europeanpatients'forum

150 Million reasons to act

EPF's Patients' Manifesto for the European Parliament and Commission 2009

The European Patients' Forum represents over 150 million patients across the EU. We call for vital new measures in 3 fundamental areas to improve the quality of health care delivered across the EU:

- **Equal and timely access** to safe, effective diagnosis, treatments and support ;
- **Better information and resources** for patients to be partners in determining their care;
- **A patients' voice** to be heard in Brussels and throughout the European Union.

Our current health systems can be unfair, divisive and fail to put the patients' perspective first.

We believe all patients within the EU have a basic right to equal access to quality medical treatment, regardless of where they live, their status or their income.

We call upon the political groups within the European Parliament, MEPs, prospective MEPs, national representatives in EU Member States, and the new Commission, to commit to the legitimate rights and needs of patients and to make our proposals their priority.

Patients have the right to be fully informed about health issues and the responsibility to manage their health.

However our members report that when they see a health professional there are often enormous and unjustifiable inequities across the EU in terms of the quality of care offered, and the treatment received. The fundamental problems are:

- Lack of equal and timely access to treatment,
- Lack of access to quality information,
- Lack of psychological, social and environment support that help the patient during treatment and recovery.

our patients' manifesto **is needed now**

These shortcomings have a negative effect on the quality of life of a huge number of patients in every Member State, regardless of their disease or condition.

The lead-up to the forthcoming European Parliamentary Elections and new Commission is a time to set new political priorities, and commit to take action.

We call for action

We, as the European Patients' Forum, call on the Political Groupings of the European Parliament, current and prospective MEPs, their MP counterparts in every EU Member State and the European Commission to ensure:

Equal and timely access **to safe and effective diagnosis, treatments and support**

1. Extend the current political emphasis on “health and wealth” within the EU - to “health, wealth and **equity**”.
2. Recognize that all EU patients have **a basic right to timely diagnosis, treatment, therapies and medicines**. We must address the huge differences across the EU in access to treatment and what we pay for it.
3. Ensure a **non-discriminatory and inclusive approach** to the provision of treatment, therapies and care to **all** patients. Certain patients are particularly vulnerable to exclusion and inequities, such as young patients, older patients and those from ethnic minority backgrounds. **All** patients' voices must be heard.
4. Maintain the **political commitment to address patient safety** at EU level. And ensure planned new laws on patient safety, pharmacovigilance[1], tackling counterfeit drugs, and research using animals are workable and sustainable.
5. Ensure EU health policy adopts a **holistic approach** to patients' needs. Many chronic patients need a life-long range of services and support- especially when their illness causes stigma and exclusion.

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[1] *The primary goal of pharmacovigilance is to ensure that medications are used to the maximum benefit while minimizing the risks of treatment.*

Better information and resources for patients **to be effective partners in determining their care**

1. Support a determined EU strategy to **improve the quality of information** given to patients about their medication, treatment, rehabilitation and support services.
   This is a vital factor in providing patient-centred health care.
2. Provide funds to help patients acquire the skills to make key decisions about their health.
   “Health Literacy” as a concept must be established at both EU and national level.
3. Acknowledge the need for **improved dialogue between the patient and medical staff.** This requires support for innovative work at EU and national level to forge better communications and trust.
4. **Encourage investment in the use of Information Technology in healthcare** providing it is genuinely patient centred. Patients should be involved at all stages of development from inception to evaluating the product or system.

A patients' voice that is **heard in Brussels and throughout the EU**

1. **Promote patient empowerment!** Patients need to be involved in a formal way in EU and national health projects and health policies. With patient input, policy is more likely to respond to their vital needs.
2. **Ensure more money is allocated for EU health policy and programmes** - and that adequate funds are given to patients' groups so their members have a voice when vital decisions are made about their health care.
3. **Support our annual review of the status of patients** across the European Union. The European Patients' Forum will conduct its survey from the patient's perspective, using criteria identified exclusively by the patients themselves.
4. **Support a European Patients' Rights Day and make our day!** We are calling for the 18th April to be designated as **“European Patients' Rights Day”**. This will give patients, their families, and organisations the chance to raise the profile of health issues they care most about.

Our manifesto **is developed by patients**

Our Manifesto is based upon views from our members. The proposals have been developed and endorsed by our members - leading patient organisations representing more than 150 million patients throughout the European Union.

Each year our Forum will review and publish the status of patients across the EU from the patient's perspective, using criteria identified exclusively by the patients themselves.

We are passionately convinced that change is crucial. Patients' rights must be established and upheld, not only for their health and well-being, but also for the good of the economy and the future of a democratic European Union.

Our Responsibilities

The European Patients' Forum, through the energy and dynamism of our members, commits to being a strong partner in achieving this change.

Patients must be **more involved in health policy**

Once a patient is diagnosed they develop a new perspective on life, and an invaluable knowledge of how to manage their disease or illness. They also have to navigate their way through health services and systems.

