:	Non-profit organization
Members	As of 31 December 2018, the AFEW Supervisory Board consisted of 6 members. There is one vacancy.

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	Michel Kazatchkine (Chairman)
	Udi Davidovich (Vice Chairman)
	Dolf Kamermans (Treasurer)
	Vladimir Mendelevich (Board member)
	Hernan Fuenzalida-Puelma (Board member)
	Mariia Yakovleva (Board member)
	As of 31 December 2018, the Managing Board consists of Anke van Dam.
	As of 31 December 2018, the management team consists of:
	Anke van Dam (Executive Director AFEW International)
	 Janine Wildschut (Director of Programmes)
	Yuliya van Polanen (Director of Finance)
	As of 31 December 2018, the Steering Committee of AFEW Partnership consists of:
	Anke van Dam (Executive Director AFEW International)
	Roman Dudnik (Director, AFEW–Kazakhstan)
	 Natalya Shumskaya (AFEW Chairperson in the Kyrgyz Republic)
	 Elena Voskresenskaya (Director of AFEW-Ukraine)
	 Ikram Ibragimov (Director of AFEW-Tajikistan) (per June 2019 AFEW
	Tajikistan has left AFEW Partnership)
	 AFEW Russia joined per November 2019
	• AFEW Russia joined per November 2019
Executive decision-making bodies	AFEW International has a supervisory board that oversees the strategy, projects and activities, finances and advices the managing board of the organization.
	The managing board, which consists of the director, is end-responsible for the management and finances of the organization.
	The director is leading a management team, consisting of the director of finances and director of programmes, that manages the day to day management of the organization.
	Board members bring to the organization their professional experience in various fields of work, from specialized knowledge of medical treatment and the HIV epidemic to expertise in management and budgeting. The Board is charged with overseeing the overall operation of the organization in order to ensure good standards of transparency and accountability. The Board approves the organization's strategy and the budget, as well as advising the Management Team and senior managers on strategic issues. The Board also evaluates and appraises the work of the Executive Director. Board members receive no financial compensation for their work.

Financial information

The total income available for core objectives in *AFEW*'s 16th operational year was

€2,287,228, which represents 49% increase compared to 2016 (€1,539,028). In 2017, AFEW Network continued its relations with donors and signed new contracts with Global Fund, Gilead, UNODC, ViiV, Project Hope and USAID.

Financial statements since 2012 are available here: <u>http://www.afew.org/policies-and-reporting/</u>

Entity's engagement with WHO Europe

As with the past collaboration with WHO/EURO collaboration is sought on a regular basis, depending on upcoming needs and developments re HIV, TB and viral hepatitis. There is regular contact with representatives of WHO-EURO during civil society forums meetings, at other meetings and conferences.

Names and contact details of the entity's focal points for collaboration:

Anke van Dam, Executive Director: anke_van_dam@afew.nl

Secretariat focal point: Helena Arntz, Office Manager, info@afew.nl, Helna_arntz@afew.nl

Phone: +31206381718

AGE platform Europe

General information

Official name:	AGE Platform Europe
Short self-description/Aims /Objectives	AGE Platform Europe is a European network of non-profit organisations of and for people aged 50+, which aims to voice and promote the interests of the 200 million citizens aged 50+ in the European Union (Eurostat, 2018) and to raise awareness on the issues that concern them most.
Website:	https://www.age-platform.eu/

Governance

Legal status:	Legally established in Belgium as an international non-for-profit association.
Members	Full list of AGE members available here: https://www.age-platform.eu/age- members
Executive decision-making bodies	AGE Platform Europe is governed by the General Assembly composed of all AGE's members, and by its elected representatives meeting in an Executive Committee and a Council of Administration. Executive Committee members: Ebbe Johansen, President (DK) Fernando Martins, Vice President (PT) Heidrun Mollenkopf, Vice President (DE) Regine Matthijsen, Vice-President (NL) Jose-Luis Tejedor, Vice President (ES) Elena Weber, Secretary (E.D.E.) Treasurer: Jean-Michel Hôte (FR)

Financial information

AGE's policy activities in 2017 were financed by membership fees and donations (20%) and by the Rights, Equality and Citizenship Programme (REC) of the European Union (DG Justice) (80%).

