



Dear EPF Members and Allies,

A warm welcome to the last EPF mailing before the summer – a slimmer issue than usual simply to give you an update on the very latest developments and a flavour of our agenda for the autumn. Since our last issue, the European Parliament elections have taken place, and like many others, EPF is assessing the new political environment – and how we can best work with MEPs dedicated to patient-centred healthcare ([section 1](#)). The impact of the economic crisis on patients across the European Union continues to be very high on EPF's agenda. We had the opportunity to address that at the OECD Forum where Anders Olauson, EPF's President, highlighted once again the importance of maintaining investment in health (see [section 10](#)).

Read the outcomes of the discussions in the Health Council of 9 June 2009 on a number of health related dossiers and how EPF plans to proceed on

these in the autumn ([section 2](#)). We also have a snapshot of the Swedish EU Presidency priorities for health ([section 3](#)).

As you will know EPF is in the process of setting up a policy advisory group – get an update on this in [section 14](#). For those members who have not responded and would like to get involved please [contact the Secretariat](#) as soon as possible!!

We take this opportunity to wish all our members and allies a restful and energising summer break and thank you once again for your unstinting commitment to EPF and our common goals. We are very much looking forward to continuing to work closely with you during what promises to be a very exciting autumn!

Warmest greetings,
Anders Olauson, President
Nicola Bedlington, Director

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1. NEWLY ELECTED EUROPEAN PARLIAMENT



The biggest trans-national elections in the EU history took place in the 27 Member States of the European Union between 4 and 7 June 2009. A total of 736 Members of the European Parliament (MEPs) were elected to represent about 500 million Europeans until 2014. The opening session for the new term will be

held in Strasbourg from 14-16 July and the MEPs' first action will be to elect a new President.

As highlighted in the EPF Work Plan 2009, EPF will be actively promoting a patient-centred philosophy and agenda with the newly elected MEPs (49,8% newcomers) as well as with the re-elected ones. Fundamental to our work with the new European Parliament will be the concepts of **patients' rights**, **patients' perspective**, and **equity** of access to healthcare as well as information, solidarity and inclusion.

Our work will be shaped by EPF's over-arching goal of involvement of patients in all areas of EU policy and programmes with an impact on health. EPF will strive to build a strong relationship with MEPs from across all the political groupings to enable us to optimise our effectiveness in the new European Parliament. Much foundation work has been achieved with our members' work with the EPF Manifestion 150 million reasons to act.

We will continue to work to foster and secure a strong relationship with the re-elected MEPs who proved to be health friendly in the previous term, and we will also identify new MEPs that have interest in and are dedicated to a patient-centered healthcare approach. Moreover, we will join all efforts to galvanise links with key MEPs leading on several legislative dossiers of interest to EPF members.

The [EPF Secretariat](#) will keep you informed with the next steps in this direction.

2. OUTCOMES OF THE HEALTH COUNCIL, 9 JUNE

The health ministers from the 27 EU Member States met in Luxembourg on 9 June 2009 at the Health and Consumer Affairs Council. EPF especially welcomes the endorsement of the *Recommendation on patient safety including the prevention and control of health care associated infections* and the *Recommendation on rare diseases*. This is an important step forward and EPF is keen to join efforts with our health allies to keep this political momentum and take action for the implementation of these two EU Recommendations. Quite constructive discussions were also held on *pharmacovigilance* and *combating counterfeit medicinal products*. More sensitive, complex and highly debated were, as expected, the dossiers on information on prescription medicines and the *Directive on Patients' Rights in Cross-border Healthcare*.

Rare diseases

The [Recommendation on an action in the field of rare diseases](#) aims to provide a coordinated EU approach to ensure effective recognition, prevention, diagnosis, treatment, care and research in the field of rare diseases in Europe.

EURORDIS - the European Organisation for Rare Diseases – an EPF's member, has done an outstanding work on moving the agenda on European action on rare diseases. The Recommendation is now a unique opportunity to build an EU-integrated, comprehensive and long-term strategy to address the needs of patients with rare diseases.

Click here to read [full article](#).

