

Minutes

First official meeting of CEE4Health

29 June 2018 (Friday), 14.00 – 15.30 h

SOFIA, Park Hotel Vitosha

Participants:

Participants:

- Andy Dyson (AD)
- Desislava Mihaylova (DM)
- Florentin Scarlat (FS)
- Guenka Petrova (GP)
- Ivanka Krasteva (IK)
- Mariela Marcheva (MM)
- Mariya Vladova (MV)
- Nikos Dedes (ND)
- Radu Gănescu (RG)
- Ruzhica Gugulovska (RG)
- Stamen Popov (SP)
- Stanimir Hasurdjiev (SH)
- Tudor Ciubotaru (TC)
- Vatroslav Zovko (VZ)
- Alexander Hristov (AH)

Participating through TC:

- Tit Albreht (TA)
- Vlad Zah (VZ)

1. Opening and greetings

1.1. Welcoming and background of the occasion:

SH welcomed the participants and admired their efforts to take part in the first official meeting of the new legal organization named CEE₄Health. This happening is actually a side meeting of the regional **Presidency conference organized in Sofia*** which gathered health experts and policy makers from all around the CEE region. This occasion was seen as a good opportunity and context for establishment of the new legal entity.

1.2. Introduction of the participants:

Each participant had the opportunity to introduce himself/herself with a few sentences to the group. It was agreed (later on) that a full list with short introduction and a photograph of all participants will be created to facilitate the organization and the work of the new entity.

2. Background of the initiative

2.1. The beginning of The Think-tank:

Later on SH gave the background of the initiative which started in 2016 as a Think-tank multi-stakeholder group of experts acting on different key hurdles in healthcare systems in Central and Eastern Europe.

The final goal of the Group was and still is to propose regional and sustainable solutions for regional challenges to national governments, health policy decision makers and other stakeholders in the region.

2.2. Participants in The Think-tank:

A full list of all participants that have been involved into the Think-tank group was provided to the audience. This information could be seen in the presentation that was disseminated by email to all participants after the meeting.

2.3. Activities of The Think-tank

Four face-to-face meetings of the Think-tank group have been held so far in Vienna as well as several teleconferences. As a result Patient Access Board have been created as an executive body of the Think-tank.

On 13.11.2015 workshop on the challenges in patients' access for the CEE region had been held – to identify the hurdles within the region.

2.4. Pilot projects of The Think-tank

* For more information about the conference: <http://hephiv2018.hepasist.com/>

As a result from the workshop in Vienna, two different workstreams have been identified to start working on the first pilot projects of the Think-tank group.

A. Breast cancer landscape mapping project: Early patient access

Objectives:

- ✓ identify challenges in patient access
- ✓ differences and best practices
- ✓ highlight the impact of new therapies.
- ✓ white paper documenting breast cancer landscape and findings

B. Health Technology Assessment: Reimbursement – Late Access phase

Objectives:

- ✓ show value of structured multi-criteria HTA
- ✓ review & refine multi-criteria HTA model
- ✓ develop full assessment methodology
- ✓ work toward their implementation

2.5. The path to a more structured approach

During the meetings in Vienna different hurdles and solutions have been identified in the healthcare systems of the countries in CEE and the workstreams managed to achieve good results. However, the lack of a more structured approach became an essential hurdle for the work of the Think-tank group.

On 15th March 2016 in Vienna, the experts of the Think-tank decided that establishment of a legal entity is a needed step to be taken, in order to:

- ✓ drive the work on the projects
- ✓ facilitate and diversify the fundraising opportunities
- ✓ legitimize the initiative and the experts behind it

In order to figure out which would be the best possible option- research and numerous of consultations have been made with experts from different fields, to decide where and how to establish the new legal entity. An official decision of the Think tank group was made on 24.04.2017 in Vienna - CEE4Health shall be nongovernmental, non for profit organization. It will be based in Vienna as it is communicable and reachable location and also the Austrian NGOs are credible due to the legal requirements in the country.

