EPF Response to the Commission's Consultation on EU Action to Reduce Health Inequalities

April 2009

The **European Patients' Forum** (EPF) was founded in 2003 to become the collective patients' voice at EU level, manifesting the solidarity, power and unity of the EU patients' movement. EPF currently represents 38 member organisations - which are chronic disease specific patient organisations working at European level, and national coalitions of patients organizations. EPF therefore reflects the voice of an estimated 150 million patients affected by various diseases in the European Union.

EPF's vision for the future is high quality, patient-centred, equitable healthcare throughout the European Union.

The European Patients' Forum welcomes the Commission's consultation on EU action to reduce health inequalities.

EPF's vision for the future is high quality, patient-centred, **equitable** healthcare for all patients across the European Union and we look forward to contributing**, from a patients' perspective,** to both this consultation and the significant actions needed to address health inequalities in Europe.

We have not addressed directly issues linked to prevention and health promotion per se, although we are very supportive of the work and input of fellow health NGO at EU level is this arena. Our focus is disease management and the needs of patients diagnosed with a chronic disease, and their families.

The following summarises our viewpoints on each of the issues raised, and offers patients' evidence to substantiate this. As some of the questions are repetitious we have 'grouped' our responses accordingly.

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On general data:

What do you think will be the trends regarding health inequalities? – are they increasing or decreasing for example – please supply evidence if possible.

In the current economic climate, EPF is learning from its membership of increasing health inequalities for patients both between and within Member States and between socio – economic groups in the European Union. A very good illustration of this is what is happening in Latvia. Our member organisation in Latvia, SUSTENTO, has shared with us in recent months the very worrying situation for patients and their families in Latvia, because of the economic crisis.

The measures introduced to attempt to stabilise the crisis in Latvia have increased dramatically healthcare costs borne by Latvian patients themselves, a cost they are simply unable to afford and which will lead in the longer term to greater inequity, poorer health and ultimately additional direct and indirect costs to the Government and society as a whole.

In Hungary the most marginalized people are the Roma population. Because of the high unemployment rate many are not part of National Health Insurance system, and therefore have no chance for diagnosis or treatment, except for emergency. In this current climate this situation is only going to get worse.

A concrete example of increasing health inequalities, again from Hungary is the alarming decrease in the number of osteoporosis patients accessing treatments (appox. by 50 %) because of the significant reduction in the reimbursement of treatments against osteoporosis. This creates a very real danger of new fractures and impacts enormously on quality of life.

Another powerful example from another specific disease area, but that could be replicated in others, is the initial outcome of the European Multiple Sclerosis Platform barometer survey that charts the situation faced by people with MS across Europe in 7 key areas. It has highlighted that cross-border differences between patients receiving disease-modifying drugs (DMDs) are as high as 88%, with out-patient rehabilitation figures coming in at 98% of total population with MS at the top end of the scale compared with a 7% at the bottom (add reference).

A very important issue concerns psychiatric patients, who experience inequalities because of limited access to medical and health care for physical illness. For example, in Russia, the physical health of psychiatric patient is much worse than that of the general population, and their life expectancy is much shorter. Similar situations exist in the majority of the European countries.

Inequalities also exist between people suffering from different mental illnesses: for instance, in Malta, persons diagnosed with schizophrenia have free access to medicines, whilst people affected by other forms of mental illness do not.

In our view, there is now a very good body of extensive research on health inequalities across the EU, using life expectancy and healthy life years as indicators. Whilst ongoing research is still important, to explore in further depth specific aspects of health inequalities, we are now aware of the key socio-economic drivers. The emphasis on action at EU level should be to translate this evidence base into coherent policies that have 'health' as the centre piece but that also integrate key policies on social inclusion, social protection, employment, education and information society. This bedrock for this should be the Lisbon Strategy.

The Joint Report on Social Inclusion and Social Protection 2009 in its section on health inequalities describes the need 'to emphasise promotion and prevention over curative care'. EPF would strongly contest that this should not be an ' either/or' scenario.

The EU political agenda on health inequalities should not focus on prevention and health promotion - which is a broader citizens/ consumers agenda – to the detriment of chronic disease management and the needs of patients that have been diagnosed with a serious illness or condition, and their families.

For instance, in the field of mental health, the EU Mental Health Pact is an example of an effort to address mental health in a comprehensive way; however, the focus is on prevention and health promotion only. Chronic disease management does not feature in this Pact. Yet, prevention, health promotion and chronic disease management are intrinsically linked. Within the spectrum of 'health equity' of citizens, patients form a clear and distinct constituency. 'Health equity' in our terms can be equated with ' patient-centeredness'. Political and economic investment in maximising 'quality of life' and reducing the disease burden on individual patients will reap dividends, by enabling patients to be economically active for longer, and place less burden on healthcare budgets. This releases targeted resources to be invested in prevention and health promotion.