3. HEALTH PRIORTIES OF THE SWEDISH EU PRESIDENCY



From 1 July to 31 December 2009, Sweden assumes the Presidency of the European Union, leading the Council of the European Union and organising the European Council which reunites the heads of state and government of all Member States. The EU Presidency acts as the driving force behind the European legislative and political work, thereby mainly functioning as a broker between the Member States to reach compromises. The Presidency rotates every six months between the Member States of the EU.

Sweden's EU Presidency is facing some major challenges. The financial and economic crisis has hit Europe and the rest of the world hard. At the same time, global climate change needs to remain a high priority topic and will certainly receive much attention. Additionally, the next six months will be characterised by institutional change, with a newly elected European Parliament, a new Commission during autumn, and uncertainty surrounding the Treaty of Lisbon. Nonetheless, the Swedish Presidency put forward a detailed programme for its priorities in the field of health. The main focus for the next half year is to make sure that the Member States cooperate on these challenging topics.

Healthy and Dignified Ageing

The goal of the Swedish Presidency is to enhance dignity and quality of life for elderly persons in Europe and to put this topic on the EU agenda in a longer-term perspective. Several Member States are already giving priority to efforts in ensuring high standards of care that provide dignity in old age. An [expert conference](#) on this topic will be held on 15-16 September 2009 in Stockholm.

Alcohol-related harm

In autumn 2006, the European Commission adopted a strategy to reduce alcohol-related harm in the EU. The Council of the European Union and the European Parliament have expressed their full support for the Commission's strategy. The Swedish EU Presidency therefore supports the implementation of this horizontal EU alcohol strategy and the establishment of long-term preventive work at both EU and national level. It furthermore wants to give

particular priority to reduce the impact of advertising and marketing on young people. An [expert conference](#) on this topic will be held on 21-22 September 2009 in Stockholm.

Cross-Border Healthcare

The Swedish Presidency will continue to pursue negotiations on the proposal for a [Directive on the application of Patients' Rights in Cross-border Healthcare](#). On 6-7 July 2009, the Presidency organised an informal meeting of the EU Health Ministers in Jönköping discussing, among others, this topic.

Pharmaceutical Package

The Commission's "[Pharmaceutical Package](#)", including the proposals concerning pharmacovigilance, the fight against counterfeit medicines and addressing the provision of information on prescription medicines to patients will also be on the Swedish Presidency's table.

Relative Effectiveness

A major conference will take place on 29 July 2009 in Stockholm on relative effectiveness of medicines to which our President Anders Olauson will attend and give a presentation from the perspective of patients. The Conference will address in particular cancer and rare diseases and a number of patient leaders from these fields will be represented. A full report on this meeting will be made available for the next issue of EPF mailing.

Antibiotic resistance

The problem of bacteria that can no longer be treated with antibiotics is growing throughout the world. The Swedish Presidency's ambition is for a decision to be taken on seeking out innovative ways to ensure the development of new antibiotics. An [expert conference](#) on this topic will be held on 17 September 2009 in Stockholm.

Finally, several issues such as the promotion of eHealth as a tool to modernise health systems and improve patient safety, the impact of climate change on the conditions for diseases that spread from animals to humans, and the outbreak of influenza A (H1N1) will also be addressed during the Swedish Presidency.

The coming six months will be crucial for a number of dossiers regarding health policy in the European Union and EPF will work hard to represent the patients' voice during this Presidency. For further information, please consult the website of the Swedish EU Presidency: <http://www.se2009.eu>.