3. Adopting structure of CEE4Health

After the introduction of the presenting experts into the entire background of the former Think-tank group, the next step in the agenda of the meeting was to adopt the structure of the new legal entity.

3.1. CEE4Health – stepping on an existing successful model

After a research and numerous of consultations with the members of the Think-tank group and experts from different fields it was decided that the proposed structure will be similar to the structure of the Patient Access Partnership (PACT). Reasons for this decision:

- ✓ Light structure (from administrative point of view) which also meets the minimum legislative requirements of Austria
- ✓ Avoid legal complications for individual experts and particularly for experts from institutions, policy makers, etc.
- ✓ Fast and easy involvement of experts
- ✓ Minimize the administrative burden
- ✓ Flexibility in terms of funding and cooperation

The PACT model requires establishment with the minimum of two founding members. In order to keep the patients' focus of the initiative it was decided the establishing members to be credible patient experts from the region of CEE:

- For the purposes of registration the Think-tank mandated to Nikos Dedes* and Stanimir Hasardzhiev† to establish and legally represent the CEE4Health's Chairperson and Secretary-General; take the necessary legal steps to form the General Assembly of the association, which meets the minimum legal requirements of the Austrian Legislation; and to conduct all other necessary legal and administrative steps.
- The Think-tank mandated also to Stanimir Hasardzhiev to call the experts at meeting for establishing the governing bodies of CEE4Health

The presenting experts agreed with the made proposals.

3.2. Membership - Experts

CEE4Health is open to a wide range of Eastern and Central European individual experts from governmental and non-governmental organizations, private sector, legal entities, and other experts.

The partnering experts will be forming different working parties corresponding to their specialization in healthcare and/or groups devoted to different topics, projects, pilots, etc.

The experts of CEE4Health will be the core driving force of the organization and are responsible for its governance, activities, strategic plan, annual working plans, budget, auditing, arbitration, etc. via

* **Nikos Dedes** - Chair of the Policy working group of the European AIDS Treatment Group; co-chair of the EU HIV/AIDS Civil Society Forum; co-chair of the Patients' and Consumers' Working Party at the EMEA; member of the Steering Committee of the European Clinical Trials Network for HIV; member of the European treatment guidelines for HIV; member of the Advisory Committee on strategic and technical planning for HIV / AIDS of the WHO; member of the European Advisory Commission DIA (ACE) and the European Centre for Disease Prevention and Control –ECDC.

† **Stanimir Hasardzhiev** - Chairperson of National Patients' Organization – Bulgaria; Board Member of EPF; Secretary-General of PACT; main initiator of the Think-tank on Patient Access project.

forming an Experts assembly, electing Steering committee, initiating working parties, collaborative multistakeholder projects, etc.

The experts will be involved as individuals with all their experience and expertise regarding their current position or employer. This will give them faster and easier access to CEE4Health without complicated legislative requirements and minimum administrative burden which will facilitate the flexibility of the activities of CEE4Health.

It was proposed that all experts of CEE4Health will be considered members of a body called Experts' Assembly, which will disengage them from most of the administrative tasks that the classical membership brings. Also, this will allow the experts to be involved faster and easier with minimum legislative requirements which will make the work of/for CEE4Health more flexible.

At this point, some clarifying questions have been asked from some of the experts to understand better the role of the Partnering Experts and their duties and obligations:

- SH and ND explained into more depths these matters and stressed on the fact that classical membership is avoided for the experts due to the legislative complications that it will cause. However, the Experts of CEE4Health will have all the powers owned by the members in the case of a classical membership, even more, CEE4Health will be governed and driven by a body consisted of **all the Experts** of the Association - the **Experts' Assembly**.

