

EPF Mailing

Issue 2 (43)

12 April 2012



Dear EPF Members and Allies,

Welcome to the EPF Mailing. Please note this will be last issue of the Mailing in this form. Henceforth EPF will produce a monthly e-newsletter to update readers more regularly and more succinctly on key developments linked to our policy priorities and our project portfolio. More in-depth analysis will be available on our website. We are confident this approach will be more user-friendly for both our membership and our wider network of allies and partners.

There have been a number of important policy and programme developments since the last EPF Mailing. Read about the first meeting of the European Patients' Academy on Therapeutic Innovation (EUPATI) Consortium that EPF is leading, and our launch meeting in Copenhagen on 27th March ([section 11](#)). Get the latest news on the European Partnership on Active and Health Ageing and how you can get involved ([section 8](#)). EPF also participated in the High Level eHealth Task Force (see [section 24](#)) and the IAPO Biannual Congress in London (see [section 25](#)).

A very important EU consultation is underway on chronic diseases, in which we hope our members will contribute, both as individual organisations, and collective through EPF. See [section 1](#) for more details.

Since our last EPF Mailing we have moved offices. The secretariat is now located at 31 Rue de Commerce, still very close to European Parliament and Commission. Our telephone numbers remain the same. Visitors to Brussels are very welcome to come to the office, and meet the Team! We are also pleased to welcome Peter Windey, our new financial and operations manager, and Clarissa Spencer our new administrative assistant – please see [Secretariat section](#).

As we go to press, the board and the secretariat is very focused on our forthcoming Annual General Meeting and Strategic Planning Seminar (18, 19 April 2012). There, we will explore carefully with our entire membership our key challenges and goals to ensure that EPF continues to deliver for patients across the EU. The seminar is the start of an extensive consultative process that will be finalized at our AGM in 2013 with the endorsement of a new Strategic Plan that will steer EPF during the next EU Programming Period 2014-2020. Shortly afterwards we will hold the Third Patient – Medtech Dialogue to focus specifically on patients' safety (24 April). We look forward to seeing many of you again in Brussels in the next few weeks!

Looking ahead to June, EPF is honoured to be a partner in the Conference 'Health and Gender through Life', with the support of the Danish EU Presidency. [Please go to for important details on how to register.](#)

Wishing you all a very happy and productive spring-time.

Warmest Greetings,

Anders Olauson, EPF President

Nicola Bedlington EPF Executive Director

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1. EU Chronic Diseases reflection process - Consultation



The European Commission Directorate General for Health and Consumers has launched a stakeholders' consultation for the chronic disease reflection process. The Commission's questionnaire is available [here](#). EPF prepared a draft consultation response which was sent to all our members on 23 March. EPF members are welcome to send their comments and input by **23 April** at the latest to Kaisa Immonen-Charalambous. EPF will then circulate to all members a final draft integrating these comments at the end of April for final input and approval by 6 May.

2. EU Clinical Trials Directive: Commission plans to make it a Regulation

The progress of the revision of the EU Clinical Trials Directive (2001/20/EC) has been extensively documented in previous issues of the Mailing.

Following two rounds of public consultation, and several stakeholder events, the European Commission is aiming to publish its proposals for the future EU legislation on Clinical Trials by June 2012, though according to the latest information this time line may well stretch to September 2012.



Commission plans a Regulation for more uniform application of the rules

The Commission's proposals will centre around simplifying the application procedures, through the introduction of one single submission via an electronic portal. Secondly, the Commission wants to improve the assessment of clinical trials and increase cooperation while reducing duplication and bureaucracy. It also wants to propose a "risk-adjusted" approach to clinical trials. The legislative proposal will take the legal form of a Regulation, to minimise divergence in interpretation at national level.

EPF advocates for patient involvement

EPF broadly agrees with these aims, but we have argued that from a patients' perspective, certain aspects such as information to patients an informed consent, should be harmonised at EU level to guarantee equitable access to high quality information on clinical trials to all patients, and an informed consent process that results in truly informed consent, regardless of which Member State a patient lives in. Furthermore, EPF has called for patient involvement across clinical trials, including representation on ethics committees, and better access to treatment post-trials. Finally, we have contributed input to the question of clinical trials conducted in countries outside the EU – both to the Commission and via our work with the European Medicines Agency. EPF's views are set out in our responses to the Commission's public consultations.

We are concerned that the Commission's proposals, particularly as far as ethics assessment is concerned, will not be bold enough to achieve fully the objectives of harmonisation. We are in touch with the Commission as they draft the text, and following the publication of the legislative proposal, EPF will re-consult our membership in order to develop an updated position paper.

More information:

- [EPF's previous responses to the consultations](#)
- [The European Commission concept paper](#)
- [The EU Clinical Trials legislative framework](#)

3. Information to patients: still no progress in the Council

The Council of the European Union still has not reached a consensus on whether to proceed with the Commission's revised legislative proposals on Information to patients, published in November 2011.

The Council had asked the Commission to split the proposals, separating the provisions related to the EU pharmacovigilance legislation from the rest of the proposals, and the split proposals, otherwise unchanged, were published on 10 February 2012.

The *pharmacovigilance dossier* is expected to proceed quickly through the legislative procedure in order to be integrated in the implementation process of the new EU pharmacovigilance legislation adopted at the end of 2010. The ENVI Committee is expected to vote on the proposals on 8 May, and the plenary vote is foreseen for 2-5 July 2012.

