



# EPF Mailing

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## Dear EPF Members and Allies,

Welcome to the first EPF Mailing of 2012. The New Year has started well for EPF and our members. We are honoured and proud to receive for the first time an operating grant from the European Commission. It is a very exciting time as we also prepare to launch the new IMI project EUPATI together with our fellow Consortium members ([see this article](#)) and move forward on other key projects. January has also seen the launch of SUSTAINS, which is focussing on electronic health records ([see article 16](#)).

On the policy side, we are advancing on our work on the chronic diseases reflection process information to patients, personalised medicines and the revision of the medical devices Directive (see [article 4](#) and [article 8](#)). Another key focus for us in the new Public Health Programme 'Health for Growth' ([see article 3](#)). We are delighted to be collaborating very closely with the European Public Health Alliance on achieving a programme that embraces health, wealth and equity – and prevention, health promotion and patient centred chronic disease management.

The EPF secretariat team has expanded over the last few weeks and we are very happy to welcome two new members of the team ([see "Secretariat" section](#)).

Our Annual General Meeting is in early spring on 18, 19 of April 2012. We will be undertaking preparatory work with our members in relation to the Strategic Planning Session that will take place on the second day of the meeting. This will be to ensure that our members and their needs and aspirations drive where we go during the next EU programming period 2014 – 2020.

Concerted work is also underway with regard to our Value + capacity building programme. It will enter its first phase in 2012 with strategic planning work with national patient organisations, and needs assessment with selected newer European EPF members that have been established relatively recently.

This Mailing also looks back at key events we have been involved in since our last issue and our contributions from a patients' perspective. Key highlights are the EUnetHTA conference in Gdansk in December, the celebration with the European Nursing Community of the 40th Anniversary of the European Federation of Nurses, and discussion with CPME on our Joint Principles underpinning our collaboration. Our trusted partnership with fellow NGOs representing the spectrum of health professionals is absolutely fundamental to our vision and our goals.

In that spirit, we look forward to our continued joint work in 2012!

Warmest greetings,  
EPF President Anders Olauson  
EPF Director Nicola Bedlington

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## 1. Cross-border healthcare: European Commission establishes eHealth network

On 22 December 2011, the European Commission adopted a Decision establishing an eHealth Network. The eHealth network is based on Directive ([2011/24/EU](#)) on patients' rights in cross-border healthcare. It will aim to foster voluntary cooperation between Member States to ensure EU wide interoperability of electronic health systems and wider use of eHealth. Specifically, the network will draw up guidelines on the minimum set of common data to be included in patient summaries to be transferred across borders; methods to enable the use of medical information for public health and medical research; and on common identification and authentication measures to ensure transferability of data in cross-border healthcare

EPF fought hard to include eHealth cooperation in the cross-border healthcare directive (Article 14), as eHealth and telemedicine services form an essential support to patient safety and the continuity of care across borders. EPF therefore welcomed the inclusion of a European eHealth network in the Directive. However, we regret that this provision is weakened by being voluntary. Furthermore, no stakeholder involvement is mentioned (unlike the HTA Network, also established by the Directive). Furthermore, EPF is concerned that the safety and quality standards applicable to eHealth should be the same as to non-electronic health services – something that is not clearly expressed in the Directive.

As readers will know, EPF is involved in eHealth through our participation in several ongoing EU-funded projects. We will follow the activities of the new eHealth network with great interest, and aim link up to our ongoing activities and projects where appropriate.

### More information:

- EC decision establishing the eHealth network available [here](#).
- Council conclusions on “safe and effective care through eHealth” (2009) [here](#).
- EPF’s statement on the adoption of the cross-border healthcare directive available [here](#).

## 2. Review of the EU Clinical Trials Directive

The progress on clinical trials has been extensively documented in [previous issues of the Mailing](#). Following two rounds of public consultation, and several stakeholder events, the European Commission's proposals for the future EU legislation on clinical trials are to be published during the second quarter of 2012.

EPF and several representatives of our member organisations met on 21 November 2011 to discuss the direction of the review. Present at the meeting were Commission officials responsible for this dossier, who explained the Commission's approach and answered questions. The Commission's proposals will centre around simplifying the application procedures, and implementing a risk-adjusted approach to clinical trials.

From the patients' perspective, EPF has argued that certain aspects, such as information to patients and informed consent, should be harmonised to guarantee equitable access to high quality information on clinical trials to all patients, regardless of which Member State they live in. Furthermore, EPF has called for more patients representation on ethics committees.

The EPF Secretariat is currently preparing an updated position document, which will be put to a member consultation in due course.

### More information:

- EPF's previous responses to the consultations can be found [here](#).
- The European Commission concept paper can be found [here](#).

### 3. Future EU Health Programme

The European Commission's proposal for a new health programme, titled "Health for Growth", was published on 9 November 2011. Background on EPF's advocacy activities independently and jointly with EPHA has been provided in previous [us issues of the EPF Mailing](#).

EPF is currently consulting members in order to submit a formal position statement on the Health for Growth Programme. The proposal is currently awaiting the first reading in the Parliament, with Françoise Grossetête MEP (EPP, France) as the rapporteur, and shadow rapporteurs being Glenis Wilmott MEP (S&D, UK) and Milan Cabrnoch MEP (ECR, Czech Republic).