3.3. Bodies of the association

A. The Experts' Assembly:

- It is consisted of **all the Partnering Experts** of the Association.
- It is the core and highest governing body of CEE4Health
- The Experts' Assembly conduct the following activities:
 - ✓ Set and approve annual report.
 - ✓ Set and approve working plan.
 - ✓ Set and approve the budget and strategy plan of the organization.
 - ✓ Elaborate resolutions about amendments of the Statutes and dissolution of the Association.
 - ✓ Set and approve the different working parties.
 - ✓ Appoint the Steering Committee of CEE4Health up to the maximum number of the Steering Committee members.
 - ✓ Consider and resolve other questions and matters on the agenda.

B. The Steering Committee:

- It is consisted of 5 to 9 individuals, representing the variety of experts, stakeholder groups and geographic spread.
- It is the executive body of CEE4Health.
- Tasks of the Steering Committee:
 - ✓ Responsible for the management of the Association.
 - ✓ Preparing the annual budgets as well as compiling the management report and the statement of account.
 - ✓ Managing the Association's assets.
 - ✓ Admitting and expelling experts.

- ✓ Suggesting and approving the association's employees.
- ✓ Responsible for the development and implementation of the annual working plan of the Association.
- ✓ Hiring and terminating Association employees
- ✓ Considering and resolving other questions and matters on the agenda.
- ✓ Admitting and expelling Association's members.

- ✓ It shall be assigned with all functions not assigned by the Statutes to any other organs of the Association.

C. General Assembly

- It is consisted of the Chairperson and the Secretary-General.
- It represents the association legally.
- The following responsibilities are reserved for the General Assembly:
 - ✓ Resolutions about the dissolution of the Association.
 - ✓ Resolutions about amendments of the Statutes.
 - ✓ Approving legal transactions between members or Auditors and the Association.
 - ✓ The General Assembly shall set, approve and resolve every case and issue of the organization upon the request of the Experts' Meeting.
 - ✓ The General Assembly shall implement activities based on the decisions of all bodies of CEE4Health.

The presented overall information about the bodies and the structure of the association raised a longer discussions among the participants.

First of all, the participants were more interested in the way that the working groups of experts will be formed. It was agreed that this should be happening from the bottom to the top instead of vice – versa. Also, this should be a process that should be happening more naturally, based on the needs of the projects.

4. Adopting the vision, mission and objectives of the association.

4.1. Vision

The participants in the meeting have discussed over the following Vision for CEE4Health:

"CEE4Health enables individual experts and different health stakeholders to join forces to develop, drive and propose sustainable solutions to ensure equitable patients' access to quality healthcare in the countries of Central and Eastern Europe and neighboring countries."

One proposal was made from the participants, to substitute the word "*patients*" as it gives narrower impression for the work of the organization. "*Patients*" will be substituted with "*people*" as a term that does not exclude anyone in terms of sexuality, ethnicity, citizenship, health condition or any other differentiating social status.

4.2. Mission

The following text have been identified and proposed to the experts, as a mission that will be followed by CEE4Health:

"By creating such a structured expert Think-tank, the association aims to identify key hurdles in access to healthcare for patients in a holistic way. While the approach is to look at healthcare systems as a whole, the activities of the organization will be guided by a patient focus, from the assessment of gaps in access to quality healthcare among the CEE countries, to the collaboration with relevant regional or national initiatives and the development of solutions."

The same comment was made for the substitution of the term "*patients*". Another proposal was made, to skip the clarification "*regional or national*" as it might put narrower scope of the initiatives that might be in favor of the organization for the achievement of its mission, objectives and goals.

4.3. Objectives

The following objectives were proposed:

- Facilitate the dialogue and improve collaboration between:
 - the experts involved, for the benefit of the CEE countries
 - regional and national health stakeholders
 - regional or national initiatives
- Assess and identify gaps in access to quality healthcare within the region
- Develop innovative and sustainable solutions for improving healthcare
- Organisation and participation in functional events for training and education
- International cooperation with organisations active in relevant fields
- Develop and support innovative pilots that could increase the access to quality healthcare

Agreement for the provided text was achieved again. The only corrections made was again related with the words "regional and national".