The rapporteur in the European Parliament is Ms Linda McAvan MEP (S&D, Ireland)

However, several Member States still remained reluctant to discuss the split dossier on *information to patients concerning prescription medicines*. EPF had sent a letter to the Member States' health attachés prior to the most recent Council discussions, asking the Council to give the proposals their due consideration; at the time of writing the discussions between Commission and Member States were concluding, but the fate of the dossier had not been confirmed. EPF will update our members in the coming weeks on this dossier.

More information:

- [EC revised \(split\) proposals on information to patients](#)
- [EPF's statement on the Parliament's first reading of the ITP dossier](#)
- [EPF's previous position statements on this issue](#)



4. Review of the Professional Qualifications Directive

On Wednesday 7 March, EPF Senior Policy Adviser, Kaisa Immonen-Charalambous, presented the patients' perspective in a panel discussion on the proposal to review the professional qualifications Directive that was published on 19 December 2011 (available [here](#)). The panel debated on the language requirements. In the draft legislation the commission has set out a proposal for patient organisation to be able to request language testing for certain categories of healthcare professionals when they wish to establish within another Member State.

The event was organised by Healthcare Professionals Crossing Borders, an informal network of professional healthcare regulators. Other key features of the proposal which we presented briefly in our last issue such as the European Professional Cards, the IMI alert mechanism and the education and training of healthcare professionals were also discussed. A summary of the event as well as presentations are available [here](#).

Next Steps:

EPF will send this week a member consultation to establish EPF position, based on our previous feedback to the Commission on the review of Directive 2005/36 available [here](#).

The rapporteur MEP Bernadette Vergnaud (S&D, France) will prepare a draft report that is expected for beginning of July. MEP Anja Weisgerber (EPP, Germany) is the rapporteur for opinion of the Environment and Public Health (ENVI) committee, and MEP Licia Ronzulli (EPP, Italy) is rapporteur for opinion in the Employment and Social Affairs committee (EMPL).

MEPs in the Internal Market and Consumer Protection (IMCO) committee can propose amendment until 12/09.

The vote in the IMCO committee is expected for end of November 2012 (provisional date).



5. Medical devices

EPF participated in February to the Medical Devices Expert Group Meetings (MDEG) on the future proposals for regulations that will revise the current directives on Medical Devices and In Vitro Diagnosis on 6th and 13th February. The MDEG is a group of Member States' competent authorities, industry and other stakeholder representatives in the area of medical devices. In closed session it is a forum for competent authorities to discuss all issues with implementation of the EU legislation on medical devices. EPF provided preliminary comments regarding the future proposal on Medical Devices based on our past contributions to the European Commission and a consultation of the Policy Advisory Group. The proposals for regulations on medical devices, and on in vitro diagnosis, are expected to be published in the 2nd quarter of 2012. EPF will then consult its full membership to form a position on this review.

On 9th February, the Commission recommended to the Member States to take immediate actions to tighten the control of medical devices in reaction to the discovery of the fraudulent use of non-medical grade silicone in breast implants in France. Actions recommended by Commissioner John Dalli include:

verifying the designation of notified bodies to ensure they only conduct assessment for products for which they have the right expertise, and that they carry out unannounced inspections,

reinforcing market surveillance by Member States, and the support to the development of traceability tools and long term monitoring for medical devices



improving the functioning of the vigilance system, for example through encouraging healthcare professionals and empowering patients to report adverse events.

In addition, EPF and EUCOMED are organising the 3rd session of the Patient MedTech dialogue on Wednesday 25 April, 10.30am-4.00pm in Brussels. This dialogue between industry and patient organisations from EPF membership aim at exchanging views on areas of common interests and on the role of medical technology. The broad theme of this 3rd session will be patient safety and will include different perspectives of that subject. The agenda and the official invitation will follow shortly for EPF Members, as well as the minutes of the last meeting. For more information please contact [EPF Policy Officer](#).

Link:

Press Release – Medical Devices, European Commission calls for immediate actions – tighten controls, increase surveillance, restore confidence available [here](#).

Working groups and task forces list is available [here](#).

6. MRI directive update

The European Commission has proposed an extension for the deadline for the application of the limits of exposure in the Electromagnetic Fields Directive (Directive [2004/40/EC](#)), which is due to enter into force in April 2012. The proposal for the extension has been adopted in Employment and Social affairs (EMPL committee) of the European Parliament, with a new deadline in October 2013. The extension will now be discussed in plenary sitting at the European Parliament, and by the Council.



In the meantime the current proposal for a Directive on the minimum health and safety requirements regarding the exposure of workers to the risks arising from physical agents (electromagnetic fields), which contains a derogation for Medical Resonance Imaging which EPF supports, is expected to be voted in the EMPL committee of the European Parliament in April. The derogation supported by various health stakeholders notably through the Alliance for MRI has encountered opposition from some Member States.

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

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

7. Data Protection Regulation – consultation

On 13 March, EPF launched a member consultation on the proposal for a Data protection regulation which was published on 25 January. The aim of this regulation is to protect individual's fundamental right to protection as regards their personal data, while setting rules to allow the free flow of these data in the EU ([see previous issue](#)). Taking into account the patient perspective is essential to ensure that the Regulation preserves quality and safety of care while protecting individual rights to confidentiality of personal health data.



For Patients, the fundamental right to protection of their data concerning health is an important issue in many different contexts, such care given through eHealth or in a cross-border context, and clinical trials.