AGE continued its work on European Research Projects throughout 2017, besides being involved in new proposals. AGE was partner of 19 projects dealing with new technologies, health, care, accessibility, sustainable mobility and senior tourism. Those projects, financed mainly by H2020 are: Athlos, Caress, Eurosen, EuroAgeism, Frailsafe, Families & Societies, I-Prognosis, JamToday, Mopact, MobilAge, Nestore, Prosperity4all, Pace, Progressive, Promiss, Seed, Sustain, UCH 2,0, and We4AHA. AGE participation in EU research projects is 100% covered by EU funding.

https://www.age-platform.eu/financial-resources

Entity's engagement with WHO Europe

AGE platform has a long working relationship with the WHO Regional Office for Europe in areas covering healthy ageing and long-term care. For the next three years 2019 – 2021, AGE will continue to work in close collaboration to bring older persons' perspective to key common areas including support around the preparation of the 'Decade of Action for Healthy Ageing' in the GPW13. This will include building on WHO material and documents within the AGE advocacy work for healthy ageing and combat age-based discrimination. AGE will continue to include in its communication all relevant WHO/UN events and provide advocacy and communication via the AGE website, newsletter and social media.

Names and contact details of the entity's focal points for collaboration:

Anne-Sophie Parent, Secretary General - annesophie.parent@age-platform.eu Julia Wadoux, Policy Coordinator for Health, ICT and Accessibility – Julia.wadoux@age-platform.eu Borja Arrue-Astrain, Policy and Project Officer - borha.arrue@age-platform.eu

AIDS Healthcare Foundation

General information

Official name:	AIDS Healthcare Foundation
Short self-description/Aims /Objectives	AIDS Healthcare Foundation Europe (AHF Europe), being the European Bureau of the AIDS Healthcare Foundation (AHF), is a provider of user-oriented HIV prevention, testing, treatment and care services across Europe.
Website:	https://www.aidshealth.org/

Governance

Legal status:	AHF Europe is an NGO registered in the Netherlands (Stichting AHF Global Immunity (AHF Europe)
Members	N/A
Executive decision-making bodies	AHF Europe is managed by Europe Bureau Chief and Executive Management team which includes Deputy Bureau Chief and Programs Director, Medical and Quality Director, Advocacy and Marketing Director, Finance Director Associate as well as Country Program Directors for Ukraine and Russia and EU Program Manager.

Financial information

Financed from AHF headquarter office in Los Angeles (USA). The annual budget for AHF Europe is 1,6 mln USD. AHF Europe assets are at the level of 0.25 mln USD.

Financial reports: https://www.aidshealth.org/about/

Entity's engagement with WHO Europe

AHF Europe past engagement with WHO Euro included participation and sharing AHF Europe experience at the WHO Europe technical meetings related to dissemination of WHO guidelines on HIV and Viral Hepatitis and meetings of national HIV program managers focusing on the EECA region. AHF Europe actively participated in the HIV Treatment Reference Group (TRG) at WHO Europe and in WHO Europe country evaluations. AHF Europe participated in the past WHO Regional Committee meetings for Europe making statements in support of effective implementation of the Action Plan for the Health Sector Response to HIV in WHO European Region.

AHF Europe planned collaborative activities with the Regional Office for Europe in 2019-2021 include active work within HIV Treatment Reference Group (TRG) at WHO Europe, support to key countries with the implementation of the Action Plan for the Health Sector Response to HIV in WHO European Region including best practices of people centered HIV care, Test and Treat, rapid treatment initiation and community-based approaches. Within its programs AHF Europe will support the implementation of country roadmaps which stem from the Amsterdam Ministerial Policy Dialogue organized by WHO Europe. AHF Europe will contribute to WHO Europe best practice in HIV/TB care repository and will carry educational activities for health care professionals in EECA with a goal to increase capacity in the region and make the professionals aware of WHO guidelines related to HIV/TB testing, treatment and care.

AHF Europe will exchange the information and experience in the EECA region including implementation of Rapid Testing (RTP) and integrated care models and will participate in WHO Europe organised events and regional consultations related to HIV/TB.

