IAPO's Comments to EU
September 2004

International Alliance of
Patients' Organizations
A global voice for patients

Enabling Good Health for all

The International Alliance of Patients' Organizations (IAPO) welcomes this opportunity to comment on the reflection process for the new EU Health Strategy. IAPO strongly supports many aspects of the paper, 'Enabling Good Health for all', a number of which will be mentioned specifically in this response. Our primary comment is that it is essential to include all stakeholders in discussions of EU Health Policy, not just through open consultations such as this but also through inclusion in all relevant fora.

1. *The focus on other issues surrounding ill health such as poverty, social exclusion, healthcare access and on health promotion and disease prevention (p2) and the need to 'promote health through all policies' (p9)*
   Other issues, such as social, educational and psychological, are inseparable from discussions of healthcare and health is a vital part of all other issues because health is a component of quality of life. Social factors such as poverty affect health directly but they also affect health indirectly and we should work to increase overall quality of health and life and to decrease inequalities in health and healthcare which result from these related factors. This means that patients' organizations, among the other stakeholders, should be involved in, for example, research ethics committees, reimbursement committees and social security discussions.

2. *The need for different actors to work together across the EU (p3) and the focus on partnerships (p9)*
   As noted in the paper, openness (transparency) and civil society participation are now enshrined in the new Constitution. This commitment is commended but structures must also be in place to ensure involvement is not just offered but encouraged and facilitated and that means ensuring that structures to involve *all* interested stakeholders must be put in place for all sectors and policies.

   The participation of patients, through representation by patients' organizations is essential. While health promotion is relevant to all citizens, those with the most invested in healthcare itself are the chronically ill; patients with long-term chronic conditions have to find a way to live every day with a condition that affects all aspects of their life. Therefore, there must be a specific focus on patient involvement as well as public involvement.

   Patients' organizations have knowledge and expertise, concerning how chronic conditions affect a person's ability to live their life, embodied within their Governing Board and Staff. They can therefore effectively represent patients in healthcare policy arenas. They must be encouraged to do so, not just by open invitation, but by a commitment to address the barriers that exist to their involvement (these range from compensation for time and reimbursement for expenses to reasonable consultation times, appropriately presented information, training on medical, technical or ethical concepts where necessary and a sensitivity to the needs of patients' organization representatives who may be patients themselves).

3. *The need to provide European citizens with 'reliable and user friendly information about how to stay in good health and the effects of lifestyle on health' (p3)*
   This is vital, not just in health promotion but for all information. We know that many people do not understand health information and this is a major factor in, for example, adherence to therapies. All health information (whether it is public health promotion advertising, the patients' discussions with their doctor, or patient information leaflets) must consider different cultures, levels of understanding by following health literacy principles. IAPO's health literacy principles state that all information (whether written, pictoral or verbal) should have: a clear and understandable message; relevant and tailored content; culturally and linguistically appropriate format; reader, viewer or listener involvement; and pilot testing on key audiences. IAPO calls on all those involved in health to follow our guidelines. These are available online at www.patientsorganizations/policy.

4. *The need for the EU to empower citizens to make healthy choice and involve them in policy-making from the start (p4)*
   IAPO is working to promote patient-centred healthcare around the world. Since all decisions in health ultimately affect patients[1], we consider that they are the ones that should make the ultimate decision on their healthcare and to enable this to happen, the patients' voice must be heard at all levels of healthcare policymaking to ensure that policies, systems and the delivery of healthcare are all designed and implemented with the patients needs and preferences at their centre.

5. *The need to realise that health is a long-term investment rather than a short-term cost (pp4-6) and to facilitate dissemination of 'evidence on health's impact on economic growth and on the financial burden of ill health'*
   The cost to national economy of ill health and the benefits of a healthier population are not always fully considered when national governments consider their spending on health. To name just two benefits of a healthier nation: more people will be at work, resulting in less sick pay and an increase in national productivity improving the economy and secondly, preventing ill-health is more cost effective than treating ill-health.

6. *The need for the EU to take a key role in facilitating the dissemination of evidence on 'health's impact on economic growth and on the financial burden of ill health' (p7)*

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[1] To mention only a few: communication with your doctor; decisions on research funding for pharmaceutical innovation; reimbursement policies for medications; and the development of training curricula

The EU is in a good position to play a key role in the dissemination of information, facilitating the exchange of good practice, promoting collaboration activities and encouraging European countries to value healthcare and recognise the link between good health and economic gain. In addition to its role in assisting Europe, the EU has a responsibility to disseminate best practice outside of Europe; to consider the global perspective, partly, but not exclusively, because of issues that cross borders such as infectious diseases.

7. *The need to invest more on research (p9)*
   A larger budget for the 7th Framework programme is essential with a stronger focus on public-private partnerships to address the slowdown of pharmaceutical innovation; a vital industry for the economics of Europe but also for the health and wellbeing of its people who desperately need new safe and more effective medications more quickly. Patients must play a role in decision-making with full and accurate information. For example, they must have the opportunity to decide what potential risk versus potential benefit is suitable for them when participating in clinical trials or taking medications.

8. *The need to base EU Health Policy on solid grounds: facts, data and scientific evidence (p9)*
   This is true but patients' experiences and preferences must be given equal consideration. These can be gathered through patients' organizations and initiatives such as DIPEx).

If you require further information on any of the points highlighted in this document, please contact Jo Harkness by emailing policy@patientsorganizations.org or telephoning: +44 20 7721 7597.

The International Alliance of Patients' Organizations (IAPO) is a unique global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world. Our members are patients' organizations working at the local, national, regional and international levels to represent and support patients, their families and carers. A patient is a person with any chronic disease, illness, syndrome, impairment or disability.

IAPO's vision is that patients throughout the world are at the centre of healthcare.

IAPO's mission is to help build patient-centred healthcare worldwide by:

- Realizing active partnerships with patients' organizations, maximizing their impact through capacity building
- Advocating internationally with a strong patients' voice on relevant aspects of healthcare policy, with the aim of influencing international, regional and national health agendas and policies
- Building cross-sector alliances and working collaboratively with like-minded medical and health professionals, policy makers, academics, researchers and industry representatives

To find out more about IAPO and our activities, please visit our website at www.patientsorganizations.org.