A fundamental change agent in relation to tackling health inequalities among patients with chronic diseases and their families is 'empowerment'. There are many dimensions to empowerment including health literacy, access to quality information, attitudinal and cultural barriers and opportunities, and the patient-centredness of the healthcare environment within specific communities.

The concepts of ' patient empowerment' , patient centredness, and health literacy should transcend all EU actions tackling health inequalities in relation to disease management.

EPF is of the view that there is a need to identify and highlight good practice emerging from Member States on how health inequalities are being addressed in relation to specific patient group populations affected by physical or mental illness, urban and rural environments and diverse cultural contexts. A mechanism is needed to ensure the critical success factors of pilot projects should then inspire ambitious, entrepreneurial policy and large scale projects. This echoes very much the discussions during the recent DG SANCO conference Delivering for Tomorrow's European Consumers.

What kind of indicators do you think would be necessary to better monitor the extent of Health Inequalities in the EU ?

A set of indicators in relation to health inequalities are being tested and developed in the context of the Open Method of Coordination on Social Inclusion, and EPF welcomes this very specific focus.

From a patients' perspective, key indicators monitoring health inequalities would also include:

- *appropriate access to screening*
- *appropriate access to early and safe diagnosis,*
- *appropriate access to necessary treatments, therapies and supports, and*
- *appropriate access to information that meet specific quality criteria*
- *appropriate attention for the 'whole picture': people affected by physical illness can also suffer from mental illness and vice versa. A holistic approach is needed*
- *appropriate access to advice in matters of civil liability or insufficient quality of care provided by carers or institutions.*

In addition to quantitative indicators, we believe it is vital to ensure a direct patients' perspective in EU monitoring of health inequalities to understand the psycho-social impacts of health inequalities on individual patients and their ability to interact with their healthcare environment and their quality of life. This is not an easy task, but crucial to move towards credible and truly patient-centred solutions.

It might also be useful to consider the creation of an Ombudsman in relation to health inequalities; this should be an independent person who should work at European level, but integrated with a network of representatives at national level. This could ensure proper reporting on health inequalities at national and European levels.

If you think monitoring and reporting needs improvement in this area, what kind of monitoring tools should be used?

As highlighted above, monitoring and reporting is crucial. Given the interdependence of health inequalities and social inclusion, the current strategy, to include health inequalities as a focus within the OMC on social inclusion should be evaluated and reinforced where necessary, in line with the outcomes of this consultation.

This approach must recognise however that the dynamic between healthcare and social care, that should be symbiotic, is often conflicting because of budgetary constraints and poor coordination. It will be of particular importance that concerted, measurable actions are identified that reflect the key findings and recommendations of the joint report in relation to health inequalities. A specific EU level mechanism and joint actions, that involve key stakeholders will be required for this (see below).

On scope of level of EU action/subsidiarity:

Do you think action at EU level could make a difference in addressing health inequalities? Why?

Health inequalities is a European-wide phenomenon, even in Member States where investment in healthcare is relatively high. A European response embracing different policy arenas is entirely appropriate, and covered by the EU Treaty. Article 152 states that a high level of human health protection shall be ensured in the definition and implementation of all Community policies and activities. It is further stated that Community action, which shall complement national policy shall be directed towards improving public health.... as well as health information and education.

There is proven added value in sharing information, exchanging good practice and peer review across Member States in terms of what works and what does not in policy terms and moving forward together towards better more coherent policy making.

With citizens' and work force mobility increasing across EU, it is crucial that there is a coordinated effort among Member States to address health inequalities and exchange information and evidence to put in place programmes that provide access to health care and necessary support to patients coming from disadvantaged and marginalised groups.

It is also relevant to highlight the positive impact effective action at EU level on tackling health inequalities could have on other regions of the worlds encountering similar and or more dramatic challenges.

How should relevant stakeholders be supported and engaged at EU level in tackling health inequalities?

Stakeholders should develop strategies to encourage those groups within their respective constituencies most vulnerable to health inequalities to be fully involved.

EPF as an organisation is acutely aware that we need to be more pro-active in involving marginalised groups within our membership.

Access to health information and knowledge systems is recognised widely as a major health quality and equity issue. Yet there exists a high incidence of exclusion of vulnerable patient groups to accessible information, and indeed to participation in patients' organisations. eTechnology can be very useful in this respect, but should not lead to 'information-haves and information-have nots' and create other forms of discrimination and exclusion.

