

Priority Medicines Project – IAPO makes urgent plea for patient involvement

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The International Alliance of Patients' Organizations (IAPO) today urges the Dutch Government, in its Presidency of the European Union, to act upon its commitment to involve patients in research prioritization and to install concrete mechanisms for comprehensive patient involvement. In addition, IAPO challenges Luxembourg and the United Kingdom, in their role taking the Presidency in 2005, to ensure that these mechanisms are implemented and adhered to.

This request is made in response to the outcomes of a meeting in The Hague yesterday where the Dutch Government presented an agenda for the research and development of medicines, vaccines and biologicals. We congratulate the Dutch Government for focusing attention on this issue because, at present, too many patients do not have access to safe and effective medications to treat their conditions. It was important to see patients' organizations at this event along with industry, governmental and health professional representatives. However, while industry and academic research and governmental viewpoints were represented during presentations and a panel discussion, the patients' view was conspicuously absent, relegated to the short questions and answers session. Considering that there was an overwhelming consensus that patients must be involved in all discussions of research priorities and the innovation process – not just at the end but from the very beginning – we call on all stakeholders to make this a reality.

The recommendations presented during the Conference are from the Priority Medicines for Europe and the World Report, investigated by the World Health Organization. IAPO welcomes the report as an important step forward in attempting to address the medication needs of people around the world. The report's value lies in outlining a method of prioritization to address the gaps in the development of pharmaceuticals, for example for neglected diseases. Its focus on developing countries recognized the important responsibility of the European Union to the rest of the world. Its public health perspective provides a useful method to attain the greatest help to the greatest number of people. However, it is essential that a method for prioritization is developed which does not neglect those with rare diseases. Rare diseases, as their name suggests, only affect a small number of people and they are therefore not addressed by a public health perspective or by an industry that needs to develop products for a large enough potential market to offset the enormous cost of pharmaceutical development.

The Conference garnered momentum to discussion of how to improve research prioritization and the pharmaceutical innovation process. This momentum must be harnessed and the recommendations developed to the benefit of patients, industry, research and governments. The subsequent developments of this initiative must ensure that the commitment made at the Conference yesterday is not forgotten. Patients with long term chronic conditions and the organizations that effectively represent them – patients' organizations – must be involved in every step of the process – not just in treatment guidelines but in all health policy including regulatory processes, because ultimately the decisions that will be made will affect patients' lives.