

Newsletter EPF - November 2019

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The European Patients' Forum newsletter – November 2019

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Dear readers,

Our much-awaited **Congress on patient involvement** has come and gone after much work, preparation, and excitement. We could not be happier with the turnout, and fruitful outcome of the many discussions case studies, challenges and solutions, inspiring and often moving stories held over these three days. We must now look to the future: a lot of groundwork towards making meaningful patient involvement an integral part of health systems has been done, and whilst efforts are welcomed and endorsed, this calls for an even stronger collaboration amongst multiple stakeholders. This edition includes a detailed update on the Congress as well as photos, and a short video!

Also featured in this issue are the **European Antibiotic Awareness Day 2019**, the launch of the **Data Saves Lives platform**, EPF's contributions to **OECD** on patient involvement and patient safety, and **EUPATI**'s latest addition to the programme: a new one-day training course on patient engagement, this time for professionals! Our **Youth Group** also shares its latest activities.

Happy reading!



Usman Khan (Executive Director)

EPF Congress 2019: for patients with patients





Earlier this month EPF hosted its first ever Congress on patient involvement entirely driven by the patient community. Over 300 delegates, including patient advocates, healthcare professionals, health NGOs, academics, members from industry and national institutions made their way to the Crowne Plaza Hotel in Brussels, where the Congress was held. Joined by more than 60 speakers the Congress considered opportunities and barriers for meaningful patient, drawing upon a myriad of examples of effective practice.

[Read more here](#)

Everyday Should be Antibiotic Awareness Day

True or False? Do YOU know the answers?

1. Antibiotics are effective against viruses

2. Antibiotics are effective against cold and flu
3. Taking antibiotics has associated side effects or risks such as diarrhoea, colitis, allergies
4. Unnecessary use of antibiotics makes them become ineffective
5. Healthy people can carry antibiotic resistant bacteria
6. Antibiotic resistant bacteria can spread from person to person
7. Every person treated with antibiotics is at an increased risk of antibiotic resistant infection

Answers: 1-2: False. 3-7: True. Source: [ECDC Survey](#).

Antibiotic resistance affects everyone – but especially people with chronic conditions. They may be more vulnerable to infections; they can also more easily pick up resistant bacteria as they need to spend more time in healthcare environments. Patients with multi-drug-resistant infections have very limited treatment options. Every year around 33,000 people in Europe and 700,000 worldwide die from resistant infections – as many as from influenza, tuberculosis and HIV/AIDS combined.

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Nutrition is an integral part of disease management

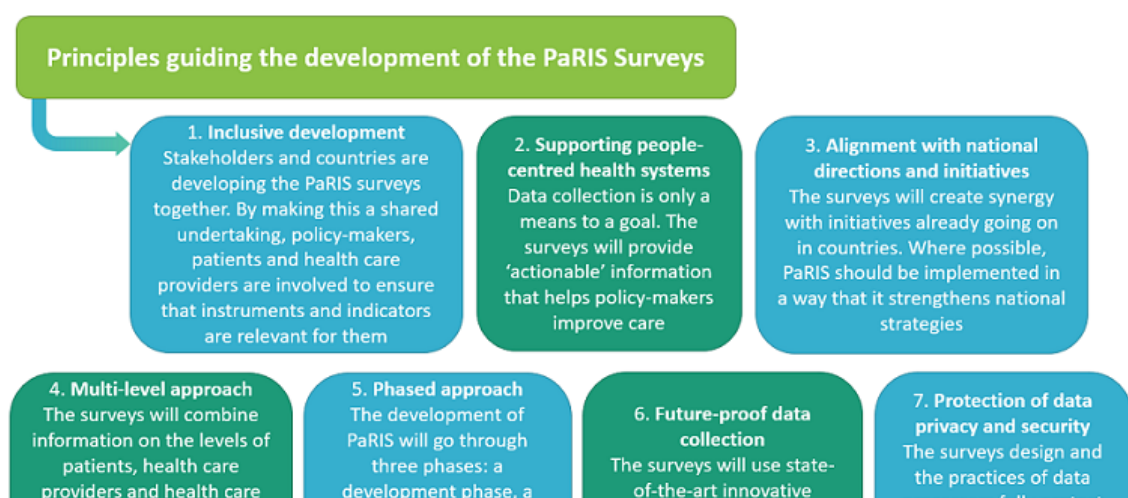




EPF has published a new fact-sheet on clinical nutrition guidelines and information about food to patients. The fact-sheet builds on EPF’s long-standing work on raising awareness of the role of nutrition and diet in preventing and managing long-term conditions, and maintaining optimal health and quality of life.