As part of a comprehensive EU strategy on information to patients, EPF would like to see opportunities for patient organisations and other stakeholders providing health information and knowledge and good practice to and among patients from specific social groups such as young people, the older patients, migrants, ethnic minorities, those with low living standards or living in poverty, and other potentially discriminated groups (such as persons suffering from mental illness).

We also feel it is of utmost importance to ensure social inclusion policies are embedded in patient organisations through strong leadership, culture, policy and

good practice, that will enhance their representativeness, and their capacity to reflect the needs of all patients within their respective constituencies.

Many examples from the European Patients' Forum membership illustrate the urgency, diversity and complexity linked to achieving these objectives. Examples range, for instance, from:

- *the need for relevant supplementary nutritional information in an accessible, effective way to children diagnosed with diabetes from a poor background,*
- *the importance of translation and cultural adaptation of patient information leaflets and other materials in localities with a large migrant population with limited use of the indigenous language of the country;*
- *supporting patients and their carers on low incomes bound in a vicious circle, who as a consequence of ill health are vulnerable to poverty, that in turn affects the quality of that care,*
- *providing information to older patients and carers who may have visual or hearing impairments or other impairments that will affect their ability to access and deal with the information.*
- *transfer of tried and tested self help programmes from one country to another, for instance in areas such as osteoporosis, that include health literacy and life skills*

This list is far from exhaustive, but highlights the extent of the challenge in every EU Member State, regardless of the socio economic backdrop, which, if weak, can then heighten the vulnerability and potential marginalisation.

A potential initiative for the European Patients' Forum and its member organisations in the context of tackling health inequalities would be to adopt ***common principles and guidelines on good practice*** *in promoting social inclusion both in terms of organisational development, and access for vulnerable groups to information, and to develop a network for the implementation of mechanisms and tools to support each other, and in turn public authorities in promoting health inclusion of vulnerable patient groups. In this respect, we would again like to stress that patients need to be approached in a holistic way, and attention is needed both for physical as well as mental health and the ways these two impact on each other : integrated health care will help to tackle health inequalities.*

Patient organisations, and those working in the health, social and equity fields have a common agenda. By promoting and sharing increased information on good practice principles and guidelines, more effective synergies, and cooperation will develop between such organisations.

Ensuring that all patients get access to health information, lifestyle supports, and high quality prevention measures, treatments and services is not simply about improving health; it is also about restoring dignity, since physical or mental impacts of chronic disease often exacerbate the experience of being excluded and manifest themselves in deteriorating health.

At macro level we would suggest there is a need for the Social Platform and the EU Health Policy Forum to engage in regular dialogue focussing on health inequities.

Should there be a common commitment at EU level to reduce health inequalities for example by committing to common milestones and reduction targets? If yes, what do you think these milestones or targets should be (what variables? what extent?)?

This approach would have a strong political and advocacy appeal and it would be interesting to draw on the lessons learned, and indeed challenges in relation to architecture, implementation and impact of the Millenniums Development Goals.

What would be the right tools to ensure that common goals are achieved on national and EU level (reporting, benchmarking, OMC, etc)?

See above with regard to reporting and benchmarking, OMC. In addition to this there needs to be strong political commitment, through a forthcoming Presidency trio, where tackling health inequalities remains high on the agenda. More active involvement of the European Parliament and national Parliaments in the OMC process, for example, is also needed. This is particularly important in the context of the current economic crisis.

As a framework for mutual learning, exchanging experiences and good practice and particularly for stakeholders' involvement, OMC is a very good tool. However, there are still has important shortcomings and a great unexploited potential, as recently stated in SOLIDAR's Position on OMC.

To what degree can health inequalities be addressed through health policy? How?

EPF believes that the role of health policy is tackling health inequalities is fundamental. If we examine the current array of ' hard ' and 'soft' EU health policy instruments, there is a health inequalities dimension in all of these, that should be properly addressed in transposition / implementation.

Also pressing is the degree to which health policy impacts on broader equity policies tacking social exclusion and discrimination.

More specific to the patients' community at EU level, EPF has been calling for a concerted and comprehensive EU strategy on 'information to patients' and health literacy. The outcomes and recommendations of the our Health Literacy Conference addresses this in further detail (see annex I), as do the conclusions and recommendations of the Pharmaceutical Forum.

Which and to what extent should other policy areas, such as social policy, contribute to reducing health inequalities?

The rationale and importance of this has been outlined extensively in other parts of this response.