Along the way they will form their own **unique perspective** on healthcare developments - it is their perspective, or their voice that we represent. This **informed view** of the patient will enhance health policy, and ensure the treatment offered is patient centred.

Details of the manifesto

EQUAL AND TIMELY ACCESS TO SAFE AND EFFECTIVE DIAGNOSIS, TREATMENTS AND SUPPORT SERVICES

1. Extend the current EU political emphasis from purely health and wealth, to health, wealth **and** equity.

   While the EU recognises the link between good health and economic prosperity, it also accepts that "health inequities" need to be challenged. Both need to be brought together in the execution of the EU Health Strategy "Together for Health". In this way tangible progress can be made. The new EU Directive on the application of patients' rights in cross-border healthcare will assist these changes; but it needs the universal support from all EU Institutions.

2. Recognize that all EU patients have **a basic right to timely treatment**, therapies and medicines. It is vital to address the huge differences across the EU between access to treatment and what we pay for it.

   All EU Institutions need to give greater political priority to addressing appalling inequities. Huge differences between and within Member States in terms of access, pricing and reimbursement, sometimes depending simply on where you live, are unacceptable and a contradiction to a Europe built on equity, solidarity and human rights. We call for a new body involving Member States, and stakeholders, to take on the explicit challenge of equal access to essential medicines, treatments and therapies by all EU patients.

3 Ensure a **non-discriminatory and inclusive approach** to the provision of treatment, therapies and care to **all** patients. Certain patients are particularly vulnerable to exclusion and inequities, such as young patients, older patients and those from an ethnic minority background.

The perspective and the real life situation of such patients is often ignored or not taken seriously. Furthermore, they tend to be underrepresented in policy debates and indeed in patient organisations themselves. EPF is working on this politically and in a practical way. We call on the support of the EU institutions to address the major barriers faced by excluded patient groups and support targeted measures to ensure they are able to access equitable, patient - centred healthcare, regardless of age, background, status or condition.

4 Maintain the **political commitment to address patient safety** at EU level. Planned new laws on patient safety and quality of health services, including the prevention and control of healthcare-associated infections, pharmacovigilance, tackling counterfeit drugs, research using animals must be workable and sustainable.

Patients who have say, suffered adverse effects from medicine, or caught an infection after being in hospital should be encouraged to report these events to help protect others in the future. However only a few Member States have national patient safety reporting systems or have undertaken detailed research on adverse events in health care settings.

The European Commission is preparing a Communication to the Council of the European Union together with proposals on patient safety and health-care associated infections, which should be launched by the end of 2008. We urge the European institutions to put their weight behind this important policy and other developments in the areas of counterfeiting, pharmacovigilance and research using animals.

We also urge that the European Union Network for Patient Safety continues to receive funding. The Network is an important platform for collaboration among Member States, international organisations and civil society organisations. It supports key actions such as:
- *Promoting a culture of patient safety;*
- *Organising materials for education and training in patient safety of health professionals, decision-makers, patients;*
- *Implementing reporting systems;*
- *Testing tools of medication safety*

5. Ensure EU health policies adopt **a holistic approach to patients' needs.** Many people need a range of services and support - especially when their illness causes stigma and exclusion.

Patients often require a lot more than medical treatment when coping with an illness or disease. They may have to be retrained, re-housed or need long term physical or emotional support. A holistic approach to their care aids recovery, helps to restore their quality of life, and gives them the opportunity to become an active citizen once more.

We would like to see this holistic approach recognized and supported by the EU. We suggest it should be reflected in practical terms by more cooperation and 'joint ventures' between different Directorates (DGs) within the Commission and DG Sanco (Health). For example DGs responsible for social and employment affairs, education, information society, enterprise and industry - and that these ventures involve patients themselves.

BETTER INFORMATION AND RESOURCES FOR PATIENTS TO BE EFFECTIVE PARTNERS IN DETERMINING THEIR CARE

1. Support an ambitious EU strategy to **improve the quality of information** given to patients about their medication and treatment. This is a vital factor in providing patient centred health care.

There should be equal access to high quality Information for all EU patients. It is important that this information is shared across the EU.

We call for the support of the European Parliament and the European Commission for a coherent strategy on information to patients, one that promotes equal access for all EU patients to information that meets defined quality criteria.

This would build on the achievements of the Pharmaceutical Forum and the wider EU Health strategy 'Together for Health'.

2 Provide funds to help patients acquire the skills to make key decisions about their health. **“Health Literacy”** as a concept must be established at both EU and national level.

It can be extremely difficult for patients to make the right decisions about their health if they do not have access to information that is easy to understand and use. Those who do not have confidence or knowledge of the health care system may not receive the high quality treatment they deserve.