4. REPORTS ON THE 3rd PATIENTS RIGHTS DAY - 18 April 2009

The report on the proceedings of the Patients Rights' Day Conference organised by the Active Citizenship Network (ACN) in Strasbourg on 22 April, as well a variety of information about activities that took place around Europe on that occasion are now available on ACN's website: www.activecitizenship.net

Meetings and Conferences

5. AGRENSKA 20TH ANNIVERSARY , 3 JUNE, GOTHENBURG

As many of you will know, our President Anders Olauson is also the founder and chairman of the Agrenska Centre in Gothenburg Sweden, a unique knowledge and support centre for young patients with rare diseases and their families throughout Sweden. Agrenska marked its 20th anniversary with an international conference in the presence of Her Majesty Queen Silvia, who opened the conference. The central theme was "Future challenges for Rare Diseases". High level speakers included Karin Johansson, State Secretary for Health, Terkel Andersen, President of EURORDIS, Sir Michael Rawlins, chairman of NICE, John Bridges from John Hopkins University and Mary Dunkle from Nord, the US organisation for rare disorders. The conference closed with the inauguration of the Agrenska academy, a virtual network on rare disease management. For more information and the webcast of the conference please go to www.agrenska.se/en .

During the afternoon celebrations, Terkel Andersen was honoured with the Major Agrenska Award 2009 for his outstanding work for people with rare diseases.

[Nicola Bedlingon](#) represented EPF at this event.

6. EFPIA PATIENTS THINK TANK, 10 JUNE, BRUSSELS

Key items of the agenda of the latest EFPIA patients think tank were: the Pharmaceutical Package and the Draft Directive on Patients' Rights in Cross Border Healthcare. The European Commission's representative present gave an overview of recent developments in the Council on the Pharmaceutical Package, highlighting a much warmer welcome than anticipated for the proposals on pharmacovigilance and anti-counterfeiting, and the general lack of support for the proposal on information to the general public on prescription medicines. Other items on the agenda included an update on animal testing, and an overview on how the Innovative Medicines Initiative intends to encourage the involvement of patient organisations in project consortia.

Nicola Bedlington represented EPF at this event.

For further information and a copy of the presentations made at the think tank, please contact the [EPF Secretariat](#).

7. EFA ANNUAL CONFERENCE , 12-13 JUNE , ROME

Nicola Bedlington joined the European Federation of Allergy and Airways Diseases Patients Associations' (EFA) annual conference in Rome to give a keynote address on "the Future of Patient Organisations". More than a dozen state of the art projects on allergy and asthma with EFA involvement and best practice examples were screened by top speakers. By doing so, the Conference highlighted the conditions needed to manage future challenges of national and international allergy and asthma patient organisations. The presentations also updated on EFA activities on allergy and asthma during the last 12 months and provided a preview of the

coming activities. This year's Conference was unique as it was run simultaneously with the [Global Alliance Against Respiratory Diseases \(GARD\)](#) Assembly and was followed by the 1st COPD (chronic obstructive pulmonary disease) Patient World Conference, all in Rome. As part of the Conference, all participants had the opportunity to join global leaders on respiratory diseases at the GARD Assembly for their session on "Patient needs".

For more information and a copy of the presentations and abstract book please go to www.efanet.org/EFAConference2009.html.

8. PGEU ANNUAL GENERAL MEETING, 15 JUNE, STOCKHOLM

Anders Olauson represented EPF at the PGEU Annual General Meeting in Stockholm 15 June 2009 and gave a presentation that explored the expectations of patients and their organisations regarding Community Pharmacists. EPF and PGEU work closely on a number of EU policy issues and are partners in a recent funding proposal on telemedicine solutions.

For a copy of Anders' presentation and more detail on the outcomes of the PGEU meeting please contact [pharmacy \(at\) pgeu.eu](mailto:pharmacy@pgeu.eu) .

9. COCIR 50TH ANNIVERSARY, 17 JUNE 2009, BRUSSELS

EPF was represented by Nicola Bedlington at the COCIR 50th Anniversary Conference and Gala Dinner on 17 June 2009. COCIR is the voice of the European [Radiological](#), [Electromedical](#) and [Healthcare IT Industry](#). COCIR is a non-profit trade association, founded in 1959, representing the medical technology industry in Europe. EPF is discussing cooperation with COCIR specifically in relation to our eHealth agenda and attended their workshop on eHealth and sustainability, and also in relation to the European Commission forthcoming scoping work on medical devices.

For more information on the event and work of COCIR please go to www.cocir.org.

