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6th Global Patients Congress

JA2015 - GPSD [705038]

START DATE: 01/12/2013

END DATE: 01/06/2014

DURATION: 6 month(s)

CURRENT STATUS: Finalised

PROGRAMME TITLE: Second Programme of Community action in the Field of Health 2008-2013

PROGRAMME PRIORITY: -

CALL: Promote Health (Hp-2013)

TOPIC: IMPROVE CITIZEN'S HEALTH SECURITY (HS-2013)

EC CONTRIBUTION: 50000 EUR

KEYWORDS: Healthcare, Patients rights, Safety evaluation and monitoring

PORTFOLIO: Tissues and Cells

General objectives

The Congress will contribute to the IAPO Strategic Objectives set out in the Strategic Plan 2010-2014 (www.patientsorganizations.org/development) in the following ways:

Strategic Objective 1: Engagement

Participants understand the value of patient engagement

A wide range of healthcare stakeholders understand the role of patients in healthcare research

A wide range of healthcare stakeholders understand the role of patients in all types and phases of healthcare decision-making

IAPO highlights its policy positions according to policy strategy

Strategic Objective 2: Voice

IAPO Members highlight their priority issues and activities to a wide audience

Patient advocates feel supported by IAPO and more able to engage in international, regional and national decision-making and research processes

Key stakeholders consider that IAPO represents the global patients' voice

Strategic Objective 3: Member-led

Provide opportunities to involve IAPO Members in IAPO's work

Communicate to members the benefits of the opportunities available to them

Communicate developments in IAPO's work to members

Demonstrate the relevance and role of partnerships between patients' organizations

Demonstrate the relevance, value and role of networks between patients' organizations

Support exchange, learning and joint working between members towards patient-centred healthcare

Patients' organizations feel more able to articulate and advocate for patient-centred healthcare

Strategic Objective 4: Sustainability

Encourage patients' organizations to join IAPO

Communicate IAPO's value to members

Communicate what IAPO is doing on behalf of members and what impact it is having on them

Promote longer term commitments from donors

Encourage partnerships and support between organizations

Learning Outcomes

a) Develop the knowledge and understanding amongst patients' organizations on current healthcare issues such as counterfeit medicines, non-communicable diseases and health technology assessment amongst others

b) Develop the capacity of patients' organizations to promote patient-centred healthcare and influence the decisions that affect them at the local, national, regional and international level

Networking Outcomes

- c) Develop new and strengthen existing patients' organizations networks so that they can have a strong unified voice
- d) Provide ongoing support and opportunities through IAPO to contribute to the global patients voice in key meetings and policy consultations, and through ongoing capacity support and resources
- e) Develop networks and initiate working relationships between patients' organizations and other healthcare stakeholders (policy makers, health professionals, industry representatives and academics/researchers)
- f) Raise the profile of IAPO with healthcare stakeholders

Expected achievements

IAPO expects approximately 200 participants at the Congress. The majority of participants will be patient representatives from IAPO member patients' organizations, however, IAPO's mission cannot be achieved without the support of various healthcare stakeholders. The Congress is a forum for sharing and discussing the work of patients' organizations, the needs of patients and the role of all stakeholders in meeting those needs. In the spirit of collaboration the Congress structure and activities will create a collegiate atmosphere. The following stakeholders will participate in the event: IAPO Members, other patients' organizations, patients, academics, healthcare professionals, healthcare professional organizations, multilateral IGOs (e.g. UN, WHO, World Bank etc.), healthcare industry (e.g. pharmaceutical, insurance, medical devices etc.), national governments and non-governmental organizations. This will include representatives from the European Commission, WHO EURO and the health professional associations from across the EU.

The following is a list of countries and number of IAPO member patient representatives based there. All members will be encouraged to attend. A bursary scheme will operate to support the attendance of members who are unable to cover their travel and accommodation.