In our Spring Conference on Health Literacy in 2008 we made the following recommendations:

- *The need for further research that explores Health Literacy and its role in healthcare delivery and health outcomes*
- *The importance of setting up an EU level Health Literacy Network*
- *Wider distribution of Health information and Information to Patients that meets core quality criteria*
- *Productive dialogue between patients and healthcare providers to ensured shared decision-making in their care*
- *The meaningful involvement of patients in health literacy policies and programmes.*

We call for funds and political commitment to put these recommendations into action.

3 Acknowledge the need for **improved dialogue between the patient and health professionals**. This requires innovative work at EU and national level to forge better communications and trust.

To receive good treatment the patient and the health professional need to be able to understand each other, and communicate on an equal level.

To improve this important dialogue we want the European Commission to pilot a training module for health care professionals. A course on “productive dialogue with patients” would be an obligatory qualification.
The patients' own stories about their journey through the healthcare system and peer support among patients themselves should be recognized as a key resource.

4 Encourage investment in the use of Information Technology in healthcare that is genuinely patient-centred. Patients should be involved at all stages of development from inception to evaluating the product or system.

It is now widely recognised that Information Communication Technology (ICT) and eHealth solutions[2] have an important role to play in healthcare. They can help empower patients, improve their safety, aid care in the home, and patient mobility. They can also encourage more personalised health care; improve disease management, and the quality and continuity of health care and health information.

However it is vital that patients and their representative organisations are appropriately consulted and involved in all stages of ICT developments to ensure these solutions are effective, and geared towards the needs of patients.

In an EU context, our Forum requests that in any follow-up linked to the e-Health roadmaps; further research; large scale transnational cooperation with e-health systems providers, infrastructure; that patients' organisations are involved and that this involvement is resourced and recognised.

A PATIENTS' VOICE THAT IS HEARD IN BRUSSELS AND THROUGHOUT THE EU

1. **Promote patient empowerment!** Patients need to be involved in a formal way in EU and national health projects. With patient input, policy is more likely to respond to their vital needs.

   Patient involvement, through their representative organisations, should be necessary criteria before funds are granted for relevant EU health projects.

   We call on politicians to encourage 'the meaningful involvement of patients' to be adopted as a key performance indicator of health systems. This was highlighted by Commissioner Vassiliou in a recent speech[3].

2. **Ensure more money is allocated for EU health policy and programmes**. Adequate funds should be given to patients' groups, so their members have a voice when vital decisions are made about their health care.

   It is widely recognised that the current funds allocated to the EU Health Budget are totally inadequate to achieve the aspirations of the EU Health Strategy - 'Together for Health' and indeed the future challenges as identified by DG Sanco (Health).

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[2] *ehealth solutions: Computerised applications in the field of health e.g. storing patient data*

[3] *EPF Spring Conference on Health Literacy, Brussels, 8 April 2008*

The EU Health Policy Forum is proposing investment in health as a priority in the next budget round. We and our sister NGOs call on Members of the European Parliament to support this move and to recognise adequate funding for patient organisations and other health NGOs is a necessary part of this investment.

3. Support our **annual review of the status of patients** across the European Union. The European Patients' Forum will conduct its survey from the patient's perspective, using criteria identified exclusively by the patients themselves.

The European Patients' Forum considers it vital that patients themselves are given the opportunity to speak out on their experience of healthcare systems and how the health care community perceives them.

Following pilot work that will take place in late 2008/early 2009, we will launch an annual review on the Status of Patients throughout the European Union; this will require sustainable and on-going financial support and should be co-financed through EU funding.

4. Support moves to make our day! We are calling for the 18th April to be designated as **“European Patients' Rights Day”**. This would give patients, their families, and organisations the chance to raise the profile of health issues they care most about.

We call upon the European Parliament to support this initiative and be as active as possible in the events organised on and around the European Patients' Rights Day in their constituencies.

In **conclusion**

We feel strongly that our manifesto will have a dramatic impact on the quality of heath care received by all patients living across the European Union. We urge you to sign up to our manifesto and become an active supporter of our aims.

Background to **the European Patients' Forum Manifesto**

These proposals have been developed and endorsed by their representative patient organisations that are members of the European Patients' Forum, collectively representing 150 million patients throughout the European Union. They are achievable, make economic sense and when implemented will make a significant difference to the health outcomes and quality of life of vast numbers of patients in every Member State.

They are focused around the core goals within our Strategic Plan:

- To promote equal access to best quality information and healthcare for EU patients, their carers and their families
- To ensure meaningful patient involvement in EU health-related policy-making, programmes and projects.
- To ensure a patients' perspective is heard in developments at EU level on health economics and health efficacy. (Health, wealth and equity).
- To encourage inclusive, effective and sustainable representative patient organisations.
- To nurture and promote solidarity and unity across the EU patients' movement.

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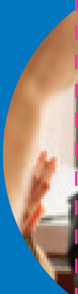

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