Names and contact details of the entity's focal points for collaboration:

AHF Europe focal point:

Mrs Anna Zakowicz Europe Deputy Bureau Chief, Director of Programs. Office address: 1017 EK Amsterdam, the Netherlands, Office: +31206266267; Cell: +31628744655; e-mail: anna.zakowicz@aidshealth.org

European Federation of Nurses Associations (EFN)

General information

Official name:	European Federation of Nurses Associations (EFN)
Short self-description/Aims /Objectives	Established in 1971, the EFN represents over 36 National Nurses Associations over the EU & Europe. Its mission is to strengthen the status and practice of the profession of nursing for the benefit of the health of the citizens and the interests of nurses in the EU & Europe by lobbying the EU Institutions (European Commission, European Parliament, EU Council) and by bringing the attention of the EU on the current and potential collaboration of nurses and nursing to meeting the healthcare needs of the population throughout the Union.
Website:	http://www.efnweb.eu/

Governance

Legal status:	Non-Governmental Organization Registration Number: 476.356.013 Transparency Register (EU): 87872442953-08
General assembly of members (or a similar body):	The EFN governance structure consists of the General Assembly, supported by the Executive Committee, the Professional, Workforce and Public Policy Committees, and the EFN Brussels Office. General Assembly - Being the EFN governing body it meets two times a year for a two days meeting, to: discuss the important issues related to the EFN lobby work that can influence the nurses and the nursing profession at EU and National levels; discuss and endorse key Policy and Position Statements; and work on several EU projects. The General Assembly includes the 36 National Nurses Associations
Executive decision-making bodies (e.g. board, board of directors, executive board, executive committee, etc):	Executive Committee – Constituted by seven members: President, Vice- president, Treasurer and four delegates elected from the EFN Members National Nurses' Associations, it meets at least twice a year (in between and prior to each General Assembly)

Financial information

With a budget income of around 450.000€, the EFN main annual income comes from EFN Membership fees (as determined and approved by the autumn EFN General Assembly, each year), and from EU projects (when involved in any).

Membership

Established in 1971, the EFN represents over 36 National Nurses Associations over the EU & Europe (drawn from the twenty-eight EU Member States + Norway, Iceland, Switzerland, the Former Yugoslav Republic of Macedonia, Montenegro, Serbia, and Albania - which are in membership of the European Union and/or of the Council of Europe)

Entity's engagement with WHO Europe

Over the last 15 years, the EFN has been engaged with WHO Europe in different ways, for example having an observer status in WHO RC meetings, participating in several WHO & WHO RC meetings and contributing to consultations/debates, to make sure that the nurses' views were taken into account in the debate.

Names and contact details of the entity's focal points for collaboration:

Paul De Raeve, EFN Secretary General

European Patients Forum

General information

Official name:	European Patients' Forum (EPF)
Short self-description/Aims /Objectives	The European Patients' Forum (EPF) is a cross-disease umbrella organisation of patients' organisations at European level. Our members are chronic disease organisations active at EU level and national coalitions of patients' organisations
Website:	http://www.eu-patient.eu/

Governance

Legal status:	EPF is registered, in Belgium, with the legal status: Non-profit 'ASBL' (association sans but lucrative).
Members	EPF has 74 members (54 Full members, 19 Associate members and 1 Provisional member). EPF members represent specific chronic disease groups at EU level or are national coalitions of patients.
Executive decision-making bodies	 EPF is administered by a Board of Members elected by the Annual General Meeting for a term of two years. The Board meets five times a year to provide political leadership, ensure the good running of the Secretariat and oversee the implementation of the annual work program. President, Marco Greco Vice-President, Radu Costin Ganescu Treasurer, Elisabeth Kasilingam Board Members: Hilkka Kärkkäinen - President of the Global Alliance of Mental Illness Advocacy Networks (GAMIAN - Europe) Marzena Nelken – Board Member of the Polish PKU and RDAssociation Cor Oosterwijk - Managing Director of VSOP, the patient alliance for rare and genetic diseases in The Netherlands Michal Rataj - Board Member of the EAMDA - European Alliance of Neuromuscular Disorders Associations Gabriela Tanasan - represents the European Network of (Ex-)Users and Survivors of Psychiatry – ENUSP Dimitrios Athanasiou - Board member of the World Duchenne Organization (WDO).

Financial information

EPF has a diversified funding base comprising membership fees, public and private funding, such as grants for EU projects and from the pharmaceutical industry. EPF is committed to transparency and independence in all aspects of its work, in accordance with a Code of Ethics and Framework for working with funding partners.