10. OECD FORUM 2009 – THE CRISIS AND BEYOND, 23 JUNE, PARIS

Anders Olauson represented EPF on a high level panel that addressed the economics of health in the framework of the OECD Forum on the economic crisis. He stressed: “How we prioritise healthcare in today’s economic crisis, that becomes tragically, a real social crisis in a number of EU countries, I believe, is an acid test for how we manage increasing demands on healthcare in the future. Austerity measures are of course critical – but slashing health budgets to the point where patients simply cannot afford the care they need is NOT the answer. We, at EPF, are learning of the dramatic and unacceptable consequences for patients and their families in several regions that will lead ultimately to many more direct and indirect costs for governments and society.

Rescue packages cannot only be about restoring financial stability – equally fundamental is the stability of society, the long term confidence and trust of citizens and this is most closely reflected in access to the

healthcare they need. International institutions and governments must recognise this and ensure that health budgets are protected in stabilisation and development packages.”

For a copy of Anders’ intervention and a resume of the discussions please go to:

www.oecd.org/document/57/0,3343,en_21571361_41723666_42942201_1_1_1_1,00.html

11. EHTEL TASKFORCE ON TELEMEDICINE, 24 JUNE, BRUSSELS

The European Health Telematics Association ([EHTEL](#)) held a meeting of its Task Force on Sustainable Telemedicine and Chronic Disease Management on 24 June 2009 in Brussels. Roxana Radulescu participated in the meeting on behalf of EPF.

Meaning basically “care at a distance”, telemedicine covers a broad spectrum of services such as teleconsultation, telehomecare and teletraining and builds on technologies such as video-conferencing supported by the exchange of medical images and medical records, as well as remote monitoring. The communication infrastructure includes ordinary telephone land-lines, internet connections of various speed and also satellite links to enable health care in remote and isolated areas.

The EHTEL meeting held this time in quite a small format, brought together representatives of health professionals, industry, health insurers, patients, European Commission and was a very good opportunity to look at areas of actions from the perspective and experience of each stakeholder. The main discussion focussed on the work of the group for the EHTEL Briefing Paper on sustainable telemedicine, which encompasses a first focus on “changing care processes” and a second one on “the enabling environment”. Members of the task force had provided in advance various interesting materials regarding studies on telemedicine, good practices or models based on patients’ real-life cases.

Although telemedicine services have been successfully piloted in various countries, they are still not widely

used across the EU. Participants pointed out the need for joint efforts to unlock the barriers for political commitment, adoption and further implementation of telemedicine. From the insurers' perspective, it was highlighted that telemedicine does not diminish health care budgets, but that it increase patients' quality of life.

Telemedicine services should not be seen separately, but integrated alongside all other health services.

EPF is keen to follow up on this issue, consult its members and provide comments to the EHTEL paper by mid September. EPF's project proposal "The chain of trust" – looking at understanding patients' and health professionals' perspectives on telemedicine services and building confidence and acceptance, and submitted to the Public Health Programme Call for Proposal 2009 – goes exactly in this direction. EPF believes that with proper quality safeguards, telemedicine can improve patients' access to healthcare, the timeliness of healthcare service provision and ultimately patients' quality of life. EPF has also initiated some important work on ethics and e-health that we shared at the EU Presidency Conference on e-health in Prague earlier this year.

For further information, please contact the [EPF Secretariat](#).

12. BIOSIMILARS WORKSHOP, 30 JUNE, BRUSSELS

Nicola Bedlington attended a workshop organised by AMGEN on Biosimilars to look at some of the core issues for patients in relation to biosimilars. Biosimilars are copies of biotechnology medicines, which are complex man-made molecules manufactured using genetic engineering technique. The International Alliance of Patients' Organizations (IAPO) has produced an excellent briefing paper on biosimilars.

Please go to www.patientsorganizations.org/biosimilars for more information.

13. ECO-SOC MEETING – NEW GLOBAL COMMITMENT TO HEALTH LITERACY, 6-8, JULY, GENEVA

Anders Olauson attended the high level UN Economic and Social Council meeting in Geneva from 6 – 8 July, as his organisation Agrenska has official UN NGO status. Anders and Nicola Bedlington also participated on behalf of EPF in two meetings on health literacy held in the framework of the ECO-SOC Council.

