Patient Advocacy Networks driving research ESMO 2016

5-7th February 2016
Brussels

FIRST DRAFT- times rough indications

Motivation and aims

Patient advocacy networks increasingly discover the need and their potential for not only participating in but actually driving research. The aim of this weekend workshop is to look at the potential of patient networks, different types of research patient networks can drive and what it takes to do this successfully, in addition to the opportunity for networking and exchange between cancer umbrella groups

Learning objectives

- the concept of social networks, their potential and how to leverage it
- what does good qualitative Evidence look like?
- how can patient networks drive clinical research in Europe?

Format

Weekend workshop (Friday evening till Sunday afternoon) for 35 European cancer patient advocates, 5th- 7th February in Brussels. Location TBC

Program

Friday, 5th February

16.00- 18.00
Welcome and Introduction- meet the other workshop participants 1.5 h
Introduction to the workshop: patient networks and research
B. Ryll, ESMO-PAWG 30 min

19.00

Dinner

Saturday, 6th February

Saturday morning:
Leveraging the potential of your Patient Network.

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. NESTA.
1.3. CrowdScience

10.00- 10.30
Coffee

10.30- 12.00
Session 2- Learning by Listening
How do we learn from networks?

2.1 'Listening in on patient networks' – Hans had suggested a speaker at some point
2.2 collecting patient input via apps
2.3 Successful advocacy example

12.30- 13.30
Lunch

Saturday afternoon:
Turning anecdotes into Evidence.
Why it matters and what patient networks can learn from the Social Sciences to generate good qualitative Evidence.

14.00- 15.30
Session 4- from anecdotes to evidence
4.1 Overview over social science tools for patient advocates- speaker?
4.2 Direct reporting of side effects by patients and why it matters- the experience of the Uppsala Monitoring Center.
Rebecca Chandler, UMC TBC

15.30- 16.00
Coffee

16.00- 17.30
Session 5- generating evidence for regulators
5.1 How does the EMA involve patients? F. Pignatti, EMA
5.2 Which type of evidence would regulators find useful- example of the R/B project.
5.3 Discussion- what can we do to ensure better patient input (e.g. how do we identify the right patients?)

17.30- 19.00
Session 6- generating evidence for HTA
6.1 Decision-making in HTA processes.
6.2 What type of evidence are HTA bodies looking for?
6.3 A successful advocacy example
6.4 Discussion-

Something else- encourage exchange and sharing of knowledge- maybe poster session on research projects networks have conducted, together with a reception?

20.00
Dinner

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- Kathy Oliver TBC
6.2 How to establish mutually beneficial research collaborations. BR
6.3 CML adherence study- lessons learned. CML network- Jan Geissler TBC

10.00- 10.30
Coffee

10.30- 12.00
Session 7- examples
7.1 Driving your own clinical trial. Myeloma UK- Eric Low TBC
7.2 Fostering academic research in Europe- CAREFOR. Rolf Stahel TBC

7.3 Teaching the next generation of oncologists- the FLIMS/ Zeist workshop. Stefan Slijfer TBC

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