The smooth processing of health data is fundamental for the good functioning of healthcare services, patients' safety, and to advance research and improve public health (e.g. with patient registries). On the other hand health data belongs to the category of sensitive data: unauthorised disclosure of personal health information could negatively impact on an individual patient's personal and professional life therefore effective framework need to be put in place for the protection of such data. This also applies to eHealth apps, to ensure that patients rights are fully protected, through some kind of a certification mechanism based on clear quality criteria.

Next Steps

EPF Member consultation is opened until **15 April**. For further information please contact [EPF Policy Officer](#).

The draft regulation will now be discussed by the Council of the European Union and the European Parliament under the ordinary legislative procedure. The rapporteur in the leading committee, Civil Liberty Justice, and Home affairs (LIBE) is expected to be nominated end of march- April. MEP Sean Kelly (EPP, Ireland) has been nominated as rapporteur for opinion for the Industry, Research and Energy (ITRE) committee.

Links

Directorate General for Justice and Fundamental Rights: Commission proposes a Data protection reform (containing press releases, factsheets, and more information): http://ec.europa.eu/justice/newsroom/data-protection/news/120125_en.htm

8. European Innovation Partnership on Active and Healthy Ageing: Commission calls for commitments and issues a Communication

On 29 February 2012, the European Commission published a [call for commitment](#) to participate in priority actions of the European Innovation Partnership on Healthy and Active Ageing. The Commission also adopted [a Communication](#) "Taking forward the Strategic Implementation Plan of the European Innovation Partnership on Active and Healthy Ageing", affirming its commitment to the implementation of the Partnership.

The Commission is now taking the next step and calling for all stakeholders who are ready to get involved and mobilise sufficient resources in support of one or more of the specific actions defined in the SIP, in partnership with other stakeholders. Please note this call is *not* for funding. An overview of calls for proposals for projects in support of the Innovation Partnership is available [here](#).

The call for commitment is available [here](#). The deadline for expressing a commitment is 31 May 2012.

The EIP-AHA Priority actions

The following themed priority actions are being implemented in the first phase of the Innovation Partnership. For the content of each action, please see the [Strategic Implementation Plan](#) and [Operational Plan](#).

- Prescription and adherence action at regional level
- Falls Prevention Initiative
- Action for prevention of functional decline and frailty
- Replicating and tutoring integrated care for chronic diseases, including remote monitoring at regional level
- Development of interoperable independent living solutions, including guidelines for business models
- Innovation for Age friendly environment (the "horizontal action")

Before expressing a commitment, please read carefully the documentation on the [Partnership website](#), which includes a "guide" document and "frequently asked questions".

What if you are interested but cannot yet commit to a specific action?

The Commission has also launched on 3 April a “[Marketplace for innovative ideas](#)”, which will be an interactive online platform open to all stakeholders willing to get involved in the Partnership but who are not yet ready to submit a commitment to a specific action. The platform will be available from the beginning of April 2012 through the main Partnership website. Visiting the platform will be free, and you can become either a passive member or an active registered member.

Background on the Innovation Partnership and EPF’s contribution

Extensive information about EPF’s role in the Innovation Partnership, and our key principles and messages, has been given in past issues of the EPF Mailing and in our [input to the Commission’s public consultation](#).

EPF was closely involved in the development of the pilot European Innovation Partnership on Active and Healthy Ageing, launched by the European Commission at the end of 2010. Our President, Anders Olauson, participated in the High-Level Steering Group co-chaired by Vice President and Commissioner for the Digital Agenda, Neelie Kroes, and the Commissioner for Health and Consumer Policy, John Dalli; while the Secretariat participated in several “Sherpa” meetings and our member organisations focusing on priority disease areas of the Commission’s public consultation (diabetes, Alzheimer’s disease/dementias, and Parkinson’s disease) contributed actively to the debates and workshops. The Steering Group adopted the Strategic Implementation Plan (SIP) of the Partnership in November 2011.

The overall goal of the Partnership is to add two healthy life years to the average healthy life span of European citizens by 2020.

The wider objective of the EIP is to achieve a “triple win” for Europe:

- improving the health status and quality of life of European citizens, particularly older people;
- supporting the long-term sustainability and efficiency of health and social care systems; and
- enhancing the competitiveness of European industry through business and expansion of new markets.

The Partnership aims to address key bottlenecks and barriers that have been shown to hinder the uptake and spread of innovations, such as fragmented evidence available on innovative solutions, lack of EU-wide standards and interoperability of systems, difficulties in scaling-up pilot projects, funding barriers, legal and other framework conditions, social and healthcare systems' complexity, organisational and budgetary "silos", and lack of integration.

The EIP is not a funding instrument. Rather, it aims to facilitate new ways of working in partnership, by mobilising and linking up the different stakeholders, EU institutions, national authorities and the regional/local level actors, and using already existing European financial instruments more effectively to support the implementation of its actions.

The Strategic Implementation Plan (SIP) sets out a vision for a new paradigm of ageing, a vision for "healthy and active" ageing, and the key action areas that will be addressed by the Partnership. These centre around *three broad "pillars" for action*: prevention and early diagnosis; care and cure; and independent living.

Within the pillars, *twelve priority action areas* were selected to develop into concrete actions. Within these, the Steering Group chose *five priority actions* for implementation, focusing on areas that have both the potential to deliver quick results and a readiness on the part of several partners to start working immediately. In addition to these actions, a horizontal action focusing on age-friendly environments was selected for implementation.