Remarkable in the general session was a new emphasis on the fundamental importance of health literacy. UN General Secretary Ban Ki-Moon referred to it in his opening speech stating “We must promote greater health literacy and behavioural changes (...) and that governments should take a strong lead in strengthening national health systems in partnership with community leaders, faith-based organisations, voluntary organisations and the private sector”. The Health Minister from China Chen Zhu focused much of his presentation on health literacy, drawing on the outcomes of the Asia- Pacific Region meeting on health knowledge, held in Beijing in April 2009. He highlighted “health is a basic human right. Promoting health literacy is a fundamental cost effective strategy in disease prevention, effective use of services, improvement of primary health care and national health level and promoting social development”. This commitment was also reflected in the ministerial declaration adopted by the meeting. Please see [here](#) for more information.

The World Health Organization’s Action plan on a global strategy on non communicable diseases, endorsed by the World Health Assembly in 2008 has also underlined advances in health literacy as a major priority.

The two health literacy events linked to ECOSOC were organised to launch the first part of the World Health Communication Associates Action Guide on Health Literacy, to which the International Association of Patient Organizations (IAPO) also contributed. Anders Olauson and Nicola Bedlington had the opportunity to present to participants the work that EPF and our membership are undertaking to drive health literacy in an EU context and our collaboration with health professional organisations.

The new global commitment to health literacy is extremely encouraging and through our strong cooperation with IAPO we look forward to continuing to support this and to ensure that it also resonates in EU health politics and policies.

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

14. POLICY ADVISORY GROUP

In 2009 and 2010, EPF will address a significant number of health policy issues like the on-going participation in the European Commission's policy campaign "A Europe for Patients"; our advocacy work with all three EU Institutions in relation to Patients' Rights in Cross Border Health Care, the EU Pharmaceutical Package of proposals on Information to prescription medicines/Pharmacovigilance/Counterfeiting, Patient Safety and Quality of Care, Health Literacy, Health Inequalities, eHealth; Health Research, the continuation of our work on Health Technology Assessment; and of course the promotion of our Patients' Manifesto "150 million reasons to act" in the lead up and the follow up to the European Parliament elections and the new Commission.

EPF as an umbrella membership organisation needs to, as far as possible, develop a consensus position that reflects the collective view of our diverse members. This requires effective consultation and dialogue with all our members, and sometimes very in-depth discussions on policy topics that are complex, controversial and/or highly political.

For this reason the board proposed to the Annual General Meeting 2009 that a Policy Advisory Group be set up, composed of representatives of EPF members and allies, to give a view on our policy input from both a strategic and content perspective, in order to support the broader membership, board and the secretariat in this work. This proposal was adopted unanimously.

The Policy Advisory Group will work mainly by email and telephone debate. On very specific issues, the Policy Advisory Group will form a smaller sub-group to develop initial proposals before taking these to the wider

group and the EPF membership for consultation. **These sub-groups may also request EPF to commission external expertise as necessary.**

At the last board meeting on 23 May 2009, the board agreed that Dr Maria Navarro, Vice President of the Spanish Patients' Forum, will support the coordination of this work on behalf of the EPF board. The link person in the Secretariat is [Roxana Radulescu](#).

15. EPF GUIDE FOR MEMBERS

EPF is working on a membership guide which will help our members to maximise the benefit of their membership in EPF by gaining a more profound understanding of our work and explain to non members what EPF stands for.

In the membership guide you will find an organigram of our organisation and membership; a short history of EPF; a statement of values and EPF's core strategic goals; an overview of EPF's policy work, activities and projects; a mention of events and conferences we participated in; a presentation of our website and publications as well as detailed information on membership categories and how to become a member. But most significantly, this membership guide **explains the advantages and the importance of being a member of EPF**, what we offer to our members, but also what we expect from them in return because your contribution is valuable and vital to us.

You will find the membership guide by the end of summer on our website.

For further information please contact Susanna Palkonen, via the [EPF Secretariat](#).