Members per country - EU (26 countries represented):

Austria: 1, Belgium: 4, Bulgaria: 6, Cyprus: 4, Denmark: 1, Czech Republic: 3, Estonia: 1, Finland: 1, France: 1, Georgia: 1, Germany: 2, Greece: 1, Hungary: 3, Ireland: 3, Italy: 2, Lithuania: 1, Macedonia (The former Yugoslav Republic of): 1; Netherlands: 5, Poland: 4, Portugal: 2, Romania: 2, Slovakia: 2, Slovenia: 3, Spain: 14, Sweden: 1, United Kingdom: 29,

Members per country RoW:

Afghanistan: 2, Argentina: 5, Australia: 10, Cameroon: 1, Canada: 10, China: 3, Croatia: 2, Egypt: 1, El Salvador: 1, Ghana: 1, Guatemala: 2, India: 1, Israel: 1, Japan: 6, Liberia: 1, Malawi: 2, Morocco: 1, New Zealand: 2, Nigeria: 8, Pakistan: 5, Peru: 2, Philippines: 1, Russian Federation: 1, South Africa: 2, Sri Lanka: 1, Taiwan: 2, Thailand: 1, Turkey: 2, Uganda: 9, Ukraine: 1, USA: 18, Venezuela: 1, Zambia: 1, Zimbabwe: 1

Members by WHO region

Africa: 27, Europe: 105, Americas: 41, South-East Asia: 4, Western Pacific: 23,

Target audience

Below is a breakdown of the target participants at the Congress, please see section 4.7 for further explanation of the European dimension of the target participants.

IAPO member patients' organizations and other, non-member, patients' organizations – 60%
Policy-makers – 10%
Healthcare professionals – 10%
Healthcare industry representatives (e.g. pharmaceutical, medical device and insurance organizations) – 10%
Academics – 7%
Other (inc civil society) – 3%

IAPO is committed to broadening the participation of patients' organizations from all over the world at the Congress. The bursary scheme is designed to assist with the attendance of a representative of an IAPO member organization that would not otherwise be represented at the Congress due to cost. Bursaries will primarily be awarded on a response to the following:

- Motivation – Interest in attending Congress.
- Engagement – Involvement in developing, delivering or supporting Congress.
- Inclusion – Understanding of how participation will ensure this is a diverse and inclusive event.

IAPO also has a dedicated a small amount of budget to cover some of the costs of expert speakers, should they be unable to cover their own expenses.

Conference programme

The 6th Global Patients Congress programme will be designed to stimulate discussion, challenge pre-existing conceptions and demonstrate the value of patient-centred healthcare across a range of healthcare issues facing millions of patients worldwide. During the Congress there will be a focus on the steps of the journey from values to actions. This journey will be explored in three different contexts, each with a parallel session stream, which reflect at a basic level the different perspectives that healthcare can be examined from.

There will be a series of plenaries and workshops which will explore a range of topics. The broad focus will be on access to healthcare and addressing inequalities. Workshop topics will include: Health systems strengthening - how have patients been involved, sharing models of patient-centred practice; Universal health coverage – how is it being implemented in resource poor settings; Role of the patient in healthcare – models of patient empowerment; Patient Safety – exploring how to build on patient involvement in patient safety e.g. IAPO's work with WHO Patient Safety and delivering patient-centred healthcare under resource constraints. The programme will explore the current legislative proposals from a European and global perspective and look at the frameworks and statements that health professional associations use that outline patient-centred practice. The programme will also look at how to promote

these tools and look at the tools available that help patients take control of their care, manage their conditions effectively and get the right care for example scorecards and checklists.

The Congress will also include a capacity building programme to offer participants the opportunity to build their skills in organizational development; specifically in the areas of advocacy, communications, fundraising and partnership building. The programme will take an interactive workshop format with best practice case studies from patients' organizations from both Europe and other world regions and representing different disease areas. Case studies will provide information and tools on how patient advocates have successfully raised funds, advocated, built collaborations or mobilized support for projects related to the Congress them; to include health systems strengthening, universal health coverage, patient empowerment and patient safety. Case studies will be delivered through a range of interviews, panels and informal presentations, followed by interactive discussion and action planning. Participants will be facilitated to develop an action plan for either advocacy, communications, fundraising, or partnership building on a specific areas related to their current priorities.