Total Income net of adjustments 2,175,260.04 €

http://www.eu-patient.eu/About-EPF/Transparency/

Annual reports: http://www.eu-patient.eu/library/Annual-Reports111/

Entity's engagement with WHO Europe

EPF has worked closely with WHO Europe in recent years. For example, in 2011 it contributed to an initiative on patient safety and rights, including a meeting and report on patient engagement in reducing safety risks in healthcare. A report published in 2013, "Exploring patient participation in reducing health-care-related safety risks", where EPF contributed content and reviews. In 2014 EPF contributed to the WHO's consultation on strengthening health system performance through innovative approaches, a Framework for Action towards Coordinated/Integrated Health Services Delivery (CIHSD). Furthermore, a high-level strategic meeting took place with the Regional Director in January 2014, which mapped out areas of collaboration. EPF has also contributed actively to recent discussions on access to medicines, and in 2017 participated in the WHO-Dutch government held Fair Pricing Forum.

Upcoming engagements include WHO involvement in the first EPF Congress on patient involvement in health systems, with representation on the advisory board (November 2019).

Names and contact details of the entity's focal points for collaboration:

Executive Director:

Name: Usman Khan Email: usman.khan@eu-patient.eu

Secretariat Focal Points:

Name: Kaisa Immonen, Director of Policy Email: kaisa.immonen@eu-patient.eu

European Respiratory Society

General information

Official name:	European Respiratory Society
Short self-description/Aims /Objectives	ERS is an international organization that brings together physicians, healthcare professionals, scientists and other experts working in respiratory medicine. We are one of the leading medical organizations in the respiratory field, with a growing membership representing over 160 countries.
Website:	https://my.ersnet.org/

Governance

Legal status:	The Society is a not-for-profit, international organization of individual persons, constituted in accordance with Articles 60 and following the Swiss Civil Code.
Members	ERS is a medical organization working to promote lung health and combat lung diseases. Membership information is available here: https://www.ersnet.org/the-society/membership#benefits
Executive decision-making bodies	The core management group is responsible for matters related to the governance and management of the Society on behalf of the Management Group. It deals with all daily administrative and executive activities according to the strategy agreed in the Executive Committee and in preparation of the regular meetings of the Management Group.
	The General Assembly has the ability to modify the statutes, on proposal of the Executive Committee, to decide the annual membership fee, on the change of domicile and the dissolution of the Society, and to put forward proposals to the Executive Committee. The General Assembly is responsible for reviewing and approving the accounts, upon recommendation of the Executive committee and the Internal Auditors.

Financial information

Annual reports since 2013, financial reporting and transparency statues are available here: <u>https://www.ersnet.org/the-society/who-we-are/ers-governance-and-transparency</u>

Entity's engagement with WHO Europe

ERS has engaged with WHO on all levels:

- Advocacy
- Policy
- Technical
- Scientific
- Online

- Funding of projects
- Events

After a long period of informal collaborations, WHO/Europe concluded a memorandum of understanding with the ERS in 2013 on a project relating to an e-consultation for multi drug resistant tuberculosis MDR TB. In addition, the Regional Director met with ERS leadership to discuss collaborations in tobacco control, air quality, influenza, joint guidelines, training courses and publications, such as a revision of the "European lung white book", participation at the Society's international congress and contributions to the "European Respiratory Journal".

http://www.euro.who.int/en/who-we-are/regional-director/news/news/2011/03/meeting-with-the-european-respiratory-society

Names and contact details of the entity's focal points for collaboration:

- Werner Bill CEO
- Brian Ward Director of Advocacy and European Affairs

Norwegian Cancer Society

General information

Official name:	Norwegian Cancer Society (NCS)
Short self-description/Aims /Objectives	 NCS's objectives as enshrined in the Articles of Association are to work to prevent and reduce cancer, and to improve quality of life for patients and their families. These objectives will be realized through the following means: broad-based cancer research; information (on the causes of cancer, manifestation, prevention and treatment); cancer care (help for cancer patients and their families); serving as a voice for the cancer cause; international work and collaboration.
Website:	www.kreftforeningen.no

Governance

Legal status:	The Norwegian Cancer Society (NCS) is a Norwegian registered non-political, not for profit organization. Organization number: 951 812 528
Members	The highest body is the Committee of Representatives, with 50 members. The Committee of Representatives elects the Board of Directors, decides and amends Articles of Association and approves the annual budget.
Executive decision-making bodies	The Committee is composed of different groups: - Personal members: 17 - Corporate members (Norwegian Nurses' Organization, Norwegian Medical Association, Norwegian Union of Municipal and General Employees): 3 - Institutional members (Faculty of Medicine, Cancer Registry of Norway etc.): 15 - Patients' associations (associate members): 12 - Employee representatives: 3 Board of Directors: The Board is a collegial and professional body with members who represent expertise in the areas of medicine/health care, research, business/ marketing, law, politics, communication, management and corporate governance, organization, and economics as well as user representatives/persons who have or have had cancer and who possess knowledge of patient experience.