[More information: European Innovation Partnership on Healthy and Active Ageing website](#)



9. Revision of the EU Transparency Directive

On 1 March 2012, the European Commission published its legislative proposal to review the so-called “Transparency Directive” (Council Directive 89/105/EEC relating to the transparency of measures regulating the pricing of medicinal products for human use and their inclusion in the scope of national health insurance systems).

The Commission proposal aims to ensure that medicines enter national markets faster following regulatory approval. This will happen through streamlining and reduction of the timelines on national decisions for pricing and reimbursement. The Commission proposal provides a limit of 120 days for Member States to come to a decision on “innovative” medicines, and 30 days on generic medicines. Currently the deadline is 180 days, but even this is not generally respected by Member States. The Commission also proposes some stronger enforcement measures for Member States who do not comply with the time limits.

The Commission is, however, careful to stress that the proposal do not interfere with the Member States’ responsibilities for the organisation and delivery of healthcare, therefore they are only concerned with process, not the substance of the decisions.

EPF consultation

EPF has given input into the public consultation process, stressing the currently wide divergences across the Union in patients’ access to treatment, including medicines, in many chronic disease areas. Clearly, the timelines for decision-making are a key factor in this, and we welcome the Commission’s proposal to tighten them. Moreover, EPF stressed that the societal context in which such decision are taken has undergone a profound transformation since 1989: notably, there has been an enormous increase in patient and civil society engagement in all aspects of public policy. EPF argued that the concept of transparency needs to reflect this 21st century context and should extend to patients and the public. Unfortunately this aspect is not well reflected in the Commission proposal.

Next steps:

The draft report in the European Parliament may be drafted by the summer, with a plenary vote and Council discussions taking place in the autumn of 2012. It is likely however that the Council discussions of this dossier will extend to 2013. The EPF Secretariat is finalising an internal analysis of the proposal and will circulate a membership consultation document in the next week.

More information:

- [Directive 89/105/EEC](#)
- [Information from the Commission concerning the review](#)

10. First meeting of the newly-established eHealth Stakeholder Group

The European Commission has established, following a call for expression of interest, an eHealth Stakeholder Group. It comprises 29 European umbrella organisations representing different groups like health professionals and managers, patients and consumers, industry, standardisation bodies. Their first meeting was held on 29th of March. The purpose was to understand the role of the group and establishing a 2012 work programme and a modus operandi.

The aim of the group is to ensure an informed dialogue with the European Commission and to add value to policy design and implementation. Areas for cooperation during the current year were agreed, namely patients' access to electronic health records, telemedicine deployment, interoperability, the EC Staff Working Paper and the eHealth Action Plan.

EPF and BEUC will take the lead on work related to patients' access to EHR.

The next meeting of the group will take place on the 7th of May in Copenhagen during the eHealth Week.

For more information please contact Liuska Sanna, Programme Manager at liuska.sanna@eu-patient.eu

11. EUPATI - Kick off meeting and Official Launch



We are pleased to inform our readers that the project “European Patients' Academy on Therapeutic Innovation” – EUPATI has successfully kicked off. The start of the project has been marked by two important events; the kick off meeting of the project Consortium took place in Brussels on the 6th of March and there was a first public launch at DIA EuroMeeting on 27th March in Copenhagen.

The consortium, led by the [European Patients' Forum](#), comprises of 29 leading pan-European patient organisations, academic and not-for profit organisations as well as EFPIA member companies.

Funded by the Innovative Medicines Initiative (IMI), the patient-led academy will develop educational material, training courses and a public Internet library to educate patient representatives and the lay public about all processes involved in medicines development. Topics will include personalised and predictive medicine, design and conduct of clinical trials, drug safety and risk/benefit assessment, pharmaco-economics as well as patient involvement in drug development.

In the first stage of the project the Consortium will work on four main areas:

- Conducting a needs assessment amongst representatives of lay patients, patient representatives and the general public to understand what their educational expectations are
- Identifying and collecting education material on medicines development processes to assess what exists already
- Establishing the EUPATI Network
- Setting up the IT Platform that will support the deployment of the education programmes.

Should you be interested to know more please visit EUPATI website www.patientsacademy.eu/index.php/en/ or contact Jan Geissler, EUPATI Director, jan@patientsacademy.eu

12. SUSTAINS



In the previous issue of our Mailing we have announced the official start of the **SUSTAINS** project. This three-year project is aimed at developing and deploying a basket of services in 11 European regions providing **patients' access to Electronic Health Records (EHR)**. SUSTAINS comprises several administrative and clinical services rather different from one another. The common denominator in terms of usage is that they are all designed to be used by the citizens/patients from their home or wherever they happen to be, provided they have access to Internet.

EPF's main role in this project is to lead on work dedicated to user requirements elicitation and use cases definition. EPF will also lead on preparing the framework for the assessment of patient empowerment.

The first activity within this context is the implementation of a set of user requirement focus groups involving representatives of users of the SUSTAINS services in the eleven participating regions. The overall objective of these focus groups is to ensure that the SUSTAINS services are aligned to the largest extent possible to the needs and expectations of patients and meet the requirements of health professionals. These focus groups will involve patients, health professionals, citizens and informal carers and will enable these different categories of users to advise the local project team about the real user needs. By enabling the participating regions to integrate requirements and concerns of the end users in the design and development of the SUSTAINS services, these focus groups should ultimately strengthen the acceptance of these services among patients and health professionals, thereby contributing to their sustainability after the project life-cycle.