16. UPDATES ON THE EUNETPAS PROJECT

In the framework of EUNetPas (European Union on Patient Safety) project, the partners involved on Work Package 2, including EPF, have been working on a draft document for “Guidelines for Patient Safety Education and Training Curricula”. Addressed to a variety of audiences – policy makers, curriculum developers within universities, professional associations who propose or regulate post-graduate education, clinical placement managers (at undergraduate and post-graduate levels), directors of quality, risk managers, health professionals, patients and families, non-clinical support staff – the document aims to promote transferability of methods on patient safety education (process and content) from one Member State to another. It could be used, for example, to enhance understanding of the various approaches that are available in education and training in patient safety and that have been tested and evaluated, as to render judgement about the applicability of a learning intervention, to guide the development of new interventions or to evaluate an existing intervention in order to judge its fitness-for-purpose.

EPF has worked with the group of Work Package 2 on including patients, their families and carers as recipients of education and training on patient safety. This could be done by building on existing good practices and in cooperation with NGOs and patient support groups, government bodies, educational organisations, and professional bodies. The outcome of the process would be an increased awareness among patients and families of the significance of patient safety and their individual responsibility as recipients for safety in healthcare.

EPF will keep you posted on further developments. For further information, please contact [Roxana Radulescu](#).

17. UPDATES ON RESPECT PROJECT

Relating Expectations and Needs to the Participation and Empowerment of Children in Clinical Trials - Second meeting of the Steering Group – Pavia, Italy, 11, 13 June 2009

The second meeting of the RESPECT project partners marks the first year of the project's implementation. The main focus of the meeting was to share progress in the assessment of the views and experiences of the various actors involved in clinical trials.

Children participating or likely to participate in clinical trials and their parents are the main stakeholders addressed, but not only. The project seeks the views of medical staff conducting the trials and will do the same with ethics committees in charge to approve the trials' protocols.

What we have done so far

The partners with direct access to children, parents and medical staff – mainly university hospitals in Sweden, Italy, Slovenia and the UK – conducted interviews and small focus groups based on an agreed set of questions related to their motivation, expectations and experiences in the trial.

EPF is doing a survey with patient organisations across the EU. The survey is accessible online at the project website. The frame for this investigation was set also with the support of the findings of a literature review focused on paediatric clinical trials and empowerment.

What we found out

Initial findings suggest that children and parents decide to participate in trials for reasons that span from personal benefit to an altruistic approach. There is however no re-assessment of their initial expectations, and the concrete reality of the trial is often different from what they had initially thought. There are clearly issues around autonomous and objective decision-making and around consent and assent: the children rely

on the parents who in turn rely on the doctors. A neutral figure in support of children and parents is envisaged; this could support empowerment. Patient organisations could fill this role; it is felt that they should be actively involved in the setting of the trials as well as in ethics committees.

The main focus related to clinical trials is on the protocol approval and the consent process. There is less attention on monitoring how the protocol is applied, how the consent is obtained and how children and parents live this experience. These aspects need to be better addressed in order to empower participants and conduct patient-centred trials.

Next steps

- More interviews and some focus groups will be carried out;
- A survey with ethics committees is in the pipeline;
- EPF will organise a focus group with representatives of patient organisations to reflect on approaches and tools for empowerment of children and parents; EPF members will be invited to put forward representatives;
- A workshop on empowerment will be held at the end of January 2010;

The contact person for more information on this project is [Liuska Sanna](#).

18. UPDATES ON CALLIOPE PROJECT

CALLIOPE Project– InterOPERability: Creating a European coordination network for eHealth interoperability implementation. Third meeting of the project Consortium – Paris, France, 28 May 2009

The primary aim of CALLIOPE is to create a network of experts to support Member States in identifying and implementing interoperability solutions. As in previous coordination meetings, the project partners shared updates and progress reporting. We describe here the main highlights.