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EPF at OECD: Focus on Patient Involvement and Patient Safety



systems to get the full picture. The different layers of information will help policy-makers identify priorities on the right level

field trial and the implementation of the main survey. Countries commit to the project phase by phase

methods for data collection and data sharing that are safe, privacy-respectful and user-friendly

processors fully protect the privacy of surveys participants, both patients and health care providers

EPF was recently granted a standing invitation to the meetings of the OECD working group on healthcare quality and outcomes (HCQO), and this month we have been contributing not only to that working group but also to a meeting of the [PaRIS working party](#) that is developing a flagship international comparative survey on patient-reported outcome and experience measures ([PaRIS](#)) – an initiative in which EPF has been closely involved.

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Vaccination for patients with chronic conditions



Article for [European Files](#), written by EPF President, Marco Greco

Vaccination does not just concern children: it is something that benefits people of all ages. A life-course approach to vaccination as part of

universal health coverage can enhance people's quality of life, including that of people living with chronic diseases. For society and governments, there may be significant savings for health and social systems from reducing the burden of chronic as well as vaccine-preventable diseases – for example by avoiding unnecessary hospital admissions through better management of chronic conditions in the community and by reducing the impact of antimicrobial resistance and thus costs associated to it. Vaccination should thus be considered a part of universal health coverage.

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'Data Saves Lives' unveiled at EPF Congress



Data
Saves
Lives

The European Patients' Forum (EPF), the European Institute for Innovation through Health Data (i~HD) and other key players from the health data communities launched the 'Data Saves Lives' Initiative at EPF Congress in Brussels on the 12 November 2019. **Data Saves Lives** is a multi-stakeholder initiative that aims to raise wider patient

and public awareness about the importance of health data and to improve our understanding of how it is used. The initiative will establish a trusted environment for multi-stakeholder dialogue about responsible use and good practices across Europe, while empowering patients and healthcare professionals to realise the potential of new sources of data and digital technologies. It will also create resources adaptable for use at national and local level and crucially, show real-life examples of how data is used for the benefit of patients.

[Read more](#)

EUPATI launched its first training on patient engagement to professionals



Following on from its established success in patient education, the Patients' Academy has launched EUPATI Fundamentals: a one-day

training course on patient engagement for professionals working in academia and the pharmaceutical industry, to ensure the accelerated uptake of effective patient engagement, and good partners for the patient community to work with.

[Read more](#)

Youth Group Blog | EAMDA Executive Committee Meeting – new strategy and ideas for the future



This year the European Alliance of Neuromuscular Disorders Associations (EAMDA) organized its annual meeting with Executive Committee members and partners of the association on the beautiful Adriatic coast. Between 18 October to 20 October rehabilitation center

Adriatic coast. Between 18 October to 20 October Rehabilitation Center “Dva Topola” in Izola was a host of 35 patient advocates and representatives of different patients’ organizations.

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Youth Group Blog | EPF Youth Group treads the boards at EPF Congress



During Congress, the EPF Youth Group was asked to carry out various activities. These activities included managing our own booth and acting out several roleplays "improv-style" both during plenary and parallel sessions. Many Congress attendees visited our booth and were interested to learn about the activities carried out by the Youth Group in 2019 and 2020. Participants were informed as to what the Group is up to and its importance as the voice for young patients.

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News from our Members | New Vacancy at Europa Donna

As Europa Donna's CEO of the past 22 years, Susan Knox, will retire in 2020, the President and Executive Board of Europa Donna are now seeking an experienced professional to lead the organisation into the future.

The candidate will be multilingual, charismatic and have strong leadership skills. S/he will direct an experienced team based in Milan and will represent the organisation at the European level.

S/he will build upon important relationships already established with collaborators around Europe. S/he will ensure Europa Donna's continued financial stability and will work to achieve Europa Donna's goals with integrity and high ethical standards.

Please note that the deadline for all applications is 6 January 2020.

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