EPF has started to work with the local partners to organise the focus groups which will take place in April-May 2012. The outcomes of these focus groups will be presented in an integrated report which will also include a list of recommendations on how to integrate the user perspective in the development of services providing patients'/citizens' access to EHR.

For more information about the project please click contact [Walter Atzori](#).

13. Chain of TRUST



The "Chain of Trust" project, led by EPF, has successfully completed the activities planned for the first phase of the project aimed at gathering knowledge on patients' and health professionals' perspective on telehealth (see www.chainoftrust.eu/objectives).

The last set of activities contributing to this objective, i.e. four European focus groups, one for each of the four constituencies identified for this project (i.e. patients, doctors, nurses, and pharmacists) were implemented in Brussels between mid-January and mid-February 2012. Overall 42 participants attended the European focus groups to help the consortium complete the analysis of users' perspectives on telehealth, and translate these findings into recommendations the project partners will take forward in the various raising-awareness activities scheduled to be implemented throughout 2012.

To this end, six National Roundtables will be organised as from mid-spring 2012 in the same countries where the [national workshops](#) took place in autumn 2011 (see [EPF Mailing of November 2011](#)). The objective of the National Roundtables is twofold:

Raising awareness of national stakeholders on the project findings and policy recommendations

Promote the integration of users' perspective in national telehealth agendas and plans.

To effectively support project's raising awareness activities the Chain of Trust consortium is working on consolidating the results collected in an intermediate public deliverable which is ought to be released in mid-spring 2012.

For more information on the Chain of Trust project, please contact [Liuska Sanna](#) or visit the project website at www.chainoftrust.eu.

14. RENEWING HEALTH



The large-scale telemedicine pilot project “[RENEWING HeALTH](#)”, in which EPF participates as co-manager of the [User Advisory Board](#), entered its third year of implementation. As our readers may remember, RENEWING HeALTH is extending pre-existing patient-centred telemonitoring and health coaching services for people with chronic conditions to large scale pilots in order to gather evidence on the use of telemonitoring in real life settings¹.

As the interventions in all participating regions has been going on for quite some months already, the focus is now shifting to the analysis of data being collected in the various pilot sites. The aim here is to make sure that analysis and reporting of results are similar and comparable project-wise. To that purpose an ad-hoc workshop was held in Treviso on 10th February where experts within the different evaluation domains of the project’s assessment methodology ([MAST](#)) gave practical advice on analysis and reporting of the results based on guidelines for reporting of scientific studies.

Over the last few months the User Advisory Board (UAB) has been busy finalising the second version of the User Requirement document. This document, which is continuously reviewed and improved throughout the project lifecycle, provides for a reference framework for representing needs, constraints and expectations of end-users of telemedicine services. The second version, complementing the initial literature review carried out in 2010 with outcomes of two rounds of consultations with the constituencies represented in the UAB, is currently being finalised and is ought to be made public in mid-spring 2012. The third version is expected to be released in autumn 2012 to include the outcomes of a series of local meetings with end users of the piloted telemedicine services.

¹ A detailed description of each of the individual services piloted in the framework of the RENEWING HeALTH project has been recently added on the project website (<http://www.renewinghealth.eu/health-services>)

To that end a first local meeting with users involved in the RENEWING HeALTH was held in Treviso on 7th February. The meeting has proved to be very successful in enriching the user requirements framework through hands-on experience of end users involved in the local sites. Likewise, the meeting was reported by the local partner (Regione Veneto) to have been very useful in helping them better understand what needs to be done in order to maximise end-users' acceptability, as one of the key pre-conditions for integrating the piloted telemedicine programmes into mainstream regional health services.

A second local meeting with RENEWING HeALTH users is set to take place in Luleå (Norrbotten) on 18th June. The event is attached to the 2012 [Arctic Light eHealth Conference \(ALEC\)](#) where EPF will participate as a speaker.

The next European-level meeting of the User Advisory Board will be held in late May and will focus on reviewing the results of pilots' mid-term evaluation reports.

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



15. InterQuality: spend no more but smarter!



Annual Meeting - “International Research Project on Financing Quality in Healthcare” (InterQuality)

InterQuality is a project based on the idea that increasing spending in health not always leads to a better quality. The objective of the project is to analyse different financing mechanisms in healthcare in different countries, in order to identify spending models which can improve quality of healthcare.

EPF’s role is to bring a patient perspective into this review of financing models and to disseminate the results of the project. Aimed at ameliorating quality of care, InterQuality will eventually benefit patients and patients’ organisations by improving spending in health services.

The InterQuality consortium came together at the beginning of February in Hannover, Germany, for the Annual Meeting of the project. The meeting started with a presentation about the German healthcare system, and the challenges it has to face with an increasingly ageing population and a lack of recent reforms. The Washington Urban Institute’s presentation showed that financial incentives should be analysed considering also different contexts, since payment methods are never pure and there are several dimensions influencing them. The University of Warsaw Partner explained the achievements of their literature reviews, especially concerning quality, cost and efficiency in financing healthcare methods. As conclusion of the first year of work, partners are looking forward to achieving successful results in the second year of InterQuality.

Next InterQuality meeting will be in Catania, Italy, on the 24th and 25th of May. After one year focused on literature review, this will be the occasion for InterQuality consortium to present some achievement also in the comparative analysis of countries’ situations and payment methods in pharmaceutical, hospital, outpatient and integrated care.