Moving the CALLIOPE project to a European eHealth Collaboration Network

A discussion on the sustainability of the network was launched. This became particularly pressing following the outcome of the eHealth conference 2009 in Prague where in an informal meeting State Secretaries from 24 member states supported:

- The establishment of a European eHealth governance process facilitating high-level and cross-border cooperation;
- The creation of a high-level eHealth governance group;

An urgent need for a common European roadmap on eHealth implementation and deployment was asserted. It was agreed that the CALLIOPE Executive Committee will start reflections on this process and will prepare a proposal to address operational issues.

CALLIOPE and the EU eHealth Landscape

CALLIOPE has been very active in networking with other European eHealth projects and initiatives. A formal partnership is currently being established with the [epSOS project](#) – European Patients Smart Open Services – whose overarching goal is to develop a practical eHealth framework and an Information & Communication Technology (ICT) infrastructure that will enable secure access to patient health information, particularly with respect to basic patient summaries and ePrescriptions between different European healthcare systems. This partnership will be called CALlepSO and foresees a joint work agreement focused on the review of epSOS deliverables through active engagement of stakeholders other than the member states.

Progress of activities

Dissemination: A dissemination strategy is being formulated and a new version of the website was developed to move from the context of the project to that of the network.

Knowledge tools: The experts' database is ready and will be integrated in the website. Regarding the document database, there is no decision yet on the type of documentation to have; nonetheless it appears that the cross-border European eHealth projects collaborations and sharing of key documents provide an opportunity for an initial set of users' requirements.

The [EC Recommendation on Interoperability](#): The scope of this work area is interoperability for the purpose of "integrated, connected and interoperable continuity of care for Europe" and the focus of the deliverable is on:

- Organisational issues (including legal issues)
- Education, awareness and training issues

The output will be a review of the Recommendation that will include observations and proposed changes, proposals for operationalising the Recommendation, stakeholder engagement and future areas for eHealth interoperability. Use cases will be employed; probably Patient Summaries and ePrescribing and Identification Management for patients and for health professionals.

A Roadmap on Interoperability: A first specific meeting of the work group for the roadmap took place. The objective of this work is to propose operational roadmap building on existing material, national roadmaps, thematic and semantic roadmaps, EU published documents. The outcome of this meeting was an overview of the partners' expectations and a work plan.

Standardisation: The aim of this work package is to support already existing initiatives on standardisation, particularly epSOS and M403 eHealth-INTEROP, which address the requirements of the EC mandate to the European Standards Organisations (ESOs) in the field of eHealth.

For more information on CALLIOPE please contact [Liuska Sanna](#) or go to: www.calliope-network.eu

19. SAVE THE DATES – VALUE + SEMINAR IN BULGARIA AND FINAL CONFERENCE IN GOTHENBURG

On 18-19 September 2009, EPF and the VALUE+ Project Consortium will organise a seminar for patient leaders of patient organisations from Bulgaria, Romania, Hungary, Slovakia, Croatia and Greece. The seminar will take place in Sofia, Bulgaria, and is hosted by the Bulgarian Confederation “Health Protection” (KZZ).

To date five highly successful European seminars have taken place. These seminars have reached out through patient leaders to the patient community throughout Europe, and particularly the new Member States, to enhance knowledge on health issues at European Union (EU) level and to build capacity on how to engage.

The purpose of the seminar is to:

- Build knowledge and know-how on working at EU level through and with EPF and influencing effectively the EU health policy debate through initiatives at national and regional level;
- Explore findings from the VALUE+ project and glean feedback from grassroots organisations as well as test some of the VALUE+ deliverables.

The seminar will have contributions from representatives of the European Parliament, the European Council, the European Commission, the Directorate General for Health and Consumers and its Executive Agency, and patient leaders.

A draft programme is available at www.eu-patient.eu/projects/valueplus/events/bulgaria-2009.php .
For more information on the seminar or if you wish to register, please contact [Liuska Sanna](#).

EPF Final Value + Conference

The conference will take place on 9-10 December 2009 in Gothenburg under the patronage of the Swedish Government and will be opened by Swedish Health Minister Göran Hägglund. This conference on patient involvement will be the final event of the EPF-

led project VALUE+. It will provide the opportunity to present the results of the project and the deliverables and be a spring board for wide-scale dissemination and implementation. This event will be an important platform for fostering continued political commitment on patient involvement underpinned by the VALUE+ basic premise that the meaningful involvement of patients will enhance projects' outcomes and results, which will then contribute more effectively to patient-centred policy making.