5. Appointing Steering Committee of CEE4Health

5.1. Defining the mandate of the Steering Committee for the next 12 months

The experts has defined the following obligations to the mandate of the first Steering Committee of CEE4Health:

- To convoke and organize the first Experts' Meeting of CEE4Health which aims to:
 - ✓ Define the priorities and the activities of the organization
 - ✓ Form the Working Groups
 - ✓ Define the short and long term goals
- To define the most appropriate experts to be invited in CEE4Health and to the first Experts Meeting.
- To raise funding for the first Experts Meeting.
- To draft the internal rules of the association.

5.2. Appointing Steering Committee

The organization aims to follow democratic principles and wide representation of all kind of stakeholders. Knowing that the both founding members and respectively the first members of the Steering Committee of CEE4Health are patients' representatives, it was decided that at least three more members should be elected to the executive body of the organization in a way that represents the variety of the geographic scope and the different stakeholder groups.

The first person to be nominated and elected as a member of the Steering Committee, unanimously by the presenting experts is Mrs. Ruzica Gugulovska:

Mrs. Ruzica Gugulovska is a Co –Founder and International Relations, Marketing and Sales at CheckPoint Cardio

She is a co-founder and managing partner at CheckPoint Cardio, with 18 years experience in international law and relationship, business and state protocol, and 16 years in education and training. She has Master degree in International Law and International Relationship from Sofia State University St Kliment Ohridski, Graduated for worldwide trainer of World-class business Etiquette and International Courtroom Etiquette at Etiquette Outreach, NY(USA).

She has taken several high positions in governmental and nongovernmental state bodies, and also, taught and trained in university and state institutions. In private sector, as entrepreneur and investor from 2003.

The second person to be elected unanimously as a Steering Committee member is Dr. Ileana Mardare –MPH, PhD:

She is a Senior Assistant Professor -Public Health and Management Dept. "Carol Davila" University of Medicine and Pharmacy Bucharest, Romania

Medical doctor with almost 30 years of experience in healthcare and over 20 in health management at different levels of the Romanian healthcare system, starting from hospital level, as chief of department and medical director, then at county level - as Medical Director of the County Health Insurance House of Bacau, up to national level - as counsellor in Ministry of Health, but also as Health Outcomes & Pharmacoeconomics expert, Public Health Manager, Project Manager in the private sector.

Dr. Mardare has been involved in various projects, in different technical working groups at national and international level (shaping health legislation, health system reform, implementation of cross-border healthcare EU Directive, public policies elaboration, monitoring, implementation and evaluation, etc.) and she has over 10 years of fruitful experience in collaborating with patient associations.

The third person to be proposed and elected as a Steering Committee member by unanimous vote is Dr. Siniša Varga, DMD.

Siniša Varga is an active politician who graduated at the Faculty of Dentistry of the University of Zagreb and then specialized in dental prosthetics at the Dental Clinic of the Clinical Hospital Center in Zagreb.

He used to leads the Ambulatory for Surgical Prosthetics at Dubrava Hospital. Dr. Varga is a consultant on a project funded by the World Bank for Health System Reform in Bosnia and Herzegovina. Member of the Croatian Dental Society, the Croatian Medical Association, where he served as the Secretary

General. Member of Croatian Society of Doctors of Homeland War Volunteers, Croatian Association of Quality Managers, as well as the Croatian Institute for Standards in two Technical Committees

From 2002 to 2004 he was an official of the Government of the Republic of Croatia the Ministry of Health and Social Welfare, as Assistant Minister of Health for Professional and Medical Affairs. In 2007, the Government of the Republic of Croatia appointed it as a working group to prepare for accession negotiations with the European Union. After being Director of the Croatian Institute for Health Insurance from April 2012 to June 2014, the Government of the Republic of Croatia appointed him as Minister of Health.