The first issue of the newsletter is now available on [InterQuality website](#)!

The website is also updated with the summary of the [InterQuality Annual Meeting](#).

For more information about the project please click contact [Liuska Sanna](#).

16. Focus on Wounds International - A new international consensus on optimising wellbeing in people living with a wound

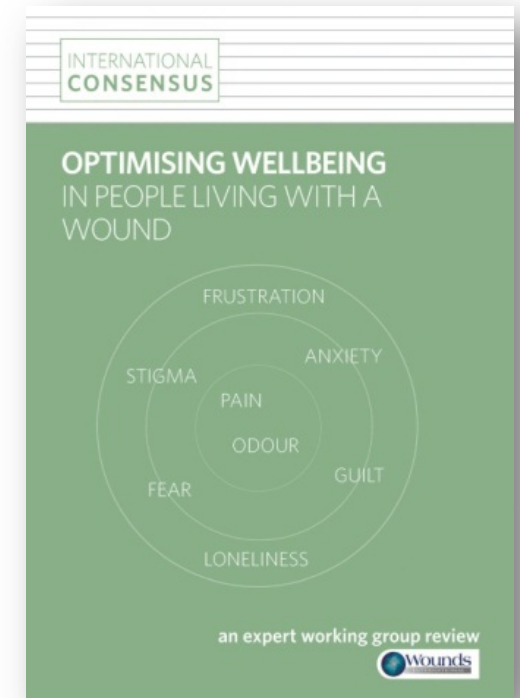
Wounds International has recently published an important international consensus on wellbeing and effective wound management. The document is targeted at healthcare professionals around the world and provides a useful resource for healthcare organisations, policy makers and industry in addressing the needs of those living with a wound. The key aims of this document are to:

- increase understanding of the impact of living with a wound on the wellbeing of patients and their carers
- improve clinicians' ability to share treatment decisions with patients
- highlight ways for clinicians to enter into a dialogue about patient wellbeing
- increase clinicians' ability to implement strategies for cost-effective wound management.

The consensus is based on the latest research, government initiatives and opinion of a number of international experts, including medical, nursing, allied health professionals and researchers. The concerns are not simply with the quality of the treatment of individual wounds, but rather the human cost of living with a wound and the role of clinicians, industry and organisations in improving the wellbeing of patients

To ensure the patient has a voice within the document, Wounds International facilitated a workshop with two service user groups at the University of Leeds in the UK. The aim of the workshop was to gain insight into the impact of living with a wound on patients, their carers and their family members.

For further details of the consensus document 'Optimising wellbeing in people living with a wound' and to download a copy, please go on [Wound International website](#).



17. EFGCP Annual Conference 2012, Brussels, 24-25 January 2012

“Informed Consent – How Less could be More: Effecting a paradigm shift so we do inform participants?”

Questions of information and consent were the focus of the EFGCP annual conference in January. The two-day event explored ways to improve information provided for patients, and how sponsors, researchers and research participants can work together to influence law, policy and ethics. Nicola Bedlington co-chaired a plenary session on “Change is long overdue – but how do we achieve it?” A report will be published in due course. For more information about this event visit www.efgcp.be.

18. Meeting on “Inequalities and multiple discrimination in healthcare”, Vienna, 29 February 2012

Kaisa Immonen-Charalambous participated in a meeting by the EU Agency for Fundamental Rights (FRA) to discuss the results of its project “Inequalities and multiple discrimination in healthcare”. The project aimed to identify barriers in access to healthcare services and experiences of discrimination that can affect patients at the intersection of the following grounds: ethnic origin, disability, age, and gender. The discussions were interesting in view of EPF’s current and future work on discrimination and health inequalities. The FRA will publish the results of its [research](#) in 2012. For further information about the Agency visit <http://fra.europa.eu>

19. Rare Diseases Day, Brussels, 29 February

February 29th was Rare Disease Day 2012, an annual event coordinated by EPF Member EURORDIS at international level, and by national coalitions of patients' organisations at national level." This fifth edition of the rare disease day, which aims at putting the spotlight on rare diseases and the millions of people affected by them, focused on the theme of solidarity in the fields of rare diseases. This year's event highlighted the need for collaboration and mutual support amongst diseases, stakeholders and across countries. Rare Disease was presented as a model of EU Solidarity, and the added value of EU action in this field was also discussed. This was followed by presentations of key initiatives in Europe by EURORDIS members such as EURO WABB, the EU registry for rare diabetes, or ENERCA, the European Reference network of expert centres in rare anaemias

Links:

More information and contact details are available on [EURORDIS website](#)

[Rare Disease Day 2012](#) also has a website, where patients with rare diseases are invited to share their stories.

20. EPF Board Meeting, Brussels, 5 March 2012

The EPF board met on 5 March to prepare the Annual General Meeting: the accounts and annual report for 2011 were approved and will be circulated in advance of the AGM. The budget and work plan for 2012 were also finalized and approved. Preparatory work took place on the forthcoming strategic planning seminar the day after our AGM. The board adopted a communications strategy for 2012 and discussed the details of the 2013 work plan submitted with the Operational Grant application in early March.

21. HPCB meeting, European Parliament, Brussels, 7 March 2012

“The new recognition of professional qualifications Directive: what’s at stake for patient safety?”