#### More information:

- The European Commission's proposal for the Health for Growth programme is available [here](#).
- The EU 2020 strategy is available [here](#).
- EPF's joint letter with EPHA is available [here](#).

### 4. Chronic diseases reflection process

The Commission launched a reflection process on chronic diseases in early November 2011, following a request by the Council in its Conclusions on ["Innovative approaches for chronic diseases in public health and healthcare systems"](#), adopted on 7 December 2010. The reflection process aims to produce an EU strategy on chronic diseases; the process is likely to conclude during the first part of 2013.

The European Commission and Member States are asked to lead the process "in close dialogue with relevant stakeholders", including patients. The Commission is expected to launch a public consultation in the early part of 2012. In the first place, the Commission consulted the EU Health Policy Forum (EUHPF), of which EPF is a member. EPF participated in the drafting process to

develop the EUHPF response, which took place mainly during the winter holiday period. Our extensive input given in consultation with the Policy Advisory Group and the Board, focused in particular on the role of health systems, equity of access, quality of care, patient involvement and patient empowerment.

Following the launch of the Commission's public consultation, EPF will circulate a draft consultation paper to all members to develop EPF's response. For a copy of the EUHPF paper, please contact the [EPF Secretariat](#).

More information:

- [EU Health Policy Forum](#)

## **5. Information to patients update**

The European Commission's revised legislative proposals on Information to patients were finally taken off the agenda of the Council discussions on 1-2 December 2011; the Council then decided to ask the Commission to split the proposals, separating those provisions related to pharmacovigilance from the "rest".

The split proposals are expected to be published very shortly, and no other changes are expected to the content of the proposals. Linda McAvan MEP (S&D, Ireland) was appointed the rapporteur on the separated pharmacovigilance dossier, while Christofer Fjellner (EPP, Sweden) will continue on the remaining ITP dossier.

The pharmacovigilance proposals are expected to be "fast-tracked" through the legislative procedure, in order to be integrated in the implementation process of the new [EU pharmacovigilance legislation](#) adopted at the end of 2010.

Still, several Member States remain reluctant to discuss the other ITP proposals. EPF is engaging the EP rapporteur and the 2012 EU Presidency countries in order to push for this dossier to be given a chance in the second reading.

More information:

- EC revised proposals on information to patients available [here](#)
- EPF's previous position statements on this issue available [here](#) and [here](#).

## 6. EPF survey on patient safety- Reminder

EPF launched on 6<sup>th</sup> of December 2011 an online survey for its members, to collect patient organisations' views and experiences regarding the implementation of [Council Recommendations of 9 June 2009](#) on patient safety and quality of care.

This survey is of fundamental importance, as the European Commission must produce a report by 9 June 2012 on the impact of the Recommendation, to assess whether the recommended measures are working effectively, and to consider whether there is a need for further action. To achieve this, the Commission has set a survey that is addressed only to Member States.

EPF considers it essential at this stage to take a proactive stance and assess the implementation of the Council Recommendation also from the patients' perspective. EPF was closely involved in its development, and the Recommendation contains specific provisions to improve patient information and empowerment, and to involve patient organisations in the development of policies and programmes in Member States. The EPF survey is a unique opportunity for patient groups across the EU to present their views concerning the state of patient safety, and patients' involvement in patient safety, in their country. It is also crucial to identify possible obstacles to full implementation of the recommendations in Member States.

EPF encourages its members to reply to the survey without delay. We also kindly ask the support of member organisations that are pan-European umbrellas in specific disease areas, in circulating this survey to their own member organisations in different EU Member States. This is particularly important to get a full pan-European picture, including from Member states where there is no national coalition of patients at the moment.

### Next Steps:

- The survey is opened until **29 February 2012**
- The responses will be analysed and a summary report prepared, which will be submitted to the Commission and shared with EPF's members. The information gleaned through this survey will also feed in EPF's ongoing work in the area of patient safety and quality of care, including the forthcoming Joint Action.

For more information or for link to the online survey, please contact [EPF Policy Officer](#).



## 7. Medical devices

The European Commission has announced that the recast of the framework for Medical Devices will take the form of two regulations – one for medical devices and the other for in vitro medical devices. This will be accompanied by a Communication regarding innovation in medical devices for the benefit of patients, consumers and healthcare professionals. The proposals and the Communication are expected to be published in the 2<sup>nd</sup> Quarter 2012.

EPF met with the European Commission on 23 November 2011 to present our general position. The Commission has appeared receptive to our views in relation to patient involvement. On the same theme, EPF and Eucomed will hold the third Medtech dialogue in Spring 2012, where we will discuss our respective positions on the legislation

## 8. Review of the Professional Qualifications Directive

Following two public consultations to which EPF gave input, the European Commission adopted on 19 December 2011 a proposal to review Directive 2005/36/EC on the recognition of Professional Qualifications (available [here](#)). EPF previous response and a joint statement with EPHA, BEUC and EWL are available [here](#).