The target audience will be wide-ranging and will include representatives of the Swedish Presidency, European Commission and governmental officials, Members of the European Parliament and Council Representatives, key health stakeholders, research organisations, think-tanks and policy units in Brussels, project leaders, patient organisations' representatives and the project partners themselves. Approximately 100 participants will convene in the Agrenska Centre, Gothenburg, Sweden. The event will also be web-streamed to enable those who are unable to be present in person in Gothenburg also to participate actively.

We expect to raise the awareness of the audience, especially political representatives, regarding the need to strengthen commitment to patient involvement with concrete means and actions and to make tools and information available on how to achieve meaningful involvement. We also aim for the policy recommendations made by VALUE+ to be included in the conclusions of the Swedish EU Presidency.

The programme will soon be available on the EPF website. The contact person for this event is [Liuska Sanna](#).



20. SECRETARIAT NEWS

Goodbye to Sophie Letorey

Sophie Letorey has left EPF at the end of May, having worked with us as assistant policy and programme officer for six months while finishing her master studies in Political and Public Strategy and Decision at the Higher Institute of Public and Political Management (ISMaPP). Sophie was active in our policy work focusing on the EU policy monitoring and contributed to our programme work by providing support in project activities and, more generally, to the office management. The Board and the Secretariat convey to Sophie our best wishes for her future professional challenges.

New intern joins EPF

EPF's new assistant policy/programme officer Yves Brand joined the secretariat on 2nd June. Yves is of Dutch origins and has finished his MA in European Studies at the University of Maastricht in 2008. He holds a BA in both European Studies and Social Work and has been very active in internships and his part-time job with children and people with physical disabilities. Since the beginning of 2009, he is board member of a newly created foundation in Maastricht that conceives and implements projects for people with physical disabilities. At EPF, Yves will be mainly involved in policy monitoring and analysis and in the organization and preparation of EPF events, while carrying out background literature research.

21. DIARY

Wed, Jul 29	Swedish EU Presidency Conference on the follow up of medicinal products Attendance: Anders Olauson
Tue, Sep 1 -- Thu, Sep 4	The Knowledge Triangle - Shaping the future of Europe - Swedish Presidency Ministers visit the European Parliament Attendance: Anders Olauson
Thu, Sep 3 -- Fri, Sep 4	CALLIOPE project - Meeting of WP4 and WP5 groups CALlepSO meeting Attendance: Liuska Sanna
Thu, Sep 3 -- Fri, Sep 4	Steering Group Value+ Place: Brussels Attendance: Liuska Sanna, Nicola Bedlington
Wed, Sep 9	Conference - Climate Change and Jobs - the EU Global Agenda -Swedish EU Presidency meeting Attendance: Anders Olauson
Fri, Sep 18 -- Sat, Sep 19	EPF Value+ Regional Advocacy Seminar Place: Sofia, Bulgaria Attendance: Mike O'Donovan, Nicola Bedlington, Roxana Radulescu, Liuska Sanna, Zilvinas Gavenas
Tue, Sep 22	Briefing and Dinner for EPF corporate funders Place: Brussels Attendance: EPF Board members and Staff
Tue, Sep 22	EFPIA Patients Think Tank Place: Brussels Attendance: Nicola Bedlington
Wed, Sep 23	EPF Board Meeting Place: Brussels
Wed, Sep 30	Gastein Health Forum Place: Gastein Attendance: Nicola Bedlington (speaker), Roxana Radulescu

Thu, Oct 8	Med-e Tech Place: Brussels Attendance: Nicola Bedlington (speaker)
Tue, Nov 24 -- Wed, Nov 25	EPF Board Meeting Place: Brussels Attendance: EPF Board Members
Wed, Dec 9 -- Thu, Dec 10	Value + Swedish Presidency Conference Place: Gothenburg