Kaisa Immonen-Charalambous represented EPF in a meeting organised by Health Professionals Crossing Borders (HPCB) at the European Parliament, to discuss the proposals to review the Professional Qualifications Directive. The meeting was hosted by MEPs Emma McClarkin and Antoniya Parvanova (ALDE, Bg). Kaisa participated in a panel discussion on “Language requirements: what’s at stake for patient safety?”. The discussion was very lively and the patients’ voice was definitely heard by the full room of participants. For more information visit the website www.hpcb.eu

22. EFPIA Patients Think Tank, Brussels, 8 March 2012

Kaisa Immonen-Charalambous and Nicola Bedlington represented EPF at the EFPIA Patients Think- Tank. A specific morning workshop was devoted to personalised medicine. Kaisa gave a presentation on this topic from the stand-point of patients, based on the work of the EPF Policy Advisory Group. Ruxandra Draghia-Akli (DG Research) presented Commission initiatives in the field of personalised medicine. Jola Gore-Booth (europacolon) gave a presentation on Personalised medicine in cancer, and Horst Kramer from Roche explored how companies are addressing personalised medicine. Please contact the EPF secretariat for a copy of these presentations.

The afternoon session looked at the revision of the Clinical Trials Directive, with a presentation by Fabio D'Atri (DG SANCO), and update on the Data Privacy Directive and an Update on the Transparency Directive (please see the policy section of this Mailing for more details from EPF’s perspective). The meeting also heard from three members of the Think Tank (GSK, European Men’s Health Forum and Pfizer on their policy and research priorities for 2012).

23. EFGCP-EORTC meeting, Brussels, 12 March 2012

“Road Map Initiative for Clinical Research in Europe: Multi-Stakeholder Round Table on Consensus and Strategy Development. How Should the Future Clinical Trial Authorisation Work?”

Kaisa Immonen-Charalambous represented EPF at this roundtable event held at the EORTC Headquarters, organised by the EFGCP in partnership with EORTC and EFPIA, and held at the EORTC headquarters in Brussels. EPF co-chaired the discussion session on assessment of clinical trials applications, and provided a patient perspective on the proposed new legislative framework. More information and the event programme is available at www.efgcp.be



24. High Level Task Force on eHealth, Barcelona, 15-16 March

Anders Olauson participated in the third High Level Task Force on eHealth in Barcelona, which developed further the Task Force’s vision and approach to eHealth. This will be presented at the eHealth Week in Copenhagen in May.

Whilst in Barcelona, Anders also took the opportunity to visit the Spanish Patients’ University and discuss with leaders there how such a model could be replicated in the framework of an EU wide Health Literacy initiative.

25. IAPO Global Patients Congress, London, 17-19 March 2012

Kaisa Immonen-Charalambous participated in the 5th Global Patients’ Congress which this year took place in London. She presented EPF’s work on the EU Pharmacovigilance legislation in a parallel session on global health policy. As usual, the Congress

provided a lot of ideas that will feed into our work at the European level. Also, during the Congress IAPO launched its consultation on indicators to measure the patient-centeredness of healthcare, to which EPF will be seeking the views of our members.

The Congress programme and photos are available at www.patientsorganizations.org

A report will be published in due course.

26. Shaping the future of healthcare in Greece, Financial Times conference, Athens, 20 March

EPF Board Member Philip Chircop participated to the conference “ Shaping the future of healthcare in Greece: Caring, curing, securing” organised by the Financial times ltd in Athens on 20 March. The event reunited Greek and international experts and stakeholders to discuss the current situation and future of healthcare in Greece.

Philip Chircop presented the central role that patients need to play in current and future health related policies in Greece, and in the EU. He made a strong case for tackling the issue of health inequalities as well as other challenges, and urged the Institutions and governments to prioritize healthcare in the current economic context. He also called on the EU and Member State to “ to put in place, rational and ambitious strategies, to support health literacy and patients’ empowerment, and to involve patient organisations, in health policy and research”.

More information and copies of speakers’ presentation are available on the conference’s website [here](#).

27. Healthcare in Europe Economist Conference, Geneva

Nicola Bedlington represented EPF at the annual Economist Conference in Geneva on the 22nd March 2012. She participated in a panel debate led by Professor Richard Sullivan, King's Health Partners Integrated Cancer Centre on healthcare reform, based on two key notes from Recep Akdağ, Minister for Health, Turkey and Sir Andrew Dillon, CEO of NICE.

For more information about the meeting and its outcomes go [here](#).

28. DIA Europe, Copenhagen, 26-28 March

Several EPF members and representatives were present at the DIA Europe meeting in Copenhagen, as part of the DIA Fellowship Programme. It was an important opportunity to launch the EUPATI project, with a special session chaired by Anders Olauson.

See <http://www.patientsacademy.eu/index.php/en/> for information and the video streaming of this event.

Anders also participated in a session on HTA. Nicola Bedlington participated in the plenary session which addressed ethical practices in the pharmaceutical sector and chaired a session on active and healthy ageing. For more information on the DIA meeting in Copenhagen, please go [here](#).

Register as soon as possible!



29. Conference on 'Gender and Health through Life', Copenhagen, 14-15 June 2012

EPF is please to invite you to join us for the "Gender and Health through Life" Conference on 14th-15th June, 2012 at the Copenhagen University Hospital, Rigshospitalet. The conference is supported by the Danish EU Presidency and organised by the European Men's Health Forum, European Patients' Forum, the Danish Men's Health Society and the European Cancer Patient Coalition.