The protection of patients was identified as one of the eight main issues the review will focus on. To reach this aim the Commission proposes to:

- Clarify the rules as regards language checks for healthcare professionals: in case of professions with patient safety implication competent authorities may carry out language checking if requested by national healthcare system, or in case of self-employed professionals non-affiliated to the healthcare system, by representative national patient organisations.
- Put in place a proactive alert mechanism between competent authorities for healthcare professionals under disciplinary sanctions
- Increase transparency between Member States on their continuous professional development procedures, through public reports published after the entry into application of the directive and every five years thereafter.



Other measures include the setting up of a voluntary European Professional Card, the extension of the scope of the directive to remunerated traineeships, and update of the minimum training requirements for automatic recognition professions (which include doctors, medical specialists, nurses, dentists, pharmacists and midwives).

### Next Steps

- EPF will send very shortly a draft position paper to its full membership for consultation, based on previous responses.
- MEP Bernadette Vergnaud (S&D, France) was appointed rapporteur in the committee responsible, the Internal Market and Consumer Protection (IMCO) committee. The first exchange of views in IMCO should take place on 28 February. The two committees for opinion are employment and social affairs, and culture and education.
- The Plenary sitting will take place end of November 2012 (provisional date).

## 9. Medical Resonance Imaging (MRI) Directive update

As reported in previous issues of this mailing (see our [November 2011 issue](#)), EPF supports the derogation for MRI proposed by the European Commission as part of the proposal to revise the Directive on the minimum health and safety requirements regarding the exposure of workers to the risks arising from physical agents (electromagnetic fields).

Several Member States have been opposing this derogation during the discussion at the Council in late 2011. No agreement had been reached, and a compromise whereby each Member State would decide of the derogation on a case by case basis was in discussion. At the European Parliament, as of December there was generally cross-national cross-party support for the derogation.

EPF alerted its membership and sent a request for actions in December, to ensure that the use of MRI for medical or research purposes is not curtailed in the European Union.

## Next Steps:

- EPF will attend a meeting of the Alliance for MRI on 25 January, to receive an update on the situations at the Council and the European Parliament. The alliance for MRI is a coalition of European parliamentarians, patient groups, leading European scientists and the medical community, which together are seeking to avert the serious threat posed by EU health and safety legislation to the clinical and research use of MRI.
- EPF will contact the Danish Presidency to express our support for the derogation and expose the patients' perspective on the negative consequences the limits would have for patient care and research.
- At the European Parliament the Environment and Public Health Committee will hold its vote on 24/25 January 2012, the Employment and Social affair Committee (responsible) will have its vote on 13th February 2012. The plenary vote is foreseen for March 2012.

For more information, please contact [Laurène Souchet](#).

## 10. Review of the Data Protection framework

The European Commission is currently drafting a proposal on Data Protection to review the [1995 Data Protection Directive](#). The aim of the data protection framework is to protect individuals' fundamental rights (article 8 of the EU Fundamental Rights Charter) and freedoms of persons with respect to the processing of personal data, while allowing the free flow of these data within the EU. The 1995 Directive laid down general rules to define when the processing of personal data is lawful. It also established key rights for individuals as regard their personal data.

The objective of the revision is to address the lack of sufficient harmonisation of data protection rules across EU Member States. Technological developments (internet, eHealth, mobile apps) and globalisation are posing new challenges for the processing of personal data, and increasing the risk to privacy. New ways of collecting personal data, less detectable, have also been developed.

The European Commission also aims to strengthen individuals' rights, through improving information, and enhancing control over one's own data with new rights

However data protection raises particular issue in healthcare and for patients.

- Health data as a sensitive category
- Healthcare as a particular area
- The rights of patients may be limited for public health reasons. This is the case, within the current framework for the individual right to access their own data- member states may decide of rules to access medical records through healthcare professionals under the current framework.
- Other areas where sharing of data is required- patient organisations as data controllers

#### Next Steps:

- The European Commission's directorate for Justice have [published its proposal](#) for a regulation on 25<sup>th</sup> January 2012, the European Parliament and the Council will then discuss it under the ordinary legislative procedure.
- EPF will, shortly after, consult its full membership to adopt a position and bring the patients' perspective into the debate.

#### Links:

- Data protection directive, citizen's summary, European Commission, available [here](#).
- For more information on the review of the data protection legislative framework, please see the dedicated page on DG Justice website [here](#).

For more information please contact [EPF Policy Officer](#).

## 11. Patient Safety- Meeting of the Patient Safety and Quality of Care working group

The Patient Safety and Quality of Care working group held a meeting on 21 November 2011, Laurène Souchet attended as EPF representative. The European Commission presented preliminary results of the response sent by Member States to its questionnaire on the implementation of the Council Recommendations on patient safety and quality of care. The European Commission will publish its report on implementation in June. EPF informed the working group that it is conducting independently a survey to gather patient organisations' perspective on the implementation, based on the Commission's questionnaire ([see article 6](#)).

A representative from Avedis Donabedian Research Institute presented the project "Deepening our Understanding of Quality Improvement in Europe" (DuQuE). It studies the effectiveness of quality improvement systems in European hospitals. The overall aim is to test whether organisational quality improvement and culture, professionals' involvement, and patient empowerment are associated with the quality of care in European hospitals (measured in terms of clinical effectiveness, patient safety and patient involvement). The project should provide a list of hospital quality improvement systems which correlates positively with patient outcomes. The field work is being carried out in hospitals of 8 countries and regions. The project is running from November 2009 for approximately 3 years and a half.

Ivan Solan from the Iberoamericano Cochrane Center presented the contributions from Cochrane Collaboration to Patient Safety. His full presentation is available [here](#).

The French Haute Autorité de la Santé (HAS) presented an update on the Joint Action on Patient Safety and Quality of Care in which EPF is involved.

The group also discussed potential follow up action to the Krakow Statement on education in quality of care and patient safety available [here](#). The last point discussed by participants was the future work and focus of the group, in parallel to the implementation of the Council Recommendations.

## Links

The agenda, list of attendees and PowerPoint presentations are available on the European Commission's patient safety webpage [here](#). The minutes of the meeting will soon be available on this page. More information on the DuQuE project is available on the dedicated website [here](#). For more information please contact [Kaisa Immonen Charalambous](#).

### 12. Call for project 2012 to support the Innovation Partnership on Active and Healthy Ageing

On 11<sup>th</sup> January the European Commission organised an info session to present the specific objective and funds allocated to support the European Innovation Partnership on Active and Healthy Ageing (EIP AHA) as part to the 2012 call for project under the health programme. 4 millions are allocated, to fund 3 to 4 projects under this heading. The aim of this action is to support the deployment of innovative solutions for care provision in terms of innovative policies and business models for collaborative and integrated care systems, based on a continuum of care approach. It will also focus on chronic diseases management and in particular for patients with multiple chronic conditions.

Mr Jacques Remacle, Director of the health unit of the European Executive Agency for Health and Consumers (EAHC) presented the health programme, and the call 2012 which was launched on 8 of December and will close on 9 March 2012. He explained the selection process for projects, and gave general advice on how to prepare a viable project. He also presented in more details the 3 objectives for the specific funds and action to support the EIP-AHA:

Supporting change in care delivery model (including integrated care, innovative care with management model rather than technology). This action is supporting systems change, and will also ensure the transfer of knowledge gained in the process of change implementation to other relevant entities, i.e. entities responsible for care organisation and delivery across the EU.

Partnering for change: to support stakeholder cooperation in changing social and care systems. Support for older people's health:

- 1) through better collaboration and coordination, (e.g. support and dissemination of models of good/best practice to promote the health of ageing populations or strengthening data systems)
- 2) through capacity building, (e.g. development of health literacy programmes)
- 3) through preventing frailty
- 4) through identifying measures to ensure that ageing considerations are taken into account in devising new health policies.

Maria Iglesia Gomez, head of the unit Innovation for Health and Consumers in DG Sanco, introduced the partnership's objectives and the existing funding tools. She explained in more details the 3 actions supported by the EAHC call described above. She presented the strategic framework of the EIP AHA. She also gave information regarding the future call/invitation for commitment of the Partnership. These calls are different from call for projects, as they do not entail financial supports for participants. Her full presentation is available [here](#).

#### Next Steps:

- The call/invitation for commitments are to be published on the European Innovation Partnership website in the first or second week of February at the latest. The European Commission would like to start actions before the summer.
- The Commission will then set up a "market place" where stakeholders who have offered commitment will be able to share their idea for actions.

#### Links:

More information call for proposals and guide for applicants are available on the [EAHC website](#).

The webcast of this info session can still be viewed online [here](#).

For more information please contact [Laurène Souchet](#).

### 13. Chain of Trust

The "Chain of Trust" project, led by EPF, started off in January 2011 with the overall objective of assessing and raising awareness of the perspective of the main end users of telehealth services across Europe. Our readers will recall that throughout 2011 a number of activities were implemented in order to gather evidence of users' perspective on telehealth. These included a **literature review**, an **online survey**, and **six National Workshops**. See: [www.chainoftrust.eu](http://www.chainoftrust.eu).

In January 2012 the Chain of Trust consortium started implementing EU-level focus groups involving leaders of the four user groups identified for this project, i.e. patients, doctors, nurses and pharmacists. These focus groups are meant to validate the information gathered through the previous activities and will pave the way for the activities envisaged in the framework of WP5 dedicated to awareness-raising of user perspective. The focus group with patients was held in Brussels on 21 January and involved 11 patient leaders from several different European countries.

In Quarter I 2012 the consortium will also start disseminating the preliminary results of the project that are being consolidated in a first public deliverable that should be available in mid-February.

More information: [www.chainoftrust.eu/news](http://www.chainoftrust.eu/news)

### 14. RENEWING HEALTH

The RENEWING HeALTH project aims to implement large-scale real-life test beds in nine European Regions for the validation and subsequent evaluation of telemedicine services for patients with chronic conditions. The project uses a patient-centred approach and a common assessment methodology (MAST). See: [www.renewinghealth.eu](http://www.renewinghealth.eu)



The project's User Advisory Board (UAB), which EPF is co-managing together with EHTEL (the European Health Telematics Association), held its fifth meeting in Brussels in early December 2011. During that meeting, it was decided to organise a regional meeting with representatives of real users of the piloted telemedicine services in Treviso (IT) alongside the Project's VII Steering Committee meeting taking place on 8-9-10 February 2012. EPF is in charge of organising this user meeting which will involve some 30 representatives of patients, informal carers, health professionals and health managers. Through this meeting the UAB intends to validate through hands-on user experience the User Requirement Framework (see [User Requirements Deliverable](#)) - a document designed to serve as a reference framework for the representation of user needs, requirements and expectations in relation to telemedicine.

The next European-level UAB meetings will focus on reviewing the results of pilots' mid-term evaluation reports which should start to be available as of Quarter II of 2012.

For further information please contact [Walter Atzori](#) or visit the project's website at: [www.renewinghealth.eu](http://www.renewinghealth.eu)

## 15. EUPATI

The EUPATI project is starting now with the overall objective of **raising patient awareness of pharmaceutical research. From 2012, the EUPATI academy will provide educational material and resources for patient representatives and the lay public on personalised and predictive medicine, design and conduct of clinical trials, drug safety and risk/benefit assessment, pharmacoeconomics as well as patient involvement in drug development.**

EPF is leader of the EUPATI project (WP1 project coordination) and leads on WP6 "Deployment and Quality Assurance". From 1 February you can read more about this project on the newly launched website [www.patientsacademy.eu](http://www.patientsacademy.eu).

The Grant Agreement was signed in December 2011 and a kick-off meeting is planned in Brussels on 6 March 2012.

## 16. SUSTAINS

The SUSTAINS project's kick off meeting was held in Uppsala (SE) on 9-10 January. SUSTAINS is a three year project providing **patient access to Electronic Health Records**. EPF active involvement in this project will help us substantiate our policy work in this key area.

SUSTAINS will provide a rich basket of services based on giving citizens online access to their EHR. The services proposed have been distilled from the experience of European regions which have already pioneered such access. Although each of these services has a specific objective, all the services contribute to the achievement of a new paradigm in healthcare in which the citizen/patient is not any longer a passive subject, but he/she becomes an active player in the management of his/her own health.

To get the whole picture about this new project, please follow this [link](#).

### Conferences & events

## 17. “New Quality Developments in Healthcare” - EU Expert Conference, November 18, Warsaw

The conference on “*New quality developments in healthcare*” was held on 18th November, 2011 in Warsaw. It was organized by Polish Ministry of Health and National Center for Quality Assessment in Health Care in conjunction with the European Society for Quality in Healthcare (ESQH). This was the occasion for Polish Presidency to provide a forum for an interactive debate in the context of Joint Action on Patient Safety and Quality of Care and the Directive on Patients’ Rights in Cross - Border Healthcare. Besides, this event was a follow up of the conference organized under the auspices of the Slovenia Presidency in Kranjska Gora (June 2008).

The conference was attended by delegates from European Society for Quality in Healthcare, Ministries of Health of EU Member States, European Commission, Standing Committee of European Doctors, European Federation of Nurses Associations, European

Patients' Forum, European Heart Surgeons Association, Polish Society for Quality Promotion in Healthcare, Committee on Ergonomics of the Polish Academy of Sciences and other experts.

The goal of this event was to raise the attention on the necessity of preparing and implementing innovative solutions (smart quality tools) and citizen participation including self-care and responsibility. The perspective was the different development level of health systems, current strategies of quality care management and escalation of costs and citizens' expectations. Adopting solutions in this field is a challenge for all health systems.

[Click here](#) to look at the presentation of Tomasz Szelagowski, EPF Treasurer and member of EPF Board.

### **18. WHO EURO conference - "Modern Health care delivery systems and the role of hospitals", 21-22 November 2011, Brussels**

This Workshop was organised by the Belgium Federal Public Health Service in collaboration with WHO Europe and tackled Modern Health care delivery systems and the role of hospitals. Nicola Bedlington participated in this workshop on behalf of EPF and gave a patient's perspective based on the work EPF is undertaking in this area. In particular, the workshop aimed to move a step further on the road to better integration and coordination of health care service delivery, by setting the scene for:

1. Reviewing the current situation in relation to hospital and health systems reform across the region, including patient choice perspective
2. Creating a shared understanding of the current state of health care delivery systems and their capacity and willingness to address change
3. Sharing stakeholders' experiences and best practice models, both theoretical and applied, in the search of optimized solutions to increase health care delivery performance

4. Exploring criteria for determining which areas should be prioritized and the potential methods for addressing challenges identified

- a) At the operational level – improving effectiveness, quality, safety, patient experience and efficiency
- b) At the organizational level – governance, budgeting, health workforce development and distribution etc
- c) At the financial level - payers and policy makers
- d) In integrating systems and levels of care to support and strengthen improvement at all of the levels mentioned above

5. Identifying unanswered questions, gaps in our knowledge and areas where further research is needed

6. Seeking expert guidance in how best WHO can continue supporting Member States in these areas.

For more information, please download [this package of documents](#).

## **19. European Health Literacy Conference Brussels, 22 November 2011**

Health literacy goes to the heart of EPF's work and we were delighted to participate in the European Health Literacy Conference in November. It is the culmination of an EU survey on health literacy led by Maastricht University in which EPF was a collaborating partner. More than 150 people from more than 20 countries took part in the conference and discussed the developments and policy impacts of the health literacy survey results. European Health Commissioner John Dalli opened the conference which was endorsed by several members of the European Parliament: Christofer Fjellner, Karin Kadenbach, Pat the Cope Gallagher and Antoniya Parvanova.

Nicola Bedlington represented EPF's viewpoint on health literacy, in particular in relation to eHealth literacy and looked at the opportunities to move forward on health literacy at EU level.

For comprehensive information on the event, please follow this [link](#).



## 20. Chronic conditions in an ageing population, November 22, Brussels

The first debate on Parkinson's disease was held in the European Parliament late last year and generated unprecedented awareness about the disease in Brussels. Organised by the European Parkinson's Disease Association (EPDA) and entitled "Chronic diseases in an ageing population – a spotlight on Parkinson's disease", the room was packed with over 80 people, including more than 20 Members of the European Parliament (MEPs) and their parliamentary assistants.

Linda McAvan MEP, who has a personal interest in brain disorders and Frieda Brepoels MEP, hosted the debate, which was moderated by ex-MEP and European health champion John Bowis OBE. Maria Iglesia-Gomez and Paul Timmers, European Commission officials in public health and health innovation policy, both spoke on the European Innovation Programme on Active and Healthy Ageing.

The event launched *The European Parkinson's Disease Standards of Care Consensus Statement*. These guidelines describe for the first time how Parkinson's disease *should* be managed- putting patients at the centre and highlight the areas that need to be focused on in order to effect change. "There has been little progress in the definition of good-quality care in Parkinson's disease – until now," said Iglesia-Gomez. "The



*Consensus Statement* proposes practical strategies that can help improve Parkinson's standards of care across Europe."

The event's highlight saw Branko Šmid, a Slovenian man who has had Parkinson's for 25 years, arriving in a wheelchair having come 'off' his treatment to demonstrate the effects of Parkinson's when no medication is available. He returned 20 minutes later, back on his treatment, and was able to eloquently discuss his disease. It was a poignant demonstration that highlighted to all present the importance of the right treatment for the right person at the right time.

Brepoels closed by saying, *"What an excellent event this has been, I have learned a great deal about Parkinson's disease through the exchange of truths, of ideas and best practices across different member states. Let's work together – there's a lot to do."*

[www.epda.eu.com/parkinsons-consensus-statement](http://www.epda.eu.com/parkinsons-consensus-statement)



## 21. Celebrating the 40<sup>th</sup> Anniversary of the European Federation of Nurses, 24 November 2011

EPF has developed a longstanding collaboration with the European Federation of Nurses. In celebration of its 40<sup>th</sup> anniversary, the EFN launched the book “Nurses’ Voice in the EU Policy Process” at a dinner hosted by MEPs Marian Harkin and Liz Lynne, bringing together MEPs, Commission officials, EFN members, and key stakeholders. EPF was invited to contribute to the book, describing the synergies between EFN and EPF and our joint advocacy and project work over the last few years, reflecting the importance of the relationship between patients and nurses.

At the event, Marian Harkin stressed the role of nurses as key players in shaping the health policy followed by Liz Lynne pointing out how the EFN made the nurses voice heard in policy making, telling real stories and talking about real people. The EFN President, Unni Hembre, recalled the evolving process of the EFN which has led to its success as a key stakeholder. She emphasised the inclusiveness of the EFN in creating strong alliances with the EFN members and with EU stakeholders, before Maria Iglesias Gomez remarked that nurses are real partners to work with for achieving concrete results in everyday life.

The book “Nurses’ Voice in the EU Policy Process”, outlines the history of the EFN from the sixties, building the capacity for the future nurses’ voice within the EU and Europe. Liesbeth Verloove (Kluwer) highlighted the role of the EFN’s history in defining the world that we would like to live in.

Powerful words came from Irene Donadio, Nicola Bedlington and Monica Kosinska, as they collectively presented the debate on the ‘European Citizens’ Voice’, the ‘Civil Society’s Voice’, the ‘Patients’ Voice’ and the ‘Women’s Voice’; voices that jointly highlighted the empowerment of nurses and women to influence the policy-making process in the European sphere.

*Contact Mr Paul De Raeve, General Secretary of the European Federation of Nurses Associations, for more information.*

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## 22. Caring for Tomorrow, 22 & 23 November. Launch of the Call to Action for Newborn Health and EFCNI White Paper on Maternal and Newborn Health and Aftercare Services

On 22 & 23 November, the European Foundation for the Care of Newborn Infants (EFCNI) launched the Call to Action for Newborn Health and *Caring for Tomorrow: EFCNI White Paper on Maternal and Newborn Health and Aftercare Services*. EPF, alongside parent organisations, national experts, academics, neonatologists and policy makers gathered together at this event to highlight the need for raising standards of care for preterm infants.

To mark the launch of the Call to Action and the White Paper, Nicola Bedlington, Executive Director of EPF, made a presentation on the issue of 'Advocacy in Action – Successful collaboration with policy makers to change the standards for prematurity and neonatal health in Europe', to nearly 100 participants. Nicola's presentation spoke to some of the synergies that EPF has with EFCNI, a pan-European organisation representing parents and scientific experts with the aim of improving the long-term care of preterm and newborn infants with illnesses and support for their families.

