

# 7th Global Patients Congress

9-11 April 2016



Selsdon Park Hotel, South London, UK • [www.globalpatientscongress.org](http://www.globalpatientscongress.org) #GPC2016

**Patient involvement in research:  
Innovation in the drug development  
and access pathways**

## Welcome!

- **12:00** - Note taking and feedback
- **12:05** - Introduction of theme
- **12:10** - Presentations (10 minutes each)
- **12:50** - Q&A and discussion (30 mins)
- **13:20** - Discussion on the key points to share
- **13:30** - Workshop ends

## Discussion points: The role of patients

- **Innovation:** What can be considered innovative in terms of patient involvement in research?
- **Success:** Are there successful examples of patient involvement in research? What makes them successful?
- **Collaboration:** What conditions need to be met if stable and fruitful collaboration between patients and other stakeholders is to be established?

# 7th Global Patients Congress

9-11 April 2016



International Alliance of  
Patients' Organizations

A global voice for patients

Selsdon Park Hotel, South London, UK • [www.globalpatientscongress.org](http://www.globalpatientscongress.org) #GPC2016

## The role of patients in research

**Alison Lightbourne**

Policy Manager, International Alliance of Patients' Organizations

## The role of IAPO in research

- Adequately exploring and considering acceptability by patients on how to develop research can benefit all of the stakeholders involved in the research process
- Because patients have unique needs, preference and values, they can identify issues and provide perspectives that may be underestimated by other stakeholders.
- By taking into account patients' preferences, researchers can gather important data whereby they can refine recruitment strategies and better motivate patients to participate in research.



**However, the contribution patients can make is not always acknowledged**





## IAPO'S involvement in GetReal

### Key Areas:

- **Impact:** To gain an understanding of patients' experiences of and in clinical trials and to identify Identification of the key challenges facing patients when taking part in clinical trials and how a more "pragmatic" approach can contribute to tackling these challenges.
- **Acceptability:** To explore patients' acceptability of research designs, RW data sources, and design options. Acceptability to be determined by jointly exploring patients' actual experiences as well as perspectives and views by patients regardless of their active involvement in effectiveness research.
- **Usefulness:** To understand "what matters to patients" when taking part in comparative effectiveness research, what motivates patients to take part in clinical trials, how they feel the impact they make could be strengthened.