Keynotes:

- *Men's Health & Premature Death in Europe* – Prof Alan White, LM University, UK.
- *Women's Health and Healthy Ageing* – Ms. Hildrun Sundseth, European Institute of Wom-en's Health, BE
- *Gender and Healthy Ageing* – Dr. Carsten Hendriksen, Copenhagen University, DK

Two parallel sessions with panel:

- *Gender and Mental Health* with Merete Nordentoft, Maria Fe Bravo Ortiz, and Svend Aage Madsen
- *Getting it Right - Gender in Prevention, Health Promotion and Patient- Centred Chronic Dis-ease Management* with Susanna Palkonen, Olesya Kolisnyk, and Dorota Sienkiewicz.

Panel discussion: Is there a need for gendered health policies?

Agenda of the event Day 1 – June 14

Morning Round Table Workshop "Gender based cancer information and early diagnosis"

Keynotes:

- *Gender and Social Determinants of Health* – Prof Finn Diderichsen, Department of Public Health, Copenhagen University, DK
- *Gender and Health in the Workplace* - Ms. Jane Korzack, Vice President of The Federation of Danish Workers, DK
- *How Men's and Women's Health Affects each Other and Society* - Dr Selwyn Hodge, Chair Royal Society for Public Health, UK

Conference End: *Recommendations for a Gendered Health Policy in Europe* – Dr. Ian Banks, North Ireland and EMHF.
Followed by panel discussion

Day 2 – June 15

Please note that the conference does not cover expenses or hotel accommodation.

For further details and to receive an invitation please contact: genderandhealth.2012@gmail.com

30. Office move

As announced in our previous mailing EPF Secretariat has now moved to its new offices. Ideally located in the EU quarter, the office is also fully accessible to patients with reduced mobility. Premises include meeting room and spare desk to welcome our Members in Brussels.

New address:

European Patients' Forum

31, rue du Commerce
B-1000 Brussels
Belgium



31. Welcome Peter



Peter Windey joined EPF in March 2012 as Finance and Operations Manager. A Belgian national, he holds a degree of chartered accountancy and a bachelor in accounting from the “Institut des Carrières Commerciales” in Brussels.

Peter began his career in the 80s in accounting and financial positions in various private sector companies.

More recently, he worked for the Belgian Cooperation Agency and, from 2002 to 2011, he was the finance and administrative responsible of the ProInvest programme funded by the European Development Fund.

32. Welcome Clarissa



In February EPF has welcomed Clarissa Spencer. She has 15 years’ experience of working in an administrative support role for both public and private held companies. Clarissa gives administrative support to the office management and the team.

A warm welcome to her.

33. EPF Annual General Meeting and Strategic Planning Seminar

EPF Annual General Meeting (AGM) will be held on 18 April in Brussels. As we approach the end of our original strategic plan, the Spring Seminar organized on 19 April at the AGM will be the occasion to work with our Membership, through analysis and debate, to develop a new strategic plan covering the period 2014-2020, in line with the next EU Programming period.

The seminar will review what has been accomplished in recent years in relation to the strategic goals established in 2007 and identify new challenges at a time when Europe and public health services are conditioned by a wide-scale economic crisis. It will be an opportunity to share with our Members experiences and views and reflect on the organization's development (its growth, its priorities, and its relationship with different partners).

During the seminar, EPF members will be called upon to participate actively in the establishment of a new framework that will provide the direction of EPF's goals and objectives for the next years.

In line with our Youth Strategy Members are strongly encouraged to nominate a young delegate to participate at both events and giving the opportunity to be a representative of the Youth Group.



34. Calendar

Date	Event	Place	Attendance
April 3	Conference on Active and Healthy Ageing	Brussels, Belgium	Nicola Bedlington - speaker
April 12-13	Patient Empowerment Conference	Copenhagen, Denmark	Nicola Bedlington - Speaker
April 17	Belgian Pharmaceutical Conference	Brussels, Belgium	Nicola Bedlington - Speaker
April 16-17,	Healthcare Innovation Conference	Brussels, Belgium	Anders Olauson & Nicola Bedlington - Speaker
April 18-19	EPF AGM and Spring Seminar	Brussels, Belgium	All
April 25	EPF – EUCOMED Dialogue Meeting	Brussels, Belgium	Nicola Bedlington – Co-chair
7-9 May	eHealth week 2012	Copenhagen, Denmark	Anders Olauson
7 May	SUSTAINS 1 Steering Committee Meeting	Copenhagen, Denmark	Walter Atzori
24-25 May	Kick-Off meeting of the Joint Action on Patient Safety and Quality of Care	Copenhagen, Denmark	Nicola Bedlington & Kaisa Immonen-Charalambous
31 May - 1 June	Nordic Conference on cross cooperation on rare diseases	Reykjavik, Iceland	Anders Olauson - speaker
12-13 June	Hospage Conference	Germany	Anders Olauson - speaker
14-15 June	Gender and ageing conference	Copenhagen, Denmark	Susanna Palkonen – speaker & Nicola Bedlington – Co-chair
18 June	RENEWING HeALTH Local Meeting of the User Advisory Board	Luleå, Sweden	Walter Atzori
18-19 June	Artic eHealth Light Conference	Norrbottnen, Sweden	Liuska Sanna & Walter Atzori
25-27 June	HTAi conference	Bilbao, Spain	Liuska Sanna