Following the action planning the programme will move into an "open space" where participants will be invited to put forward and host a conversation based on the morning's workshops. Trends from previous discussions will be identified to assist participants in developing discussion questions or themes, however, participants are free to choose a subject as they wish and the space is entirely open. The open space will draw to a close with participants coming together for feedback and identification of where the outcomes of their discussions might take them. Participants will come away from the capacity building programme with best practice case studies, contacts, action plans, guidelines and tools to support their organization's mission. These outcomes will also support the development of IAPO's capacity building programme and online resource library.

Enclosed you will find the 6th Global Patients Congress Draft Programme, and the report and the handbook for the 5th Global Patients Congress held in London in 2012.

COORDINATOR



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PARTNERS

No partners related to the current project

D01 - Gantt Chart (EN)

International Alliance of Patients' Organizations

6th Global Patients Congress (IAPO Congress)

Published on: 01/12/2013

http://persond.cc.cec.eu.int:8082/publications/20134202/20134202_d01-00_en_ps.pdf

D02 - Congress Budget (EN)

International Alliance of Patients' Organizations

6th Global Patients Congress (IAPO Congress)

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http://persond.cc.cec.eu.int:8082/publications/20134202/20134202_d02-00_en_is.pdf

D03 - Preliminary Programme (EN)

International Alliance of Patients' Organizations

6th Global Patients Congress (IAPO Congress)

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http://persond.cc.cec.eu.int:8082/publications/20134202/20134202_d03-00_en_ps.pdf

D04 - Congress Sponsorship Prospectus (EN)

International Alliance of Patients' Organizations

6th Global Patients Congress (IAPO Congress)

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http://persond.cc.cec.eu.int:8082/publications/20134202/20134202_d04-00_en_ps.pdf

D05 - Congress handbook and set of tools/materials provided (EN)

International Alliance of Patients' Organizations

6th Global Patients Congress (IAPO Congress)

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http://persond.cc.cec.eu.int:8082/publications/20134202/20134202_d05-00_en_ps.pdf

D06 - Social media transcript (EN)

International Alliance of Patients' Organizations

6th Global Patients Congress (IAPO Congress)

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http://persond.cc.cec.eu.int:8082/publications/20134202/20134202_d06-02_en_ps_healthcare_social_media_transcript.pdf

D06-01 Website (EN)

International Alliance of Patients' Organizations

6th Global Patients Congress (IAPO Congress)

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<http://iapo.org.uk/6th-global-patients-congress>

D07 - Patients' organization action plans (EN)

International Alliance of Patients' Organizations

6th Global Patients Congress (IAPO Congress)

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http://persond.cc.cec.eu.int:8082/publications/20134202/20134202_d07-00_en_ps.pdf

D08 - Congress presentations (EN)

International Alliance of Patients' Organizations

6th Global Patients Congress (IAPO Congress)

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http://persond.cc.cec.eu.int:8082/publications/20134202/20134202_d08-00_en_pscompilation.pdf

D09 - Congress Evaluation Report (M5) and final technical and financial reports (M6). (EN)

International Alliance of Patients' Organizations

6th Global Patients Congress (IAPO Congress)

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http://persond.cc.cec.eu.int:8082/publications/20134202/20134202_d09-00_en_is.pdf

D10 - Final report assessing key outcomes of the meeting and making recommendations for future work (EN)

International Alliance of Patients' Organizations

6th Global Patients Congress (IAPO Congress)

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http://persond.cc.cec.eu.int:8082/publications/20134202/20134202_d10-00

Final report (EN)

International Alliance of Patients' Organizations

6th Global Patients Congress (IAPO Congress)

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http://persond.cc.cec.eu.int:8082/publications/20134202/20134202_d10-00_en_ps1.pdf