



## Cancer Patient Advocacy Networks driving research ESMO workshop 2016

**5-7<sup>th</sup> February 2016, Brussels**

### Programme

**Friday, 5<sup>th</sup> February**

**16.00- 18.00**

Welcome and Introduction- meet the other workshop participants  
Introduction to the workshop: patient networks and research

**19.00**

**Dinner (details TBD)**

**Saturday, 6<sup>th</sup> February**

**Saturday morning: Leveraging the potential of your Patient Network.**

**Saturday morning  
Social networks**

**8.30- 10.00**

**Session 1- Networks**

What do social networks look like and how can they be leveraged to generate data?

- 1.1 Social media and networks
- 1.2 Collective intelligence- the power of social networks
- 1.3. CrowdScience

**10.00- 10.30**

**Coffee**

**10.30- 12.00**

**Session 2- Mapping**

Why map, how to do it and how to use the data for action.

- 2.1 Mapping access to treatments
- 2.2 How to map- the missing drug example
- 2.3 Turning mapping into advocacy action

**Discussion**

**12.30- 13.30**

**Lunch**



## **Saturday afternoon**

### **Turning anecdotes into Evidence.**

Using Social networks to generate good qualitative evidence

**14.00- 15.45**

#### **Session 4- From anecdotes to evidence**

- 4.1 Overview over social science tools for patient advocates
- 4.2 Direct reporting of side effects by patients and why it matters- the experience of the Uppsala Monitoring Center.
- 4.3 CML adherence study- lessons learned. CML network
- 4.4 How to establish mutually beneficial research collaborations

**15.45- 16.15**

**Coffee**

**16.15- 17.15**

#### **Session 5- generating evidence for regulators**

- 5.1 How does the EMA involve patients?
- 5.2 Which type of evidence would regulators find useful

**17.15- 18.15**

#### **Session 6- generating evidence for HTA**

- 6.1 Decision-making in HTA processes.
- 6.2 What type of evidence are HTA bodies looking for?

**18.15- 19.00**

**Discussion** with panel - what can we do to ensure better patient input (e.g. how do we identify the right patients? What type of data is helpful? What do we need to understand about social networks?)

**20.00**

**Dinner (venue TBD)**

## **Sunday**

**Subjects no more.**

### **Patient networks and clinical research.**

**8.30- 10.00**

#### **Session 6- what to study and how to get started**

- 6.1 Research priority setting. James Lind Alliance
- 6.2 Clinical research benefiting patients.
- 6.3 Data- what patient advocates should know. eTRIKS?



**10.00- 10.30**

**Coffee**

**10.30- 12.00**

**Session 7- clinical trials**

7.1 Driving your own clinical trial.

7.2 Patient involvement in clinical trial design- the ECAB example.

7.3 Fostering academic clinical research in Europe- the CAREFOR initiative.

**12.00- 13.00**

**Session 8- discussion: where are we heading?**

Action points, Workshop summary and Closure

**Lunch and departure**

**Links**

**CrowdScience**

<http://www.sciencedirect.com/science/article/pii/S0048733313001212>

[https://en.wikipedia.org/wiki/Citizen\\_science](https://en.wikipedia.org/wiki/Citizen_science)