Possible Actions and impacts:

Given the current economic situation can you think of any immediate action that EU or Member States could take to avoid an increase of health inequalities in the short term?

An immediate step would be to ensure that there is a provision within all stability or rescue packages in which the EU is involved to make certain that current health budgets are not diminished AND there is particular focus on protection of vulnerable patients and citizens who have become even more vulnerable because of the economic crisis.

Another step would be to introduce a requirement that a percentage of Structural Funds should be allocated to addressing health inequalities and this should be reflected in Member States' operational programmes.

Do you believe that investments through structural funds could help to reduce health inequalities. If so, how and why?

Where do you think should future investments through structural funds be mainly spent to be effective for reducing health inequalities and what would be the expected impact of that spending?

Notwithstanding the proposal above, It is important to recognise that Structural Funds per se will never be the panacea to tackling health inequalities, but there is potential for these to be a springboard to showcase good practice in areas such as patient-centred infrastructure, enhanced training skills for health professionals to help dialogue with marginalised groups and to take a more holistic view of illness, to encourage health professionals from minority groups to become professional health educators

Structural funds also have an important role to play in relation to translating EU level commitments and soft instruments in to meaningful actions on the ground. As outlined above, many instruments have a clear and integral link with health inequities.

What in your opinion are other areas that EU and Member States should be encouraged to focus on to achieve a reduction of health inequalities ?

As outlined elsewhere in this response, EPF alongside other health NGOs would wish to see a comprehensive information to patients' strategy at EU level, to help reduce the significant inequalities in relation to access to information across the European Union, in which health literacy would form a key pillar.

An integrated and holistic approach to illness would also be needed.

In terms of the follow up to the Pharmaceutical Forum, we would also suggest that the issue of equity of access to treatment (medicines as well as other forms of therapy) should be remain high on the agenda. As the MS barometer indicates, there are huge and unjustifiable differences across the EU Member States.

To what extent would existing coordination and monitoring processes at EU level need to be improved to strengthen joint action on health inequalities.?

This question is addressed earlier in this response

What could be possible actions in other EU policy areas on health inequalities and what could be there impact?

This question is addressed earlier in this response

What shall be done by the EU in order to facilitate the exchange of experiences between Member States, regions and cities?

The allocation of greater resources to the public health programme and a specific and on-going strand in the work plan to encourage joint actions, projects and conferences

Specific focus on health inequalities at the next Open Health Forum.

How should EU policies be stream-lined in order to reach targeted beneficiaries in the best way? (Disadvantaged, women, migrants, children)

Experience from gender mainstreaming and disability mainstreaming in EU policy has demonstrated that in addition to ensuring systematic reference to specific beneficiaries in EU policy instruments, and including their participation as an eligibility critierion in programme work, there needs to be a structure in place that spearheads, and supports this actively and that 'proofs' proposed policies to ensure that they are not discriminatory.

To what extent do you think is the improvement of research capacities advantageous for fighting HI? Can you name any concrete examples?

As was highlighted before there has been extensive and very good research and analysis on the causal factors behind health inequalities, more emphasis is now needed on targeted research on 'pockets' of good practice and if and how this can best be replicated, taking on board diverse cultural and social contexts.

One arena which EPF would like to explore with the Commission, linked to the EU Health Literacy Network relates to the role of health literacy and its role in healthcare delivery and health outcomes, and also the impacts of health illiteracy (see annex I for the health literacy conference conclusions and recommendations).

ANNEX I

EPF Conference on Health Literacy
8 -9 April 2008

MAIN CONCLUSIONS AND RECOMMENDATIONS

This conference, a unique opportunity to address the theme of health literacy at EU level brought together 130 patient leaders, health policy makers and health stakeholders from throughout the European Union to explore health literacy, its importance and why and how this should be taken forward as a policy priority. A detailed report will be produced and the following brief document summarizes the main conclusions and recommendations emerging from the two days' discussions.

Main Conclusions

- Although there are different definitions of health literacy, common elements include skills, understanding, access, use of, information, knowledge, empowerment, decision-making. One definition that was taken up in the working groups was '*the ability to make sound health decisions in the context of everyday life at home, in the community, at the workplace, the health care system, the market place and the political arena*'[1]

- From a patient's perspective, the knowledge and competence gained through health literacy lead to the strength and empowerment needed to manage well a disease/condition and its impacts on quality of life.

- Health literacy is a right, and also a critical strategy to move towards health equity, empowerment and patient-centred healthcare in modern society. There are significant differences across EU Member States on how health literacy is perceived and prioritized.

