



# Return on engagement: from the perspective of patients, industry, regulators, HTA, research, policy makers.

**Dominique Hamerlijnck EUPATI Fellow, patient advocate**  
**IMI Stakeholder meeting**  
**19 October 2017**



# Conflict of interest



- Patient advocate
- EUPATI fellow

No conflicts of interest to declare.

# Taking a journey together



- Engagement
- Examples
- Challenges
- Working together

# What is engagement about?



Adding other knowledge, information to your own knowledge and information and giving value to that knowledge and information – adding context.

Contextualising: looking outside of the science to the real world stories  
That is where patients, their family, their caregivers are the expert.

This asks for open mindedness, willingness to start a conversation.  
Cooperation, two sided.

# Patient involvement and engagement has development over the last decades



The past decades:

- Personal health decisions
- Health care delivery and policy making
- Development of clinical guidelines
- Development of care guidelines
- Market access of medicines and medical devices (EMA)

The inclusion of patients has resulted in positive effects.

# New development in patient involvement and engagement



New developments:

- Health related research
- HTA
- