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Issue 3 (30): 1 June, 2010

Dear EPF Members and Allies,

Welcome to the EPF Mailing – Our special feature in this issue is the EPF's Spring Seminar on Health Technology Assessment and the outcome of our Annual General Meeting. Both were lively, informative meetings which brought together many patient leaders from throughout the European Union. During this time, we said "au revoir" to EPF treasurer for four years Mike O' Donovan who was thanked warmly for his superb contribution to EPF during a formative period for our organisation.

Since the last EPF Mailing, in addition to preparations for those big events, EPF has been extremely active in the European Parliament on the key policy dossiers of Pharmacovigilance, Anti-Counterfeiting and Information to Patients – Get the latest update in section 1. We have also been working closely with the Commission and followed Council developments on Cross Border Healthcare (section 2).

Significant work has gone on over the last few months regarding networking, policy and projects linked to eHealth: At our AGM, members gave a strong mandate to the board and Secretariat to continue our investment in this area and more specifically undertake an in-depth consultation with the membership on eHealth challenges in their disease area and country, that will help to substantiate our eHealth input at EU level.

June promises some other interesting new policy developments. EPF has been involved in the preparations of the Open Health Forum to take place on 29 and 30 June and in particular the parallel session on health and Structural Funds. Significant meetings will also take place with DG Research to help embed patient involvement in health research projects. These are crucial topics for EPF and our membership and we look forward to briefing you on outcomes before the summer.

We also have some important news regarding the EPF Secretariat. Roxana Radulescu, Senior Policy Advisor, who has been working with EPF since January 2007 will be leaving EPF to go to work in the European Parliament. We would like to take this opportunity to thank Roxana very much for her very outstanding contribution and huge personal commitment to EPF and wish her all the very best in her future career. EPF is in the process of finalising a recruitment procedure for Roxana's successor. Further news on this will be given in the next issue of the EPF Mailing before the summer break.

Warmest greetings,
Anders Olauson, President
Nicola Bedlington, Director

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EPF ANNUAL GENERAL MEETING AND HEALTH TECHNOLOGY ASSESSMENT – HIGHLIGHTS

EPF's Annual General Meeting (AGM) and our Spring Seminar on Health Technology Assessment on 18, 19 May this year was deemed a huge success according to the evaluation responses of 80 members and observers from patient groups around Europe who participated.

During the AGM business session, the minutes from the last AGM and the 2009 annual report, accounts and audit report for 2009, and EPF's budget and work plan for 2010 were approved unanimously.

EPF welcomed the largest number of new members to date. A total of seven members were approved at the AGM. The following organisations joined as full members: Association of European Coeliac Societies (AOECS), COPAC, the Coalition of Patients' Organizations with Chronic Diseases, the European Parkinson's Disease Association (EPDA), Federation of Patients and Consumer Organisations in the Netherlands (NPCF), Fertility Europe and the Malta Health Network (MHN). The European Institute of Women's Health (EIWH) joined as an associate member. More information on each organisation can be found in section 27.

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The AGM also welcomed three new board members: EPF members voted in Philip Chircop nominated by the Malta Health Network, Avril Daily, nominated by Retina Pigmentosa Europe and Tomascz Szelagowski, nominated by the Federation of Polish Patients. EPF President Anders Olauson and Vice President Susanna Palkonen were re-elected by the AGM to serve an additional two-year term and current board members, Vida Augustinienė, Guadalupe Morales, Maria D. Navarro, and Timo Nerkko will continue their mandate. (EPF Board on the website). Outgoing Treasurer Mike O'Donovan and Panos Englezos stepped down after completing their terms in office and were both warmly applauded by the members for their work.

There were important changes made to the EPF Constitution to ensure that EPF retains its unique selling point as an organisation of patients, families and their carers. The changes were accepted unanimously by the AGM. For the final version please go to our website.

The afternoon session of the AGM comprised of a policy review session where an update was given on policy developments in the area of Clinical Trials, eHealth, Health Technology Assessment and the role of EPF with the European Medicines Agency. Roxanna Radulescu gave a brief summary of the work and impact of Policy Advisory Group meeting, providing important advice on core policy topics. A brief summary of EPF's current policy consultation procedure was explained for new members and observers indicating member's role in providing input and feedback to the consultations.

The policy review was followed by a working group session that enabled the participants to work together in smaller groups. The aim of these working groups was to gather information from our participants focusing on the following three key questions:

1. How can we build and grow EPF based on our key achievements and challenges to date?
2. How can our membership best guide, strengthen and reinforce EPF to the benefit of all our members?
3. Where would we really like to be in 2020 as a European Patients' Movement?

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The working groups were moderated by EPF Vice President Susanna Palkonen, outgoing Treasurer Mike O'Donovan and board member Maria Navarro. The aim of these working groups was to provide reflection on how to build EPF's foundation to ensure the strongest possible patient representation towards the EU Institutions.

The meeting ended on a high note where a high-level representative from DG SANCO delivered a personal message to EPF members and observers on behalf of Commission Dalli. In his message he noted that it is important for the 150 million patients whose interests EPF represents, to be heard. He reiterated his commitment to put patients high on his agenda but also hopes to count on patients themselves for their input and expertise. Mrs Paola Testori Coggi, new Director General for Health and Consumer Affairs was delayed in the Council but joined the meeting at the very end and had an important discussion with EPF President on the key outcomes of our AGM.

Presentations of the AGM, including all reports are available on EPF's website.

HTA Seminar Highlights

With Health Technology Assessment (HTA) becoming a priority area at the EU level, the timing of organising an HTA seminar for EPF members was ideal. The primary aim of the seminar was to provide patient leaders from across Europe with information on the science, methodologies, and policies behind the HTA process. More than 80 participants including HTA agencies, clinicians and industry representatives attended, bringing their unique perspectives on HTA.

The seminar supported the need for patient involvement in the HTA decision-making process as patients themselves, are experts in their own experience of illness. As Jean Mossman, an expert on HTA process who

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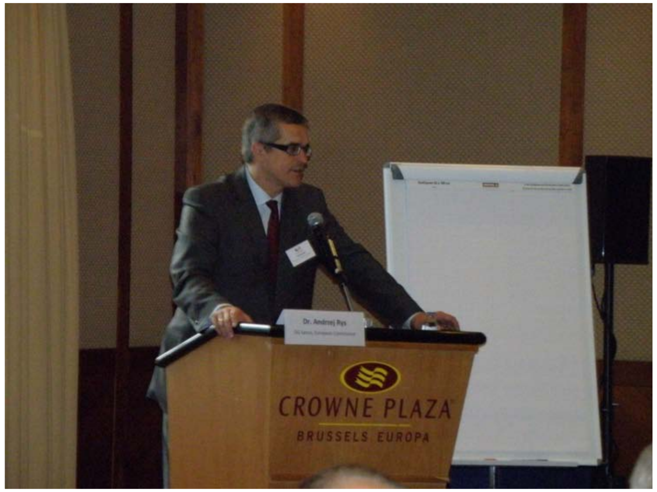
works with the European Federation of Neurological Associations says adequate epidemiological studies have been done within HTA; however, what is most lacking is the need for more qualitative research that explores more about the emotional, physical, and financial side of a treatment such as fatigue, loss of dignity due to immobility, inability to work etc.



The morning session opened with a keynote address from Dr. Andrzej Rys, Director of Public Health and Risk Assessment at the European Commission. He noted that in order to play a constructive role, patients' organisations have to work together to be a united voice in order to provide decision-makers with clear input and non-conflicting information. This, he stated, is possible through an organisation like EPF. He also reiterated the need for patients' organisations to play an integral part in the HTA process and reminded participants of the Health Commissioner's priority to promote EU cooperation in the HTA process.

Jean Mossman presented a helicopter view of HTA in different settings and what is at stake for patients. She stressed the need for patient involvement in HTA process as patients have unique and vital experience and expertise to offer. She also addressed the fact that the patients' perspective are currently not taken into consideration in economic and clinical HTA indicators.

The morning session presentations continued with Michael Wilks from the Standing Committee of European Doctors. He said that HTA can help in conceiving 'trust effectiveness' since efficiency and effectiveness are not synonyms.

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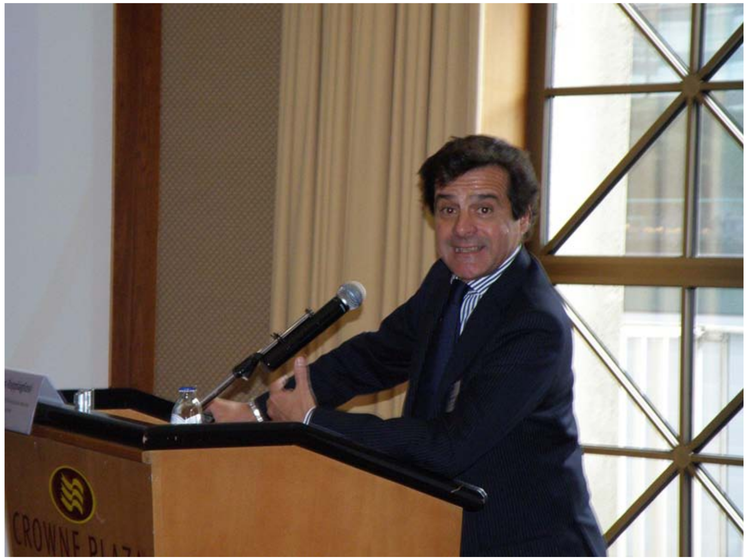

Andrea Rappagliosi from EFPIA presented the industry perspective on HTA and Jerome Boehm from the European Commission addressed the EU added value of HTA emphasizing that the HTA network of Member States, Commission and Stakheholders 'EUnetHTA' can decrease the double work that occurs, improving the relevance of HTA and providing unbiased answers to common issues. Iris Pasternack looked at the EUnetHTA Joint Action in helping to improve the quality and relevance of HTA by developing common methodology and exchanging good practice.

The seminar then broke out into three different working groups. The parallel workshops were repeated providing participants with the opportunity to attend two different workshops. The workshops enable participants to communicate their different views on issues discussed and provide recommendations, enriching the experience for all participants.

Jean Mossman moderated the first workshop on the **Science and Methodologies behind HTA**.

Highlight of Issues:

- Lack of resources including time, money and expertise
- Weak data collection
- More needs to be understood about the impact of HTA in question on daily life of the patient in his specific environment

Recommendations:

- There is a need to find a mechanism that can assist with exchanging HTA specific experiences among participants

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- Further training is needed for health professionals to better understand the impact of HTA on patients. More emphasis is needed on health literacy and health education
- Make patient involvement obligatory

The second workshop, moderated by **Panos Kavanos** from the London School of Economics looked at The **Politics of HTA at EU level and national level and how patients' groups can best get involved**.

Highlight of Issues:

- Lack of patient involvement in HTA decisions which results in lack of transparency and low level trust and acceptability
- Lack of mutual understanding between patients and key HTA experts
- Too much emphasis placed on cost-effectiveness of HTA and not on overall effectiveness of the overall healthcare system

Recommendations:

- Ensure patient involvement from the very beginning and provide and provide information in a timely and accurate manner to the patient
- Bridge the gaps between knowledge and language between experts involved in HTA processes and patient representatives
- Involve patients in HTA criteria and priority settings
- Decision-makers must understand patients' point of view to effectively integrate patient considerations.

The third workshop moderated by **Maria Navarro** from the Spanish Patients' Forum and a board member of EPF looked at **Applying the Value+ Model on Patient Involvement in the HTA Processes**.

Highlight of Issues:

- There is a lack of information and training for professionals and patients' advisors
- Lack of appropriate measurement criteria for the patients' perspective
- Lack of funding

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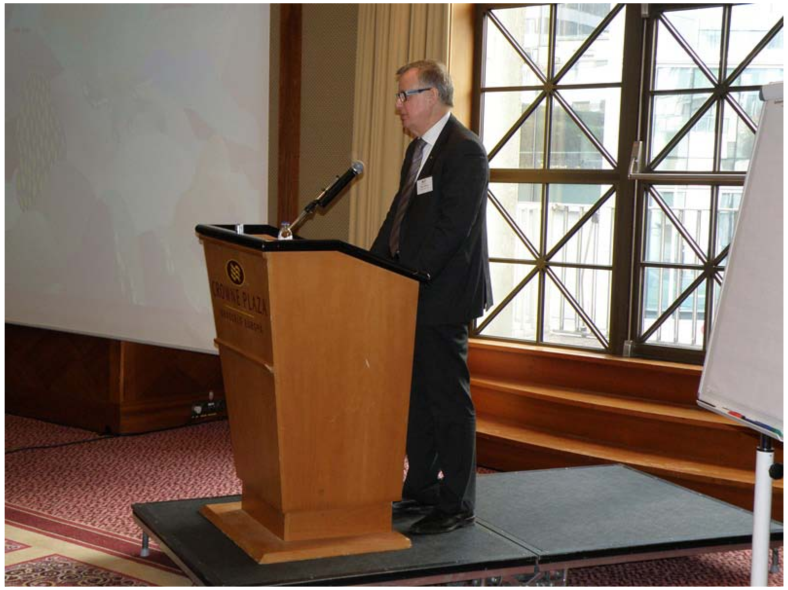
Recommendations:

- Develop a specific methodology for better involvement of patients' and patients' organisations
- Provide training on HTA to create common standard of understanding
- Develop indicators to measure social and ethical aspects and quality of life to integrate into HTA methodologies



The seminar concluded by emphasizing that HTA in the EU is a democratic process and therefore it should engage on an equal basis among all key stakeholders. In order to get a good assessment of health technology, it is important to understand all the factors involved. From the budget to the number of doctor visits in a day.

In closing the meeting, EPF president Anders Olauson stated

"We will be following up this seminar with a resource kit and glossary for EPF members, participants and other patient group allies that will build on existing tools to enable patients and their organisations to be involved meaningfully in HTA processes. Your input today will contribute towards this resource kit that will also be translated into several languages and disseminated widely."

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1. PHARMACEUTICALS PACKAGE – WORK IN THE PARLIAMENT

Pharmacovigilence and Anti-Counterfeiting Legislative Proposals

In preparation of the ENVI Committee (Environment, Public Health and Food Safety) vote on 27 April, EPF and the European Cancer Patient Coalition (ECPC) prepared voting recommendations on the two legislative proposals and discussed them with political advisors from various political groups in the European Parliament. Please see attached. The final vote in the European Parliament plenary session is scheduled for 14 June.

Information to Patients Legislative Proposal

MEP Fjellner's report on the Directive and Regulation of information on prescription medicines was released on 4 March. The report places a strong focus on health professionals as the remaining main source of information, while the market authorisation holders are seen as a complementary source of non-promotional information, in the context of a "wider information to patients" strategy. EPF worked in close cooperation with ECPC on this issue with much of our input incorporated in the revised text.

The report was discussed by the ENVI Committee on 16 March and received strong support from the liberals (ALDE) and the right wing parties (EPP), while some representatives of the Greens and the Socialist & Democrat groups expressed reservations, anticipating high costs for Member States to take up such a commitment. EPF and ECPC sent letters to health coordinators of all political groupings calling them to take

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into account the patient community's views and to give this proposal a real chance to be debated and improved in the European Parliament through the parliamentary legislative procedure.
Moreover, before 20 April, EPF and ECPC proposed a set of amendments and comments to Mr. Fjellner's report and circulated them to all members of the ENVI Committee. The amendments concentrated mainly on the need to give more focus on patients, and the role of their representative organisations. Please see attached the suggested amendments.

For further information, please contact the EPF Secretariat.

2. PATIENTS' RIGHTS IN CROSS-BORDER HEALTHCARE

In the last few weeks EPF has been working closely with the Commission and followed Council developments on the *Directive on Patients' Rights in Cross-border Healthcare*. The Spanish EU Presidency recently made progress on moving forward the proposal towards a compromised text and a political agreement. The latest discussions took place at the Committee of Permanent Representation's (COREPER) meeting on 19 May.

The Spanish Presidency highlighted that the directive should be founded on the common values and principles that the Council endorsed in June 2006 as underpinning the EU health systems. From this perspective, patients going abroad for healthcare should have all the guarantees on the quality and safety of the healthcare they will receive independently of Member State's approach to treatment and type of healthcare provider. Therefore, some progress was made with Member States about improving EU cooperation in areas related to quality and safety of healthcare.

The discussions on eHealth aspects were more difficult, in particular on issues around electronic health records, data protection and data transfer. The Spanish Presidency supports the improvement of eHealth

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provisions in the Directive and is keen to work on concrete aspects linked to the interoperability of technologies. However, some Member States are not yet ready to implement this and several delegations would like to keep the text proposed by the Swedish Presidency (which minimises eHealth), while other Member States expressed a certain support. However, so far no decision has been taken to exclude eHealth from the proposal.

Discussions will continue during the following weeks and it is hoped that at the Employment, Social Policy, Health and Consumers Council (EPSCO) meeting on 8 June a political agreement will be reached. This would be an important step forward, as it would allow for the Directive to be debated and amended in the second reading in the European Parliament.

EPF will continue to screen developments, as this is a crucial topic for EPF and our membership.

For further information, please contact the EPF Secretariat.

3. EMA PUBLISHES STATEMENT ON UNREGULATED STEM CELL THERAPIES

In April, the European Medicines Agency (EMA) published a public statement highlighting concerns over unregulated and potentially dangerous stem cell therapies in Europe.

Stem cell therapies are a hot topic, with just cause. Therapies derived from stem cells, whether adult, embryonic or from umbilical cord blood, have the potential to treat a wide range of conditions that currently have no cure or treatment. Patients look towards these therapies with a great deal of hope and expectation.

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Unfortunately, some organisations and individuals are taking advantage of this hope. For the past 15 years, organisations around the world have been charging large amounts of money to provide stem cell therapies to patients who have few options remaining. These organisations have the following in common: they offer treatment to patients with almost any condition, from arthritis to Parkinson's disease, and from spinal injuries to diabetes; they have not published any peer-reviewed material describing their therapy; they do not report any side-effects or risks associated with their therapy; and they provide little or no post treatment follow-up.

Patients who have tried these treatments are understandably quiet about the outcomes: they have often raised the money for the treatment through donations, and are embarrassed at having been taken advantage of. These are the lucky ones though as these poorly controlled treatments can result in significantly worse problems, such as tumours or infection.

This issue has been confined to countries outside of the European Union until recently, but over the past few years a number of clinics that fit this description have arose in Europe. This communication from EMA is intended to inform patients of the concern with which the Agency's Committee for Advanced Therapies and the Agency regard the problem; and to inform patients of the legal means by which they can receive products of the developing stem cell field in Europe through hospital exemption and in clinical trials.

The statement can be found here:

www.ema.europa.eu/pdfs/human/cat/76346309en.pdf

Article Contributed by Nick Meade
EGAN – Patients Network for Medical Research and Health.

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4. EMA ROAD MAP TO 2015

On 31 March, the European Medicine Agency (EMA) launched a public consultation regarding its strategic Road Map to 2015. The Road Map sets out the Agency's vision, elaborates on the main drivers for progress and change, and explores the main initiatives to be undertaken. This vision encompasses the Agency's strategy for medicines both for human and veterinary use.

EPF consulted its members and submitted a response on 30 April. In general, EPF highlighted that EMA should continue its work of providing high-quality scientific resources for the evaluation and supervision of medicinal products, in the spirit of close interaction with patients' organisations' representatives. EPF also underlined that EMA should further enhance its work on transparency through providing more information targeted to patients.

EPF is represented in the EMA Consumer and Patient Working Party by Susanna Palkonen, EPF's Vice President and in the Management Board by Mike O'Donovan, EPF 's former Treasurer. EPF is often involved with EMA in the quality review of documents, preparation of guidelines and specific requests from EMA scientific committees.

For a copy of EPF's response, please see attached.

For further information please contact the EPF Secretariat.

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5. VITAMIN D CONFERENCE

On March 23, the Standing Committee of European Doctors (CPME) held a conference in the European Parliament on a Vitamin D Nutritional Policy in Europe to Address the Widespread Deficiency of Vitamin D in Europe. EPF sat on a panel discussion at the conference, represented by Madgalena Machalska. Others on the panel included experts, doctors, politicians, and patients' representatives. The purpose of the conference was a call for action for policy-makers and to express a need for prevention, education and consumer choice.

Panel participants advocated for education and information training provided both to healthcare professionals and the public as such, to make them aware of the added-value of Vitamin D on human well-being. Within this context, Anja Weisgerber, MEP in the European People's Party group (EPP), drew attention on the ongoing process on information to patient legislation within the European Parliament. She focused on the importance of information provided to patients, which should go above simple information on medicines and include information on available alternative treatments and health condition as such.

For more information please consult the Standing Committee of European Doctor's website: www.cpme.be/news_eunews.php?id=1119

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6. NEW DIRECTOR-GENERAL OF DG SANCO APPOINTED

Director-General of the European Commission's Directorate General for Health and Consumer Affairs (SANCO) Mr. Robert Madelin, a UK national has replaced Fabio Colasanti to become the new Director-General for Information Society and Media.

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Paola Testori Coggi who has been Deputy Director-General in the health and consumers department of Sanco since 2007 replaced Robert Madelin in April this year. She has worked with the Commission since 1982 where she began working on pollution policies. She has also worked in the office of European Commissioner Emma Bonino and in the environment and research departments.

EPF is establishing strong working relations with Director-General Ms. Testori-Coggi whom EPF President has met on several occasions in recent weeks.

We have also been in contact with Mr Madelin in his new post, reiterating the importance of a patient-centred approach to eHealth.

Projects

7. RENEWING HEALTH PROJECT – SECOND MEETING OF PROJECT PARTNERS

The objective of RENEWING HEALTH (REgioNs of Europe WorkINg toGether for HEALTH) is to implement large-scale real-life test beds for the validation and subsequent evaluation of innovative telemedicine services using a patient-centred approach and a common rigorous assessment methodology.

On 4-6 May the partners met for the second time in Berlin; Liuska Sanna participated on behalf of EPF, a member of the project User Advisory Board.

After looking at the overall progress of activities and deliverables, the group focused on the most pressing issues:

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Finalisation of clusters' identities: clusters aim to group pilot settings addressing the same disease with similar technologies. Due to the variety of settings and applications reaching a clear grouping was challenging, but the partners have now defined the seven clusters.

Evaluation methodology: the project is using a very specific methodology called MAST, which is adapted from the results of the project TELEMED. Partners discussed the topic of indicators to be evaluated in relation to the health outcomes, economic and social aspects and patient satisfaction.

Scientific trial protocols: each cluster is defining the protocol for carrying out the clinical trials to test the telemedicine applications. Partners updated each other on the progress achieved in drafting the protocols, which define number and type of patients to be included in the trial and the recruitment procedures.

User Advisory Board: EHTEL and EPF (that are leading this board) – shared with partners draft terms of reference for the board and ideas on its composition. The ideal number of UAB members is 15 organisations. 25-30 people will be invited to meetings. The next steps will be to start the recruitment process of members, setting up advisory groups, refine the ToR. The first meeting of UAB will take place in June 2010.
Standard and interoperability framework definition: this is in relation to technical interoperability. Partners need to identify clinical use cases to define the workflow, and hence identify the technical interfaces needed to support use case.

Security, privacy and ethical issues: the key activity at this stage is a report on security and privacy issues at regional, national and European level. Therefore, the state of art of local law and regulations needs to be defined. The project will draw on similar work done already by the epSOS project and will address these gaps.
The next partners' meeting is planned for 9-10 September in Greece. Until then the priorities are: carry out procurement of equipment, get the approval of local Ethical Committees and carry out the recruitment of patients.
For further information please contact Liuska Sanna

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8. EPF LEADS A RESPECT AND PATIENTPARTNER JOINT WORKSHOP - EMPOWERING PATIENTS AND PATIENT ORGANISATIONS IN CLINICAL TRIALS RESEARCH

RESPECT and PatientPartner are two European projects that are exploring from different angles how to improve outcomes of clinical trials research. While RESPECT focuses on the needs of children and their families participating to clinical trials, PatientPartner sets out to improve the role of patient organisations in research. Both have an important common feature: they want research to meet patients' needs.

The workshop was organised by EPF in Brussels on the 10 April with the purpose to get a better understanding of the:

- Needs of children and parents/families participating in CT (or who might in the future)
- Methods, approaches and good practices for empowering them
- Role that patient representatives/organizations could/should have in clinical trials research with children.

The workshop was meant for representatives of patient organisations, representatives of parents' associations, parents with knowledge of pediatric clinical trials (either through direct experience or through work experience) and young patients.

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The participants represented different diseases and had diverse experiences of clinical trials. They discussed in depth needs ways of turning these needs into empowering practices, and the role that patient organisations may play to support children participating in CT.

The recommendations resulting from this workshop will feed into the conclusions of both RESPECT and PatientPartner. Moreover, EPF envisages adapting the Value+ Model on Meaningful Patient Involvement in the context of clinical trials.

For additional information on InterQuality, please contact Liuska Sanna

9. CALLIOPE

The 6th CALLIOPE plenary meeting was held on May 7, 2010 in Brussels. Liuska Sanna represented EPF at this meeting, the main focus of which was to clarify the relationship between CALLIOPE's current workflow and organisational elements and the new eHealth Governance Initiative which will be implemented in the form of a Joint Action (JA) coupled with an associated Thematic Network (TN).

The CALLIOPE Thematic Network should deliver its work programme together with its foreseen deliverables by the end of November 2010. Ms. Flora Giorgio (DG INFSO) stressed that CALLIOPE has largely succeeded in operationalising the existing commitment of health administrations and stakeholders to taking concrete steps towards achieving eHealth interoperability. There is now a strong need to build upon what CALLIOPE has produced by ensuring a smooth transition between the latter and the new eHealth Governance Initiative, which will represent the key platform for following up on the CALLIOPE Network. On the other hand, it is

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important for CALLIOPE to focus on moving forward with the EU Interoperability Roadmap as this is the key contractual project deliverable to which high expectations have been attached.

A number of recommendations were made and communicated to the French Ministry of Health in charge of the EU Interoperability Roadmap. Moreover, several meetings and workshops will be organised over the remaining duration of CALLIOPE to collect further input for the Roadmap. In this context, a key event will be the Semantic Convergence workshop will be organised in Reykjavik (Iceland) on June 3, 2010 which will focus on semantics and patient safety.

During the meeting attention was also paid to the finalisation of CALLIOPE Sustainability Report, which investigates how to actually implement activities not foreseen in the future eHealth Governance Initiative. One possibility could be to make sure that the need to find ways to implement additional actions outside the eHealth Governance Initiative is adequately taken into account by the Commission in drafting its next updated version of the eHealth Action Plan which is to be presented during the next eHealth Conference in Budapest in Spring 2011.

EPF will continue to keep you informed on CALLIOPE's further developments, particularly with regards to future steps towards the elaboration of the Roadmap and the transition from CALLIOPE to the new eHealth Governance Initiative.

For more information on CALLIOPE contact Liuska Sanna or visit the CALLIOPE website.

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10. EUNETPAS

The European Network for Patient Safety (EUNetPaS) project aims to establish an umbrella network of all 27 EU Member States and EU stakeholders to encourage and enhance collaboration in the field of patient safety. EPF is an associated partner in this project, which is now coming to an end.

The final EUNetPaS coordination meeting will be held on 1-2 July in Brussels. The first day will focus on patient safety developments in the EU and will include presentations of the EUNetPaS deliverables as well as presentations from the World Health Organization (WHO), OECD and various national patient safety platforms. The second day will be devoted to finalising the deliverables from the project Work Packages (WP) and to the preparation of a Joint Action on Patient Safety for 2011. Nicola Bedlington, EPF's Director, will participate in a panel discussion on views and contributions of civil society organisations on patient safety in the EU.

EPF has been particularly involved in WP 2 (Education and training on patient safety) and contributed to the preparation of "A General Guide for Education and Training in Patient Safety". The guide aims to support healthcare providers on national and local levels to design, establish and evaluate training interventions in patient safety in order to ultimately promote transferability of methods (process and content) from one Member State to another. The document is furthermore designed as a practical tool which is accompanied by a web-based version, which provides context-specific examples from various EU countries. The target audience for the guide consists of all relevant stakeholders: health professionals and other healthcare workers, relevant management and administrative staff in healthcare settings as well as healthcare policy makers and patients themselves.

For further information, please visit www.eunetpas.eu or contact the EPF Secretariat.

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11. 1st MEETING OF THE EHEALTH JOINT ACTION AND THEMATIC NETWORK

Readers will recall from our previous mailing that EPF has been involved in preparatory work for the new eHealth Governance Initiative which will be implemented through a Joint Action on eHealth (JA) and the related Thematic Network (TN). These are two initiatives will be supported by DG SANCO (through the Public Health Programme) and DG INFSO (through the CIP-ICT-Policy Support Programme) respectively on which Member States' Ministries of Health have been working during the last couple of months.

The establishment of JA and TN represents the first systematic endeavour towards setting up a structured and well-defined platform for delivering the eHealth Governance initiative in an attempt to consolidate new ways of working in this area not only between the Commission and the various governments across Europe, but also with the stakeholders.

Despite being supported by two different instruments, the eHealth governance will be regarded as a single mechanism aiming at promoting and capitalising on the resources produced by some key EU-supported projects (e.g. epSOS, CALLIOPE, STORK, eEHIC, etc), thereby bridging the gap between existing evidence and actual deployment of eHealth applications.

The proposal for the JA was submitted last March to the European Agency for Health and Consumers (EAHC), while the proposal for the Thematic Network is currently in the process of being finalised with deadline for submission being on June 1, 2010.

On May 6, 2010 the core group of Member States and stakeholder group representatives involved in these two initiatives gathered in Brussels to discuss in more detail how to actually implement the JA and establish effective links between the latter and the TN. Another major objective of this meeting was to better define the role of stakeholders and the nature of their input in this renewed platform for EU eHealth Governance.

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Although the JA-TN is pretty much a Member State-driven exercise, user stakeholder groups are expected to be playing an important role, specifically, albeit not exclusively, through the Task Force for Trust and Acceptability in which EPF will be involved. This Task Force, whose aim is to take action to overcome the lack of evidence of mutual trust among different eHealth user groups, will be implemented as part of the Work Package 4 chaired by the Belgian Federal Ministry of Health.

Apart from their involvement in the Task Force, stakeholders will be also inputting into other areas covered by the JA-TN, notably legal issues and data protection, interoperability and standardisations as well as dissemination and evaluation strategy. Moreover one user group representative will be sitting on the JA-TN Executive Committee, while all user groups will be represented in the Steering Committee.

As the representative body for patients' organisations throughout Europe, EPF, through its participation in the JA-TN, will ensure that the interest of the patient community is at the heart of current and future eHealth policies at whatever level they are implemented.

For further information on the European eHealth Governance Initiative, please contact Liuska Sanna.

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12. INNOVATION IN HEALTHCARE – FROM RESEARCH TO MARKET

This first major Conference on Research and Innovation in Healthcare organised by the European Commission on 20-21 May, aimed to discuss the challenges facing European Healthcare enterprises and European and National policy developments required to address them. It provided an important forum to widen and enrich the healthcare research and innovation debate. The aim is to re-focus R&D and innovation policy on the challenges facing our society, among which are health and demographic change. The “Innovation Union” plan is one of the flagship initiatives proposed by the new Commission aiming to boost investment in research and innovation, making Europe an attractive place to develop new products and derives from the EU’s new strategy for sustainable growth and jobs “Europe 2020”.

EPF President Anders Olauson was invited by DG Research to make a presentation during the Plenary Session. In his address he said ‘The fact that EPF is here with Commission and European Parliament leaders for Research and Enterprise and fellow stakeholders sends out a very important message, patient involvement in healthcare innovation and research matters, can make a real difference, and will lead to more patient centred policy and practice. It is this message that I want you all take home and think about in your future work’.
He went on to describe the rationale behind, and added value of involving patients meaningfully in health related research, fostering innovation that is patients’ centred and reflects patients ‘ own unique experience and expertise.
The presentation drew on the findings and the outcomes of the Value+ project on Meaningful Patients’ Involvement in EU Health-related Projects and Policies.

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In conclusion Anders Olauson highlighted that advances to patient research practice over the next decade will require:

- Establishing the effectiveness of patient research in achieving health outcomes
- Linking patient practices, processes, and core elements to health outcomes
- Increasing patient research education and training opportunities
- Patients being seen as equal and respected research partners, rather than purely subjects
- Achieving greater support for Patient Research approaches among funders and institutions

For more information on the event, please go to: http://ec.europa.eu/research/health/events-01_en.html

13. EUROPEAN SOCIETY FOR QUALITY IN HEALTHCARE

On behalf of EPF, Magdalena Machalska attended a Spring Workshop on performance measurement which was organised by the European Society for Quality Healthcare (ESQH) and the Turkish Society for Quality Improvement in Healthcare (SKID) on April 29 and 30 in Istanbul.

The purpose of the session was to discuss achievements and possible barriers for further developments in safety and quality assessment with regard to healthcare. It gathered experts, researchers, and decision-makers, not only from EU countries, but also from other countries, such Turkey and Albania.

Thursday's session focused on a PATH Project launched by the World Health Organization (WHO) in 2003, as a means to conceive indicators to measure safety and quality in healthcare. Its purpose is to gather hospitals on a voluntary basis, to help them exchange best practices, compare and thus avoid possible wrong decisions.

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The Workshop was divided in two working groups, one of which was specifically focused on patient experience within the performance measurement procedures. This was a good opportunity for EPF to introduce itself to the public and to inform the audience on EPF's work in quality of healthcare and finally to promote the Value+ project. The project has an added value particularly for those countries, who are currently trying to conceive specific strategies to involve patients in safety and quality assessment, such as Turkey.

EPF is very committed to high quality, equitable healthcare. As both, safety and quality healthcare are strategic for EPF, it is very keen on further cooperation with ESQH on patient participation in health policies.

For more information please contact Magdalena Machalska

14. EPF INVOLVEMENT IN OPEN HEALTH FORUM 2010 CONFERENCE

The fourth Open Health Forum Conference will be held in Brussels on June 29-30, 2010 at the Charlemagne Building under the overall theme of "Together for Health – a Strategy for the EU 2020". One of the major objectives of the conference will be to increase the profile of health within the new Europe 2020 strategy to make sure that the principle of “health in all policies” is effectively integrated in the delivery of this strategy.

The conference will be opened by a key note address by Commissioner introducing the participants to a round table in which the Commission and EU Parliament's officials, Member States representatives as well as healthcare stakeholder groups'

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representatives will address the key issues and challenges for EU public health policy for the next 10 years.

The round table will be followed by two rounds of three-hour parallel workshops (three in the afternoon of the first day and three in the morning of the second day), looking from different angles at on-going and future developments in key EU policies areas and the implications they are likely to have for health at the European, national, and regional levels. A second plenary session, chaired by the newly-appointed DG SANCO Director General, Ms. **Paola Testori Coggi**, will follow the parallel sessions to discuss the main outcomes that emerged during the workshop' discussions.

The organisation of the various parallel workshops has been delegated to different organisations involved in the EU Health Forum. EPF is responsible for organising the parallel workshop "**Positioning Health at the Centre of Post-2013 Cohesion Policy**" devoted to discussing the opportunities for health-related investments under the Structural Funds and the role of health in the post 2013 Cohesion Policy. During this workshop high-level speakers from EU institutions, national and regional authorities, and senior experts will bring their own experience and ideas on how to ensure a better use of Structural Funds for health. EPF President Anders Olauson will be the rapporteur and presnt key outcomes to the plenary session.

While the workshop will pay particular attention to the current funding settings and lessons learnt from the past, emphasis will be also laid on the key challenges for the next multi-annual programming period which will cover the years 2014-2020.

This Workshop will be a thought-provoking exercise whereby participants will be invited to challenge the speakers by bringing their own experiences, highlighting the problems and difficulties they face in working with the Structural Funds and making suggestions for future improvements.

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The organisation of this workshop is part of EPF's commitment to stimulating a wider debate on how to maximise health gains from the Structural Funds, to promote more equitable and accessible healthcare across European Regions.

For this reason we will be pleased to see you at our workshop on **29 June, 2010 from 2:00 to 5:30 pm**.

The conference website has been launched and can be accessed at:
http://ec.europa.eu/health/interest_groups/eu_health_forum/open_forum/2010/index_en.htm#fullwidth
On line registration to the Open Health Forum 2010 Conference is also possible at:
https://webgate.ec.europa.eu/fmi/scic/Health10/start.php

For more information please contact: Walter Atzori

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15. EUROPEAN IMPACT OF INTERNET PHARMACY SERVICES AND MEDICINE SERVICES ON PATIENT HEALTHCARE AND SAFETY

Nicola Bedlington represented EPF at a European Parliament meeting on the Impact of Internet Pharmacy Services and Medicine Services on Patient Healthcare and Safety. The ALDE event was co-organised by Antonyia Parvanova, MEP and Marian Harkin, MEP.

The meeting focused on the fact that the supply of medicines via the Internet is an area of growing concern to health practitioners, patients and policy-makers alike. Patients have no assurance as to the safety and appropriateness of medicines supplied online. The absence of direct contact with a pharmacist to give advice and guidance leads to a potential misuse of pharmaceutical products by patients, and therefore put their health at risk. Effective action to enhance and enforce controls must be prioritised.

For more information on this topic:
http://www.alde.eu/index.php?id=42&no_cache=1&tx_ttnews[tt_news]=22975&L=0

For a copy of Nicola's presentation please contact the EPF Secretariat.

16. EPF AND PGEU SECRETARIATS TO SET UP A JOINT MEETING IN THE EUROPEAN PARLIAMENT ON DIRECT PATIENT REPORTING

Key members of the EPF Secretariat met with the PGEU Secretariat (Pharmaceutical Group of the European Union) in April to say goodbye to our close PGEU colleague, Ivana Silva, who has moved to the European Medicines Agency. This meeting was also an opportunity to re-affirm the active collaboration that PGEU and EPF have enjoyed over the last few years, on core policy issues such as patient safety and eHealth. It was

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agreed that we will arrange a joint meeting in the European Parliament in September that will focus on direct patient reporting of adverse events, that is a central part of the proposed Directive on Pharmacovigialnce. More news on this event in the next issue of the EPF Mailing.

17. HEALTH FOR ALL CARE FOR YOU

Experts agree that personalized healthcare is important but why isn't it more widely used in clinics, hospitals and labs across Europe? What are the barriers to adopt the new Information and Communication Technologies (ICT) in healthcare? To answer these questions, a conference was organised by Science Business on 22 April in London, where EPF was represented by Magdalena Machalska.

The conference brought together over 200 researchers, executives, academics and policy makers to examine the potential challenges of ICT applied in healthcare, especially from technology, financing and cost, and administration perspectives.

To have a better understanding of the current situation, Science Business, together with Karolinska Institutet conducted a survey on a wide range of stakeholders in personalized healthcare across four EU countries, namely Belgium, France, the Netherlands and the UK. Its purpose was to understand what is really needed to get personalized healthcare out of the lab and to the market.

Further discussions, which took place in London focused on key barriers to ICT in healthcare such as financing, accessibility and inclusion of all patients, privacy of data collected which thus lead to an exchange of ideas with peers and address guidelines directly with experts.

For more information on this event, please consult the Science Business website: www.sciencebusiness.net/events/healthforall_london/

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18. EHEALTH USERS' STAKEHOLDERS GROUP MEETING

Ms. Liuska Sanna represented EPF at the eHealth Users' Stakeholders Group (eHUSG) meeting which took place on 23 April.

The meeting was an opportunity for the eHUSG members to update each other on latest eHealth developments since the last group's meeting in February 2010, including the outcomes of the eHealth conference held in Barcelona and the discussions around the eHealth Governance Initiative, i.e. the Joint Action (JA) and Thematic Network (TN) on eHealth. The participants were reminded that the next eHealth conference will be organised in Budapest under the patronage of the Hungarian EU Presidency in Spring 2011. Ms. Flora Giorgio (DG INFSO) highlighted that on the occasion the Commission will most likely publish the new updated version of the 2004 eHealth Action Plan, although a draft version is scheduled to be issued in 2010. It was suggested that once this draft is ready, the eHUSG chair will ask for a meeting with the newly-appointed DG INFSO Director General, Mr. Robert Madelin, with a view to giving user groups input into the eHealth Action Plan.

Michael Wilks, eHUSG chairman, presented what is the foreseen evolution of the users' input into the JA and what is expected in relation to the application process for the TN (see article on this issue). The group agreed that Dr. Wilks and Liuska Sanna would represent the eHUSG at the executive committee of the JA.

The second part of the meeting was dedicated to discussing latest development in epSOS and CALLIOPE projects and Michael Wilks was invited to take over CALLepSO chairmanship following Ivana Silva's leaving PGEU.

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EHTEL (European Health Telematics Association) presented the FP7-supported ETHICAL project ("Promoting international debate on ethical implications of data collection, use and retention for biometric and medical applications") and invited the group to provide feedback on some proposed questions for discussion, particularly on EHTEL's wish that ethics becomes a core topic for the eHUSG.

Before closing the meeting EHTEL also informed the eHUSG members of the recently-launched large scale pilot RENEWING HEALTH Project and introduced the role of the User Advisory Board (UAB) in which EHTEL and EPF sit. While EHTEL and EPF have already agreed that some members of the eHUSG will be formally invited to join the UAB, it was also proposed to create dynamic links between eHUSG and RENEWING HEALTH's UAB with a view to giving the latter a more political dimension.

The next two eHUSG meetings will be held on 17 September and 10 December, 2010 respectively.

For more information on the eHUSG, contact Liuska Sanna.

19. PATIENTS' RIGHTS DAY IN THE PARLIAMENT

The 4th European Patients' Rights Day on 18 April was celebrated in the European Parliament with a conference on 6 May in Brussels. The event, hosted by MEP Antonyia Parvanova and organised by the Active Citizenship Network gathered approximately 100 representatives of patients' and citizens organisations and other healthcare stakeholders from across Europe interested in promoting European Patients' Rights Day. John Dalli, the European Commissioner of Health and Consumer Affairs gave the opening speech fully supporting the celebration of European Patients' Rights Day.

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Several key MEPs reaffirmed their support for this initiative and committed to endorse a Written Declaration for the institutionalisation of the European Patients' Rights Day. The authors of the Written Declaration are Members of the European Parliament (MEPs) Antonyia Parvanova (Bulgaria, ALDE), Françoise Grossetête (France, EPP) and Gianni Pittella (Italy, S&D). The Declaration will stand in the European Parliament's register for three months. EPF fully supports the Declaration and the work undertaken by Active Citizenship Network and commits to campaign, with the support of our members, to promote the Declaration among MEPs, so that the necessary number of signatures (a minimum of 369) is collected.

The afternoon session of the conference was an opportunity to share innovative experiences regarding citizens and patient involvement. Roxana Radulescu, EPF's Senior Policy Advisor, gave a presentation of the Value+ work in promoting patient involvement in projects that will ultimately lead to more patient-centred policies.

For further information about the European Patients' Rights Day and the events organised in various European countries, please go to: www.activecitizenship.net/content/blogcategory/68/159/

20. INTEREST GROUP ON CARERS MEETING WITH COMMISSIONER ANDOR

The European Parliament Carers Interest Group (EPCIG) is a joint initiative by Marian Harkin MEP (President of European Parliament Interest Group on Carers) and Kathy Sinnott (former MEP 2004 - 2009) set up in 2007. Its purpose is to ensure that policy developments at EU levels address the needs of carers.

The last EPCIG meeting was held on 4 May in the European Parliament which gathered experts involved in both the health and social protection sectors to take a proactive stance on carer issues. The meeting provided

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the opportunity for direct dialogue with Commissioner Andor, Commissioner for Employment and Social Affairs. During his speech, Commissioner Andor called for a larger pool of carers across Europe, as Member States are committed to ensure universal access to high-quality, affordable long-term care, as highlighted in their strategies on social protection and social inclusion.

The Commissioner also highlighted activities being carried out by the Open Method of Coordination (OMC) in sectors such as social protection and social inclusion. This shows that the key challenge for health and long-term care systems is to ensure the availability of a qualified workforce.

The second speaker, Mr Carlos Garcia de Cortazar (Social Affairs Attaché, Spanish EU Presidency) drew the audience's attention on the crucial impact of demographic ageing on all aspects of society, which also includes the provision of long-term care. For instance, 38 % of men and over 53 percent over 80 need special care. If this trend is to continue, Europe will be a 'long-term care continent'. We have to understand the implications of these demographic developments and act on them accordingly.

EPF supports this initiative as patients are carers and thus the core activity areas of the EPCIG group go along with the EPF core strategy.

For more information, please consult the EPCIG website: www.marianharkin.com/index.php?id=56 .

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21. EU HEALTH POLICY FORUM

The EU Health Policy Forum (EUHPF) met in Brussels on 20 May. Roxana Radulescu and Liuska Sanna represented EPF at this event.

The EUHPF was set in 2001 with the aim to serve as an information and consultation mechanism between DG SANCO (Directorate General for Health and Consumers) and health stakeholders. This was the first meeting of the renewed group which now comprises 52 members organisations, including representative organisations of patients, health professionals, health service providers, and industry - one third more than the previous set of members.

During the morning session, the discussion focussed on the follow-up on the EU 2020 Strategy and SANCO's main priority for 2020 - responsible innovation for the benefit of humanity. This looks in particular at considering innovation and sustainable financing of different aspects related to health and active ageing, enabling patients to manage their own care and monitor their own health, while contributing to sustainable health technology assessment cooperation at EU level.

Regarding future work and activities of the EUHPF, an update was given on the follow-up and implementation of the EU Health Strategy "Together for Health". This was followed by a report from the Spanish EU presidency on the implementation of its health priorities and the on the work of the Council Working Group at senior level. The afternoon session focussed on strategic priorities and the Work Plan for 2010, next steps 2011-2012, as well as the EU Open Health Forum conference on 29-30 June. During the session on important communication by members, Liuska Sanna gave a short presentation on the achievements of the VALUE+ project on patient involvement in EU health-related projects.

For further information, please visit: http://ec.europa.eu/health/interest_groups/eu_health_forum/index_en.htm or contact the European Public Health Alliance who is in charge of the EUHPF Secretariat at secretariat@euhealthforum.org.

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22. HEALTH EXECUTIVE SUMMIT

Nicola Bedlington represented EPF at the Health Executive Summit in Paris on 20 May that held a specific session on eHealth.

The session opened with key note addresses from **Louise Beauchesne**, Executive Regional Director – Quebec, Canada Health Infoway, Canada Promoting Collaborative Care and Making Patients Co-producers of their Own Health and **Charles Gutteridge**, Clinical Director for Informatics, Department of Health, United Kingdom Quality and Informatics: Engaging People in their Own Care.

Nicola was involved in a panel discussion that brought together Dr **Niels Boye**, Physician, Specialist in internal medicine, Endocrinology, and Health informatics, Denmark **Michel Gagneux**, President, ASIP Santé, France **Lucien Engelen**, Health 2.0 Ambassador, Head of Regional Emergency Healthcare Networks, Radboud University Nijmegen Medical Centre, The Netherlands **Lee Aase**, Manager, Syndication and Social Media, Mayo Clinic, USA Moderator: Dr **Mike Bainbridge**, Clinical Architect, NHS Connecting for Health; Principal Consultant ASE Ltd UK, United Kingdom.

For a report on the debate that took place please go to: www.health-es.com

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23. EFPIA THINK TANK

The EFPIA Think Tank met on 4 May and discussed a wide range of topics, including the Patients' expectations for the Innovative Medicines Initiative, the PatientPartner Project that focuses on patient involvement in clinical trials, and the current state of play regarding the Animal Testing Directive. The European Commission gave an interesting update on the move of pharmaceuticals from DG Enterprise to DG Sanco and an overview of the Pharmaceutical Package of proposals (see section 1). Nicola Bedlington gave an outline of the work undertaken jointly by the European Cancer Patient Coalition and EPF in the European Parliament on the three key legislative dossiers.

For a copy of the presentations made at the Think Tank please contact the EPF Secretariat.

24. MOBILE EHEALTH: EPF PARTICIPATION AT THE GSMA EUROPE MEETING

On 28 April 2010, GSMA Europe organised a breakfast meeting to discuss challenges and opportunities of mobile eHealth technology and applications. GSMA Europe is the public face of European mobile operators and the key representative forum for the European wireless industry.

EPF Director, Nicola Bedlington, was invited to this event to give a presentation focused on patients' expectations towards mobile eHealth. High-level panelists included MEP Mrs. Antonyia Parvanova, Mrs. Joanna Darmanin, Head of Commissioner Dalli's cabinet, and Patrice Cristofini, Vice-President Orange Healthcare Strategic Partnerships.

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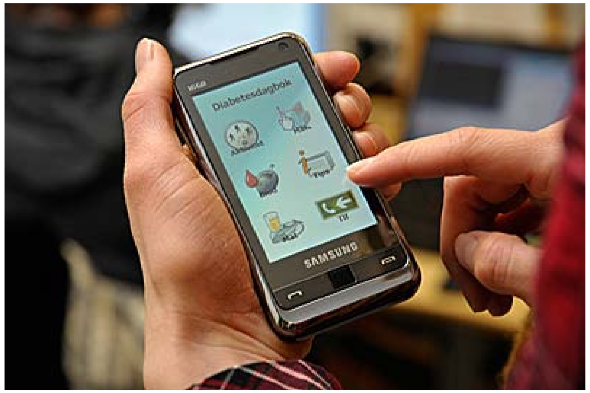
Mobile eHealth (mHealth) typically refers to portable hardware coupled with software applications with the capability to create, store, retrieve, and transmit data in real-time between end-users. Data transmission is realised by technologies common in everyday life such as mobile phones, Bluetooth, infra-red, wifi, and wired technologies, all of which operate as part of an interoperable network.

In her presentation, Ms. Bedlington highlighted that mHealth services present a number of opportunities for the patients, such as improving patient safety, enhancing quality and continuity of care, and helping address health inequalities. In addition to improved patient outcomes the use of mobile devices can produce cost savings for both the users and taxpayers by reducing workflow and administrative costs, thereby contributing to more sustainable healthcare systems.



mHealth solutions can be used for many purposes, such as remote monitoring of vital parameters of patients with chronic conditions (e.g. COPD, diabetes and CVD), reporting adverse events, remote diagnosis decision-support, self-checks, management of clinical trials and real-time two-way information exchange. While most of these features apply to all existing eHealth applications, the key advantage of mobile solutions is that they make it possible for the patient to receive optimum care “anytime” and “anywhere”.

A recent study on people with diabetes revealed that patients prefer wireless eHealth solutions, rather than having to stay at home to log on to a stationary desktop platform[1]. A key element in ensuring that mobile applications are used is that the patients must be able to bring the device with them everywhere they go, or chances are that they are less likely to use it. Another key challenge is to ensure that these technologies are

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[1] Naoe Tatara, Eirik Årsand, Heidi Nilsen, Gunnar Hartvigsen, "A Review of Mobile Terminal-Based Applications for Self-Management of Patients with Diabetes," etelemed, pp.166-175, 2009 International Conference on eHealth, Telemedicine, and Social Medicine, 2009.

user-friendly, tailored to the specific needs of the patients and the characteristics of their disease. The patients are unlikely to use mHealth applications unless they fully understand the added-value of these solutions.

mHealth development in Europe has been so far limited to pilot initiatives which have in most cases fallen short of wider scaling up. During the meeting at GSMA, some Mobile industry representatives have called attention to the fact that technology is already available, but there is still a lack of leadership and political will to boost deployment and wide up-take of innovative applications.

While there is a clear need for enhancing trust and acceptability between end-users and mHealth providers, a major obstacle to the deployment of mobile applications in the EU is the highly-fragmented legal framework applicable to healthcare services and eHealth in particular, specifically when it comes to cross-border situations. In this context, EPF would suggest that the legal nature of eHealth services, data protection legislation, data ownership, reimbursement needs to be addressed urgently.

In line with the subsidiarity principle, responsibility for healthcare policy lies with the national (and regional) authorities, but living up to citizens expectations in terms of improved safety, quality, flexibility and cross-border access to healthcare requires stronger action at the European level. Reinforcing eHealth governance is crucial to ensuring, for instance, that innovative applications which have been successfully validated can be effectively used by the patient without this resulting in reduced safety in the way a given healthcare service is provided when he/she happens to be abroad.

The participation of EPF in this event was part of our renewed commitment to exploring opportunities **and** risks and threats associated with eHealth services and applications for the patient community that we addressed at our Annual General Meeting. EPF will continue to monitor the evolution in this area to make

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sure that the needs, requirements and expectations of the patients are fully taken into account in further discussions on mobile eHealth technologies and applications.

For more information contact Nicola Bedlington.

25. FP7 HEALTH RESEARCH OPEN INFORMATION DAY AND BROKERAGE EVENT

The European Commission Directorate General for Research will organise an **Open Information Day** (Info Day) on the **Seventh Framework Programme** (FP7) - **Health Research** on 8 June, 2010 at the Centre Albert Borschette in Brussels.

The aim of this Info Day is to highlight the priorities, novelties and special features of the **2011 Work Programme** for FP7-supported health-related research projects and provide potential applicants with guidance on proposal preparation and opportunities for partnering.

The final version of the 2011 Work Programme, which is due to be published in July 2010 foresees major efforts in the following areas: brain-related diseases, diabetes and obesity, immunisation, epigenomics and social determinants of health, as well as other global health issues, such as anti-microbila drug resistane and emerging epidemics. Cross-cutting features of the 2011 Work Programme include a number of topics for **clinical trials** and SME-targeted topics.

During the morning plenary session, **EPF Director Ms. Nicola Bedlington** will give a presentation focused on **patient involvement in health research projects**.

The plenary will be followed by four parallel sessions, one of which will focus on **Clinical Trials**. During this session the EPF-led **Value+ project** will be showcased as an example of good practice in promoting meaningful involvement of patients in EU projects.

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The information session will be followed by a **Brokerage event** which will offer the participants the possibility to present their organisation's expertise and specific interest in cooperation with international partners in the health sector.

Due to the high number of people wishing to participate in this event, registration has already been closed. However, it will be possible to follow the two plenary sessions of this event via web-streaming at the following link: http://webcast.ec.europa.eu.

Why should patient organisations be interested in FP7 Health Research?

Experience has shown that involving patients and patients' organisations in health research projects leads to significant benefits in terms of effectiveness and validity of project results. When patients are engaged right from the onset in the research planning process, they are more committed to applying the research findings in real life and policy settings.

Evidence from our Value+ project that explored patient involvement in a whole range of EU funded programmes, including FP6 and FP7, revealed that patient involvement has been so far clearly weaker in research projects than in other projects, especially those focused on clinical trials, studies or development of technologies and devices.

It was highlighted however that project coordinators expressed a clear interest in developing or improving patient involvement in their projects, but needed support in knowing how to translate this in practice. This event is, therefore, a great opportunity for patient organisations not only to gather information on technical aspects and administrative procedures of FP7 projects, but also to get in touch with potential project partners.

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In order to support patients' organisations in getting involved in FP7 projects, EPF will continue to advocate for the need to carry out "research with" rather than simply "research on" patients and call for the European Commission to include an explicit criterion on patient involvement in relevant Calls for Proposals. EPF will also follow-up on the FP7 Health-Research Info day to make sure that patients and patients' organisations can benefit to the highest extent possible from EU research funding in the years to come.

Anders Olauson will be taking this forward in the forthcoming High Level Research Advisory Council on 24 June 2010.

For more information please visit the FP7 Health Research website, or contact Nicola Bedlington.

26. DUTCH GOVERNMENT OFFICIALS AND INSURANCE REPRESENTATIVES MEETING

In mid-April, Nicola Bedlington met a group of Dutch Government officials and health insurance representatives who were in Brussels to learn more about EU health policy from key stakeholders. A significant point emerging from the meeting was the importance of greater dialogue and trust between patients' groups and health insurance bodies. EPF is currently developing stronger relations with ESIP and AIM, the two umbrella bodies representing the health insurance sector at EU level.

For more information please contact Nicola Bedlington.

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27. WELCOME TO NEW EPF MEMBERS

EPF welcomed seven new members at their annual general meeting on May 19. After the board's approval and a unanimous vote by EPF members, all seven members join EPF bringing our total membership to 45 members.

The European Institute of Women's Health joined EPF as an associate member. The aim of the organisation is to ensure women's health issues are on the European agenda.

We are also pleased to welcome the European Parkinson's Disease Association who joined as a full member and represents 43 national European Parkinson's organisations.

The Malta Health Network and the Federation of Patients and Consumer Organisations in the Netherlands both join us as full members. They represent and share the common goal of bringing together the interest of patients.
Fertility Europe, also an umbrella organisation joins us and represents European patients and other associations involved with fertility issues.

COPAC, the Coalition of Patients' Organizations with Chronic Diseases also joined EPF as a full member. They are the biggest organisation in Romania, fighting for promoting and protecting the rights of patients' with chronic diseases.
Finally, the Association of European Coeliac Societies joins the EPF membership as a European umbrella organisation grouping 33 member associations in 29 countries.

Our success lies in the collaboration between our Secretariat and our members to achieve our vision of patient-centred quality healthcare for all EU citizens. We look forward to continuing our successful relationships with our current members and building new ones with our new members in order to realise the mission and vision of EPF.

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28. EPF WEBSITE ACCREDITATION

EPF is pleased to announce that our website has been certified the by Health on the Net Code of Conduct (HONcode). The HONcode was created with the aim of improving the quality of information for both patients and medical professionals, allowing quick access to up-to-date and relevant medical information. This provides our readers with reliable, credible information and ensures the most up-to-date information is posted on our website. There is a wealth of information that can be found on the Internet, and as a visitor to any website, there needs to be assurance that the information provided is valid and up-to-date. This is ever more important when it comes to medical information.

29. POLICY ADVISORY GROUP MEETING

The EPF Policy Advisory Group (PAG) met for the second time in Brussels on 6 April. The group was set up to advise the EPF's Board and Secretariat on policy topics prioritised by EPF's annual general meeting and which, because of their complex, controversial and/or highly political nature, required a more detailed and in-depth discussion. The group is made up of elected representatives or staff of EPF members - both European patient organisations and national patient coalitions - who have a particular interest in the policy areas EPF is working on.

The current policy consultation procedure within EPF is the following: a draft paper is prepared by the Secretariat and Board, drawing on existing EPF documentation and statements linked to the issues, and indicating areas where members' input is crucial. The draft paper is then sent to the members for their additions, comments and endorsement. Should there be proposals that would change the substance of a

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position, a further round of consultation takes place, in order to arrive at a consensus across the membership. On rare occasions when a member is unable to endorse an EPF position, this is indicated.

At the meeting on 6 April, the group exchanged views and advised on several topics of crucial interest for EPF and our members : the "Information to Patients" legislative proposal, legislative and policy developments in relation to the Pharmacovigilance" and "Anti-counterfeiting" proposals, the Commission's draft reflection paper on Patient Safety and Quality of Care, funding opportunities for patient organisations and ways of building up on the achievements of VALUE+ project.

The next Policy Advisory Group meeting will be held in September 2010. Should EPF members who are not yet involved and wish to send a representative please contact Nicola Bedlington.

For a copy of the minutes of the EPF PAG meeting, please contact the EPF Secretariat.

30. EPF AUTUMN SEMINAR 2010

EPF has confirmed the date and the location of our next autumn regional seminar- Budapest, 25-27 October. This year's invitation only regional advocacy seminar will focus on young patients. The main purpose of the seminar will be to build capacity for patient organisations' young representatives from the Central and South-eastern European countries. It will focus on developing participants' communication and advocacy skills to influence policies that affect their lives and their patient communities.
More information on the seminar will be provided in our next EPF mailing.

For further questions about the seminar, please contact Liuska Sanna.

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31. INVITATION TO EUNETHTA STAKEHOLDER FORUM

The EUnetHTA JA is a formal 'collaboration between EU Member States and the European Commission, aiming at putting into practice an effective and sustainable HTA (Health Technology Assessment) collaboration in Europe that brings added value at the European, national and regional level'. They launched an expression of interest inviting all relevant health stakeholders involved in HTA who could provide their input and expertise. EPF applied and the application was accepted and EPF was invited to participate in the EUnetHTA Stakeholder Forum. The Stakeholder Forum is part of the governance structure of the EUnetHTA Joint Action (JA). The aim of the Forum is twofold: to observe and comment on the JA work and to provide advice to governance questions. This is an excellent opportunity for EPF to represent patients as individual experts and the importance of involving both patients and patient organisations in the HTA process. Other contributions EPF will make as a member of the Stakeholder Forum is to provide input in relation to draft reports from the Work Packages, information and communication tools and EUnetHTA policy documents of general interest.

The first meeting will take place on 9 June in Dublin. Outcomes of the meeting will be available in our next EPF mailing.

32. ALLIANCE FOR MRI

EPF is a member of the Alliance for MRI (Magnetic Resonance Imaging). The alliance is a group of MEPs, patient groups, leading European scientists and the medical community who work together to prevent serious threats posed by EU health and safety legislation to the clinical and research use of MRIs.

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The current EU Directive restricts and limits the use of MRI in interventional applications and in imaging vulnerable patients and children where closer patient contact is required. Furthermore, new research and developments in MRI will be severely restricted as will routine cleaning and maintenance of MRI equipment.
MRI has been used for over 25 years without evidence of harm to workers due to electromagnetic field exposure. It is also well known that MRI is free from most health risks compared to alternative techniques (such as the use of x-rays).

There has been a significant delay in the adoption of the proposal to revise the Directive 2004/40/EC by the European Commission which has set back the kickoff of activities organised by the Alliance for MRI.

In March of this year, an MR expert group meeting was held with the European Commission which confirmed the Commission's proposal on safeguarding the future of MRI while ensuring the protection of workers.

The Alliance for MRI expects Laszlo Andor, the new Commissioner for Employment, Social Affairs and Inclusion move forward the proposal to amend the EMF Directive in autumn of this year.

Alliance for MRI expects that more industries will be affected by this Directive, therefore we need to ensure that the patients voice is heard. They have launched an online petition to broaden their support network. The petition will be used to convince EU institutions, national governments, and key decision-makers of the importance of MRI for healthcare and research.

To sign the petition, click here: http://petition.myesr.org

A meeting between the Alliance for MRI and Commissioner Laszlo Andor will take place in June and July. For more information and developments, please visit: www.alliance-for-mri.org

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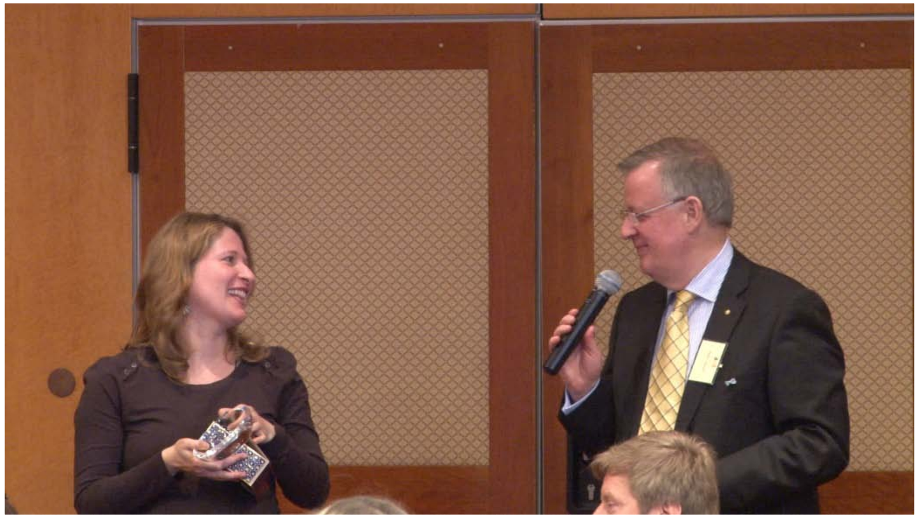
33. GOOD LUCK AND THANK YOU ROXANA!



Roxana Radulescu, EPF's Senior Policy Advisor will be leaving the EPF Secretariat at the end of this month. Roxana has been with EPF since the beginning of 2007. She began her career with EPF as a Policy Officer and has played a fundamental role in shaping EU health policies on behalf of patients. Roxana will be leaving EPF at the end of May to begin her new job in the European Parliament. She has accepted an opportunity to work as an advisor for the Group of the Progressive Alliance of Socialists & Democrats. We are also delighted to share with you that Roxana is expecting twins, due in early August.

We would like to thank Roxana for all her contributions and personal commitment to EPF and wish her all the best in all her new endeavours.

Roxana gives her thoughts and experiences during her tenure at EPF:
"Working for EPF for more than three years has been a real privilege for me. I have been delighted to be part of an organisation with such good governance, strong values and committed and professional board and director. EPF has grown tremendously in the last three to four years and I had a beautiful opportunity to contribute to developing its policy portfolio, to work with colleagues from the European Commission, the European Parliament, the rotating EU Presidencies and various health NGOs from whom I have learnt a lot. I enjoyed this very much. I also enjoyed working in a team committed to values of equity, social solidarity and better quality of life for people living with chronic diseases. But, most of all I appreciated the insightful and

meaningful exchanges I had with our members. I would like to warmly thank them, their families, the people they represent, the board and my colleagues for what they have given to me during this time. I am moving now towards a new challenge, but I will keep EPF close to my heart. I wish EPF a most successful journey in its important work to advocate for a stronger patient voice in EU health policies!"

34. DIARY

June 1 – 2	IMI Strategy Meeting Location: Brussels Speaker: Nicola Bedlington
June 3-4	International Conference on Patient Safety Madrid under the Spanish Presidency Speaker: Nicola Bedlington
June 7	National FP7 Coordinators Meeting Location: Brussels Speaker: Nicola Bedlington
June 8	Open Information Day Health Calls Location: Brussels Speaker: Nicola Bedlington
June 9	EUnetHTA Stakeholders Meeting Location: Dublin Attendance: Liuska Sanna
June 10-11	Global Health Conference Location: Brussels Attendance: Anders Olauson

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June 11	Stakeholders Conference on Health and Structural Funds Location: Brussels Attendance: Walter Atzori
June 14-17	Respect Meeting Location: Slovenia Attendance: Liuska Sanna
June 14	IMI Stakeholder Group Meeting Location: Brussels Speaker: Nicola Bedlington
June 21	EFPIA AGM Location: London Speaker: Nicola Bedlington
June 23	Health Literacy Meeting in the European Parliament Location: Brussels Speaker: Anders Olauson
June 22	EPF Board Meeting Location: Brussels
June 24	FP7 Advisory Council Location: Brussels Attendance: Anders Olauson
June 29	COCIR Meeting on eHealth Location: Brussels Attendance: Nicola Bedlington
June 29	Patients Rights and Insurance Meeting Location: Brussels Attendance: Nicola Bedlington

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June 29-30	Open Health Forum Location: Brussels Attendance: Rapporteurs Anders Olauson, Walter Atzori
July 1	EUNetPaS Conference Location: Brussels Attendance: Speaker Nicola Bedlington

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