

# Risks and Benefits II – The European Perspective

Deliberative Workshop in Dublin, May 2013

## Background

Genetic Alliance UK are working in partnership with Professor Marcus Longley and Amy Simpson at the Welsh Institute for Health and Social Care (WIHSC) at the University of Glamorgan to deliver a second *Risks and Benefits* project. This work is designed to ensure that patients' perspectives on the risks and benefits of new medicines are understood and valued as part of the regulatory process.

The first *Risks and Benefits* project (2010-11) was set in the UK and based on a Citizens' Jury model, and worked with patients to explore how they perceives the balance between the risks and the benefits of new medicines. The jurors argued that the current regulatory system does not meet the needs of those with rare and/or serious illnesses. They made a case for a more permissive regime, which gives greater weight to a range of psycho-social factors, and would allow individual patients greater opportunity and support to make complex decisions about their therapy for themselves.

*Risks and Benefits II* is a 15-month project (Dec 2012 - Feb 2014), which aims to explore similar issues in the European context, and develop recommendations for relevant bodies across Europe. Using an online survey, the original project findings will be validated against groups of patients and families in Europe, in order to test their meaning and importance more widely. In addition, two workshops will be held in Dublin and Amsterdam – working with small groups of non-UK patients and families to explore the issues.

## Deliberative Workshop in Dublin

### Provisional Details

- For 15-20 patients with a rare and/or serious medical condition (or family members/carers)
- All participants will be from the Republic of Ireland – Patients and/carers from Northern Ireland will be given the opportunity to participate via the Europe-wide survey later this year
- To be held on in May 2013. Details TBC following discussions with potential participants
- The workshop will be prepared for and facilitated by WIHSC – no IPPOSI staff are required (but would be very welcome to attend should they so wish)
- IPPOSI will source a free venue in the Dublin area for the workshop (European Union House?)
- There is a total budget of 1200 euros to pay for participant travel expenses and/or catering

### Recruitment Process

1. WIHSC will develop the recruitment material for distribution on websites and in newsletters.
2. IPPOSI will distribute the material from February to relevant contacts and networks in Ireland.
3. IPPOSI and WIHSC contact details will be provided on the advertisements if individuals wish to get further information about the project or the event.
4. All individuals who are interested in taking part in the workshop will be asked to contact Karen Munnelly.

5. Colleagues at WIHSC and IPPOSI will review the recruitment process in March.
6. WIHSC will work with IPPOSI to select the workshop participants, to ensure, as far as possible, that the group is balanced and diverse.

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