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**EU Primary Immunodeficiency Consensus Conference**

**JA2015 - GPSD [705038]**

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<thead>
<tr>
<th><strong>START DATE:</strong></th>
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<tr>
<td><strong>END DATE:</strong></td>
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<tr>
<td><strong>DURATION:</strong></td>
<td>12 month(s)</td>
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<td><strong>CURRENT STATUS:</strong></td>
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<tr>
<td><strong>PROGRAMME TITLE:</strong></td>
<td>First Programme of Community action in the field of public health (2003-2008)</td>
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<td><strong>PROGRAMME PRIORITY:</strong></td>
<td>-</td>
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<td><strong>CALL:</strong></td>
<td>Health Information (Hi 2005)</td>
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<tr>
<td><strong>TOPIC:</strong></td>
<td>Developing mechanisms for the reporting and analysis of health issues and producing public health reports</td>
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<td><strong>EC CONTRIBUTION:</strong></td>
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<td><strong>KEYWORDS:</strong></td>
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<td><strong>PORTFOLIO:</strong></td>
<td>Major and chronic diseases</td>
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General objectives

The general objective of this project was the organisation of the EU Consensus Conference on the subject of Primary Immunodeficiencies (PIDs) with the participation of 100 experts and delegates in clinical immunology, PID care, public health, genetics, EU/national ministries of health and agencies, academic centres, public health laboratories, professional organisations and patient groups, in order to identify and develop public health strategies that can be applied to PIDs. The strategic objectives - use the meeting as the basis for wider recognition of PID as a public health issue in the EU, and to be the forum whereby European experts can outline a framework for a public health approach to PIDs. Results of this work are available for national policy makers, public health experts, researchers and the general public. This framework has the potential to become a public health model to other single-gene disorders.

Strategic relevance and contribution to the public health programme

Project strand - Health Information.
Contribution to the assessment of the public health impact of PIDs; review of data available for a PID public health assessment; review of inventories of sources and definition indicators for PIDs; review of how comparable epidemiological data can be developed at EU level; examination of public health interventions to prevent morbidity, disability, and mortality and to improve health outcomes; examination of uses of laboratory tests – particularly genetic tests - and their role in clinical practice; discussion on potential disease prevention public health interventions, including enhanced early clinical recognition, population-based screening, and education and outreach programmes to improve recognition and diagnosis and development of recommendations to increase co-operation between Member States on framework implementation.

Methods and means

To deliver the expected project results, a consensus methodology was employed by the project partners, lead by IPOPI, to reach agreement on all project aspects. A formal working group was developed, with integration of the objectives of the lead partner and the associated partners. As the lead partner for this project, IPOPI had the responsibility for the completion of the project according to the strategy. In particular IPOPI was responsible for: The set up and running of a partner working group, The development and execution of the conference itself, the conference website and the dissemination of conference outputs, The financial management and reporting, The fundraising needed to secure the outstanding 40% of the project fees.

The role of the working group was: Communication by teleconference on a monthly
basis, Co-ordinate input and participation from the relevant organisation`s members, Making of key decisions and provide expert advice regarding conference content, Being a part of a formal decision process to chose sub contractors, Taking responsibility for approving or “signing off” key project milestones, Taking a leading role at the conference itself. An online dialogue was created (through a website and access to online documents) to ease the flow of information and ensure that the working group are updated on project developments.

The website was managed by the lead partner, IPOPI, with added contribution from the associated partners.

Expected outcomes period

Work package 1: Coordination of the project WP 1 is linked to all 6 specific objectives in P.4.3 as project co-ordination will be essential to ensuring: The EU PID Consensus Conference is organised and takes place (objective 1) An agreed upon set of Conference recommendations is created (objective 2) A Conference website is developed (objective 3) The Conference recommendations are adequately disseminated (objective 4) WP 1 is also specifically linked to strategy implementation (objective 5) That evaluation activities are undertaken (objective 6) Work package 2: Dissemination of the results. WP 2 is linked to specific objectives 3 and 4 in P.4.3. Objective 3 related to the set up a conference web site states that one of the key objectives of the site is to be a medium to disseminate conference outputs. Objective 4 focuses on the dissemination of conference outputs to national health policy makers, public health officials, patient representatives, health professionals, the general public and scientific communities. It then details specific activities which are recorded as milestones in WP 2. Work package 3: Evaluation of the project WP 3 is linked to the 6th specific objective in P.4.3 as WP 3 focuses on evaluation of the project with specific reference to: The execution of the conference itself, The success of the conference web site, The geographical reach and quality of articles generated in the media, The publication of the conference outputs in a peer reviewed journal, The quality of the conference output materials
## COORDINATOR

IPOPI - International Patient Organisation for Primary Immunodeficiencies (IPOPI - International Patient Organisation for Primary Immunodeficiencies)

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United Kingdom

## PARTNERS

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<td></td>
<td>Europese Vereniging voor Immunodeficienties (European Society for Immunodeficiencies) (ESID)</td>
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Consensus statement, recommendations and report
IPOPI - International Patient Organisation for Primary Immunodeficiencies
EU Primary Immunodeficiency Consensus Conference (-)
Published on: 01/01/2006

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