- Improving health literacy skills of patients, citizens and health professionals should be achieved through strong partnerships involving all of the relevant stakeholders, including the European institutions. We need to 'mobilise actors and fuel momentum'. This echoes very much the spirit of the last EPF Spring Conference ' Moving forward together'.

- There is increasing recognition across the patient and healthcare community of the need to move from 'monologue' to dialogue between the patient and the healthcare provider, to have the opportunity to share decision making. Health literacy is a key driver for this to happen effectively.

- The dynamics of health literacy highlight the vulnerability of those patients and citizens who are not health literate and who are exposed to double inequities –

[1] This is the definition used by Prof. Kickbusch, WHO

first in relation to using health promotion information and advice on prevention, second in relation to acquiring the knowledge and the skills set to deal with a disease or illness.

- Patient organizations have a key advocacy role to play to ensure that health literacy is embedded as policy and programmatic priority in all EU member states; and ensuring ‘ quality’ health literacy and ‘ health literacy proofing’.

RECOMMENDATIONS

Collectively, all of these recommendations should be used to strengthen the ‘health literacy’ component of the EU Health Strategy – ‘ Together for Health’. The European Patients’ Forum is committed to contributing actively in taking forward these recommendations in partnership with the European Commission and other stakeholders.

- **Further Research**

  Further targeted research is required that explores and evaluates

  - the concept of health literacy and its role in healthcare and health outcomes, recognizing that current literature tends to focus only on reading ability and health.
  - patients’ challenges in navigating the health care system, that will enrich the understanding of health literacy.
  - the cost of health illiteracy
  - links and data collection on health literacy and inequality across Europe

  and identifies good practice and dissemination strategies.

- **A comprehensive EU project leading to an EU Health Literacy Network**

  The proposed EU Health Literacy Project currently limited to six countries should be given the political and financial resources to advance and extend its scope across the EU with minimal delay. The project should involve EPF and other patients’ organizations at EU and at national level and have an explicit link with the EU Health Strategy.

  One of the key deliverables of the project should be the setting up of an EU Health Literacy Network involving all interested stakeholders to benchmark, stimulate and promote good practice in health literacy.

- **Health Information and Information to Patients**

A wider distribution of 'information to patients' is needed that meets core quality criteria [2]

- A "guide" should be developed for information providers on how to make information user-friendly and usable to the average citizen.

- An EU "quality mark" initiative should be explored, based upon existing food labelling practices.

- The EU health portal should further be developed in order to provide approved information in all EU languages.

- NGOs should be able to seek funding from the Commission specifically to help them translate information on management of disease into a greater number of languages.

- Patients throughout the EU should have the right to access their medical records in an understandable and transparent format. E-health records should also be "owned' by and accessible to the patient him or herself.

Patient and Professionals Education and Productive Dialogue

An EU capacity building programme involving 'patient experts' should be set up. This should address education and training for health care providers on communications and shared decision-making and draw on current good practice in this area.

The European Commission should pilot an education module for health care providers on "productive dialogue with patients" that you must have studied and passed in order to be able to work across borders

- Patients' organizations should be provided adequate resources to carry out quality health literacy programmes with patients, particularly regarding the key questions to ask their healthcare providers, and getting the most out of their consultations.

- In this regard; the patients' own stories and anecdotes regarding their patients' journey should be recognized as a key resource.

Involvement of patients and their representative organisations

[2] The document on quality criteria was agreed in the framework of the Pharmaceutical Forum

- The meaningful involvement of patients should become a baseline performance indicator of health systems and *inter alia* the application of policies and programmes on health literacy.

- Patient groups and their allies should explore how 'patients rights' instruments can be used effectively in promoting health literacy, particularly among disadvantaged and marginalized groups.

- Patients organizations alongside other independent stakeholders also have a role in ensuring quality assurance linked to health literacy initiatives and 'health literacy proofing' healthcare and health information developments.

- Patient organizations across the EU should set up of a 'clearing house' to translate and adapt high quality information to patients and not re-invent the wheel

Political Momentum and Resources

- Health literacy should be part of a broader patients and citizens' information strategy that respects and optimizes what can be achieved at EU level and what can be achieved at national level.

- The EPF Patient Manifesto should encapsulate the broad patient perspective on health literacy and engage MEPs' and national parliamentarians' support.

- EU Institutions and Member States governments should 'institutionalize patients' empowerment, and through this commit to supporting and implementing health literacy policies and programmes

- Given the importance of supporting actions at regional level and local level, greater emphasis should be placed within the EU Structural Funds to resource health literacy interventions.