Specifically, the EFCNI Call to Action for Newborn Health, demands that European and national policy makers address the growing health inequalities encountered by preterm infants and their families by such things as:

- Making **maternal and Newborn Health a top priority** in public health programmes
- Establishing **national plans** for the care of preterm infants
- Engaging in large-scale **public awareness campaigns on healthy pregnancy**
- Agreeing **harmonised and comparable data standards** to assist with health outcome comparisons
- Investing in the **necessary policies and practices** to improve aftercare for families

Hosting the launch in the European Parliament on day 2 of the EFCNI Conference, Dr Angelika Niebler MEP, and patron of EFCNI, said, "There is a general lack of European-wide accepted standards of care for preterm infants and newborns with illnesses today.

Urgent policy action is required at both the European and national level. We know that healthy ageing starts at birth and preterm infants must have the same chance at life as their full-term counterparts. Given ongoing policy priorities to increase competitiveness and ensure active and healthy ageing in Europe's society, it is about time that Europe understands the need for identifying the provision of high-quality family-oriented maternal and newborn health services as a public policy priority."

One in ten children is born premature therefore premature infants make up one of Europe's largest patient groups. Moving on from the conference and international celebrations of World Prematurity Day which took place on 17 November this year, EFCNI will continue pursuing widescale political and stakeholder endorsement of the aims of the Call to Action and White Paper: to reduce health inequalities and improve newborn and maternal healthcare in Europe.

For more information on the Call to Action, the White Paper or EFCNI's activities at EU level, please visit their [website](#) or contact [info@efcni.org](mailto:info@efcni.org).

### **23. Mobile Doctors, Mobile Patients - How Does Patient Safety Travel in Europe? - CPME conference on 25 November 2011**

The European Standing Committee of Doctors ( CPME) held a Conference on mobility and patients' safety in the context of the CPME Board meeting and General Assembly in Warsaw. Nicola Bedlington participated in this event, and explored with CPME members, and representatives from the Polish EU Presidency and the European Commission, the patient safety considerations linked to the EU Directive on Patients' Rights in Cross Border Health care and EPF's strategy in working with our members at national level on the provisions of the Directive.

For more information on the Conference please contact the [CPME secretariat](#).

The meeting was also an excellent opportunity for Nicola to meet formally with representatives of the executive of CPME to revisit Joint Principles between CPME and EPF endorsed 4 years ago, and to evaluate our common work since then. There was a strong affirmation of the importance of the joint principles and how they have underpinned the significant collaboration we have at both

policy and project level. It was agreed that a joint CPME/ EPF board meeting should take place during the course of 2012 to look at future work priorities in the framework of the next EU Programming period.

#### **24. EPF Board meeting 28 November 2011**

The EPF board met in Brussels to review the progress on the work plan 2011, interim accounts and to look forward to 2012, and our key milestones and activities and finance.

Paola Testori –Coggi, Director General SANCO attended part of the meeting and gave the board an overview of the work of the Council High Level Working Group on Health, and preparations for the new EU Public Health Programme.

The board also discussed EPF's approach to social media and agreed to move forward on a strategy, with a view to launch in April 2012 .

The new staff structure and office move was discussed and agreed. This will take place in late February.

For more information please contact [Nicola Bedlington](#).

#### **25. EFPIA Patients Think Tank, 29 November**

Nicola Bedlington represented EPF at the Think Tank which included on its agenda a presentation of priorities from EPF, the European Multiple Sclerosis Platform, the European Institute of Women's Health, Roche and Merck. An exchange of views took place on the Information to Patients legislative proposal, the Transparency Directive, the European Innovation Partnership on Active and Healthy Ageing. Nicola gave a presentation on the EUPATI project ( European Patients' Academy on Therapeutic Innovation) and Data privacy was also on the agenda

For more information contact Erica Poot [ericapoot@efpia.org](mailto:ericapoot@efpia.org)

## 26. EHN Patient Seminar, 30 November 2011

Kaisa Immonen-Charalambous represented EPF at the European Heart Network (EHN) patient seminar, held on 30 November at the Silken Berlaymont Hotel, Brussels. The session focused on eHealth, with the European Commission's perspective presented by, while Kaisa gave an overview of EPF's activities in the area of eHealth and outlined some of the potential benefits for patients, concerns and barriers to overcome, and how EPF is building an evidence-based position through involvement in projects such as Chain of Trust and Renewing Health. For a copy of the presentation please contact the EPF Secretariat.

## 27. Microsoft Health User Group, November 30-December 2, Brussels - Innovation for the benefit of patients

Microsoft's vision of the future: home monitoring systems, e-health records and contacts lenses that check glucose levels!

Tomasz Szlagowski, EPF Treasurer and member of EPF Board, took the time to share his insight on the future of healthcare in Europe at the Microsoft Health User Group. Entitled "Partnering for Better Health: improving care, acceleration growth and efficiency", the event took place in The Square, Brussels, on November 30.

How innovative technologies can be applied to health was the main focus of the day. The conversation explored ways of harnessing innovation to deliver better services more efficiently and in a way that benefits patients, payers and policymakers. Patients' opinions rang strongly out thanks to the presence of two patient's representatives, both M. Szlagowski and M. Johnstone, EPF Board member.