Financial information

Assets: For the most recent revised accounts (2018) assets under management sums up to a total of NOK 935 million (USD 115 million), comprising NOK 483,4 million in unit trusts and NOK 451.8 million in interest rate instruments. Returns on external funds under management in 2018 were NOK minus 15 million. This corresponds to a return of minus 1.6%. In comparison, returns in 2017 were NOK 93.4 million, or 10.2%. NOK 40 million was withdrawn from the portfolio during 2018.

Funding: At the end of 2018, the Norwegian Cancer Society had bank deposits of NOK 150 million (USD 18 million).

For the most recent revised accounts (2018); annual income was 533 million NOK (65 million USD). NCS is mainly financed through fund raising, testamentary gifts and national lottery funding. Bequests represented one of the largest sources of income in 2018, totaling NOK 115.4 million.

NCS had 37,000 regular donors who donated NOK 44.6 million. They received NOK 49.7 million from donor letters and NOK 25.2 million in memorial donations (donations given in memory of a deceased person). The Norwegian Cancer Society does not use telemarketing. We received NOK 69 million in 2018 from the National Lottery Fund. In 2018, the Norwegian Cancer Society received NOK 2.7 million in public grants and NOK 27.2 million in VAT compensation.

Annual report:

https://kreftforeningen.no/wp-content/uploads/2019/06/NorwegianCancerSocietyAnnualReport2018.pdf

Entity's engagement with WHO Europe

NCS have collaborated with WHO Europe since 2016 on organizing an annual workshop on Law and Tobacco control in Europe. The workshop aims to support the legal work in tobacco control by 1) sharing information on legal policy design and tobacco industry opposition, 2) sharing information on legal challenges and 3) facilitating networking and information sharing among countries. The target audience of the workshop is selected European countries and leading NGOs working on legal issues in tobacco control.

In June 2017, NCS launched a campaign aiming to increase awareness among the cancer community and the general population of the importance of AMR to cancer treatment, and to secure support for national government initiatives to curb AMR. WHO Europe was represented in Oslo at World Cancer Day February 2018 which we used to focus on the adverse consequences of AMR to cancer treatment. At the event, NCS opened an exhibition dedicated to AMR and cancer. Following a request from WHO Europe, the artwork "Hanging by a thread" central to the exhibition was donated by NCS to WHO Europe for use at the launch of World Antibiotic Awareness Week 2018. As part of the opening, NCS Sec Gen took part in an Facebook Live event together with AMR Manager Danillo Lo Fo Wong.

A 3-year plan for collaboration has been developed and agreed on jointly by the Norwegian Cancer Society and WHO Europe. Areas of collaboration is listed below.

Antimicrobial resistance: NCS will support the Work of WHO Europe, Department of Health Emergencies and Communicable Diseases by:

- Bringing forward WHO advocacy messaging on Antimicrobial Resistance, using the impact on cancer patients as an illustrative case of the adverse effect of Antimicrobial resistance on global health;
- Contribute, as appropriate and in collaboration with WHO Europe, to the impact of the annual World Antibiotic Awareness Weeks through hosting high level events aimed at decision makers, health workers and the general population;
- Financial and practical contribution to bring the artwork "Hanging by a thread" from UN City Copenhagen to other WHO offices, including WHO HQ Geneva.

Cancer: NCS will support the Work of WHO Europe, Department of Division of Noncommunicable Diseases and Promoting Health through the Life-course:

- Support the Action Plan for the Prevention and Control of Noncommunicable Diseases in the WHO European Region 2016–2025 with a specific focus on;
- Cancer, including cervical cancer;
- Tobacco control, including continue hosting annual workshop on Law and Tobacco control in Europe / NCDs for selected European countries and NGOs.

Names and contact details of the entity's focal points for collaboration:

For AMR and Cancer: Ms Carina Alm carina.alm@kreftforeningen.no +47 90 89 34 97

For Tobacco: Head of Legal: Ms Marianne-Hammer Marianne.hammer@kreftforeningen.no +47 99157672