The European Patients' Forum newsletter – May 2018

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Hello there,

The highlights of June for EPF include <u>our call on the Council to put patients</u> first and make progress on HTA negotiations, and <u>our reaction to the</u> publication of the European Commission's proposal for the 9th Framework Programme for Research and Innovation, called "Horizon Europe".

W have also published a couple of articles with the take-home messages of two events we attended, on <u>homeless people and access</u>, and <u>on the HTAi</u> <u>Annual Meeting</u> respectively.

In other news, we give you some updates on the main projects we are working on, including <u>EUPATI</u>, <u>PARADIGM</u>, <u>CHRODIS+</u>, and <u>COMPAR-EU</u>.

Finally, we invite you to read more about the upcoming <u>EPF Summer Training</u> <u>Course for Patients Advocates</u> starting this weekend.

Policy Updates

<u>EPF calls on EU Member States to put patients first and make</u> progress on HTA negotiations \rightarrow

In the run-up to the EPSCO Council meeting, EPF sent a letter to national ministries of health and their representatives in Brussels, calling on member states to "*put patients first and make progress on HTA negotiations*".

<u>Horizon Europe must invest more in health to support high-</u> <u>quality, accessible and equitable health systems \rightarrow </u>

EPF welcomes the European Commission's proposal for "Horizon Europe" but we believe the budget allocated to health is not enough given the unprecedented, global health challenges Europe is facing.

HTAi Annual Meeting: Patients Included →

From 1 to 5 June, hundreds of delegates from around the world gathered in Vancouver for the HTAi Annual meeting. The overall theme this year was 'Strengthening the Evidence-to-Action Connection' and, for the first time, the meeting got the label 'Patients Included'.

Homelessness and Access to Health \rightarrow

Four million of people are homeless in Europe. 23.4% of the EU population is estimated to be at risk of poverty and social exclusion, and one out of three homeless people have at least one chronic condition. Read more about EPF's work on vulnerable groups' access to healthcare, in cooperation with Rais Fundación.

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Projects

2018 Summer Training Course for Young Patients Advocates is about to kick-off \rightarrow

40 participants representing 23 European countries will participate

EPF Newsletter - June 2018 | A new image for our monthly updates on 1 July. EPF's 2018 summer training for young patient

advocates. The theme of this year is '*Count Us In! Inclusion, Non-Discrimination, and Societal Change*'.

PARADIGM Survey: the way to find out what YOU expect from patient engagement \rightarrow

PARADIGM consortium has co-created and launched a survey to better understand the patient engagement expectations from different stakeholder groups involved in the medicines lifecycle.

CHRODIS+: including the patient perspective in every step! \rightarrow

CHRODIS+ partners working on *Fostering quality of care of chronic diseases* met in Ljubljana (Slovenia) to make sure that the patient perspective is taken on board in every step during the pre-implementation phase of the project.

EUPATI Network of National Platforms - Annual General Meeting \rightarrow

The Annual General Meeting of the EUPATI national platforms took place in Berlin in May. The meeting brought together approximately 50 patient advocates from the 18 European countries where a national EUPATI platform operates, and also the EUPATI project coordinators were present.

<u>COMPAR-EU: focusing on patient priorities outcomes \rightarrow </u>

Forty participants and four moderators, including patients and their carers, specialists, primary care providers, nurses and researchers, will join us on 10-11 July for a workshop in Berlin to discuss the results of the Delphi Consensus Process on preferred outcomes launched within the COMPAR-EU project.

EPF Members & Youth Group

<u>Transparency is our legitimacy currency: let's protect it! \rightarrow </u>

Transparency is a multi-dimensional process: it applies across all the organisation's activities. But what are the actual rules that one should respect, and what are the processes to implement them?

Making personalisation possible, by National Voices \rightarrow

Personalised care offers countless benefits to people living with multiple long-term conditions. When shaped around the individual, personalised care empowers people to manage their conditions, prioritising the needs and wants that are most important to them.

<u>5 Questions to SAFE, the Stroke Alliance for Europe \rightarrow </u>

From time to time, we like to put the spotlight on one of our members. Today, we are delighted to catch up with SAFE, the Stroke Alliance for Europe, who recently joined EPF.

<u>The youth factor \rightarrow </u>

Last month, EPF Youth Group president Andreas Christodoulou had the honour to be invited as a speaker to a multi stakeholder conference in Amsterdam, the Third Annual Patient Engagement and Experience Conference organised by Fleming. Read more about his experience there!

Events



Youth Group Meeting 29 June -1 July 2018 / Vienna, Austria EPF attendance: Lyudmil Ninov, Sara Gayarre

Summer Training Course for Young Patient Advocates

1-4 July 2018 / Vienna, AustriaEPF attendance: Lyudmil Ninov, Sara Gayarre, Anna Trzcinska, and ValentinaStrammiello

Train the trainers

4-6 July 2018 / Amsterdam, The Netherlands EPF attendance: Elena Balestra

DIA Europe 2019: Face-to-face Programme Committee Meeting

10 July 2018 / Brussels, Belgium EPF speaker: Nicola Bedlington

Second internal expert workshop on measuring access to healthcare pilot project

16 July 2018 / Brussels, Belgium EPF attendance: Katie Gallagher

Publications





EPF Impact Report 2018 →

This Impact Report is a first edition of a compact and elegant summary of EPF's main achievements in the last years.



<u>The Added Value of Patient</u> <u>Organisations \rightarrow </u>

This report emphasises the unique value of patient organisations in representation, mobilisation and empowerment of patients and provides specific recommendations to maximise the potential of patient organisations.



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