One important milestone was reached, the launch of the "[Manifesto for an eHealthier Europe](#)". Microsoft will focus its business development, partnerships and communications on the six Breakthrough Solutions for Real Impact that they identified in this Manifesto.

The final word was optimism. The event laid another brick in the foundation to overcome some of the challenges: interoperability, data protection, and buy-in from patients and health professionals.

For more information please contact [Elena Bonfiglioli](#).

## **28. European Parliament workshop on clinical trials, 1 December 2011**

Kaisa Immonen-Charalambous represented EPF in a discussion panel at a workshop held in the European Parliament on “The Benefits of a Simplified and Coherent Clinical Trials Framework in Europe”. The event, held on 1 December 2011, was sponsored by Europabio, the European biotech industry association, and hosted by Philippe Juvin, MEP (EPP, France). The workshop focused on discussing how a simplified and coherent clinical trials framework in Europe could benefit patients by improving the development of, and access to, innovative medicines, while contributing to the goals of the EU 2020 strategy. Views were heard from all stakeholders, including prominently the patients’ perspective presented by Flaminia Macchia of EURORDIS. A panel discussion followed.

The next meeting of the Think Tank will take place on 8 March 2012.

## **29. 4th Annual Health Technology Assessment World Europe 2011 30 November - 01 December 2011**

EPF was invited to join a panel session at this event, to give an overview of EPF’s work on HTA over the past few months.

For an overview of the event and its outcomes please go to on [their website](#).

### 30. EUnetHTA conference, December 8-9, Gdansk, Poland - The impact of new health technologies on patient's perspective

European network for Health Technology Assessment (EUnetHTA) conference held in Gdansk, Poland on December 8-9, 2011, was attended by EPF president, Anders Olauson, who gave a presentation describing EPF's stance and work on HTA. He highlighted the importance of the impact of new health technologies on the personal and professional lives of patients.

He took also the opportunity to raise some issues such as the difficult access to information and communication, the lack of resources, the lack of mutual understanding between patients and HTA experts (language, lexicon) and the cost-effectiveness approach vs. quality-of-life approach.

Next steps for EPF will be to contribute to informing and building capacity among patient organisations, HTA agencies and decision-makers. EPF will also tackle the development of appropriate resources to complement what already exists out there.

More information about [EPF Research on EU Patient Involvement in HTA](#).

For information, *Health technology assessment (HTA)* is a multidisciplinary process that summarizes information about the medical, social, economic, and ethical issues related to the use of health technology. Its aim is to inform the formulation of safe, effective, health policies that are patient focused and seek to achieve best value.

More information about the [EUnetHTA](#) or about the [2011 EUnetHTA conference](#).

### 31. Au revoir Gaya

EPF said goodbye to Gaya its programme officer, Gaya Ducceschi. She left EPF beginning of December to begin her new job in as a consultant for the European Commission. We wish her the best of luck in her new career endeavour and many thanks for her contribution to EPF over the last year.

### 32. Welcome Giulia and Cynthia



Giulia Evolvi joined EPF in January 2012, after an experience in a European-level medical NGO based in Brussels, where she worked on the administration of international projects and EU funds. She has a degree in Foreign Languages (English, Japanese and French) and a master in World Religious Studies. She then specialized in Fundraising and Marketing for non profit organizations, and volunteered for a medical association. Giulia works at EPF as Programme Officer.



Cynthia Bonsignore has joined EPF in January 2012 as Communication Officer. She is responsible for raising awareness about EPF's work and influence amongst our members and external stakeholders through the EPF mailing, the Annual Report, press relations, website content updates, Social Medias and other communication tools. She has worked as a freelance journalist for both press and radio stations and as a communication officer in various sectors.

A warm welcome to Giulia and Cynthia.





## 34. Calendar

Date	Meeting	Location	Attendance
23 January	EPF board meeting	Brussels	EPF Board
24 January	EFGCP Conference on Informed Consent	Brussels	Nicola Bedlingotn (Co –chair)
6 February	European Innovation Partnership on Active and Healthy Ageing Sherpa meeting	Brussels	Nicola Bedlington
7 February	Commission Working Group on Transparency and Ethics	Brussels	Nicola Bedlington
29 February	Fundamental Human Rights Platform Meeting	Vienna	Nicola Bedlington
5 March	EPF Board meeting	Brussels	EPF Board
6 March	EUPATI Consortium meeting	Brussels	Anders Olauson (Chair) Nicola Bedlington
8 March	EFPIA Patients Think Tank	Brussels	Nicola Bedlington Kaisa Immonen Charalambous (speaker)
14-15 March	COPAC Annual Conference	Bucharest	Nicola Bedlington (speaker)
15-16 March	High Level eHealth Task Force	Barcelona	Anders Olauson
22 March	Healthcare in Europe Economist meeting	Brussels	Nicola Bedlington (speaker)
27 March	EUPATI meeting in the framework of DIA	Brussels	Anders Olauson (chair)
26-28 March	DIA Europe	Brussels	Anders Olauson (speaker) Nicola Bedlington (speaker)



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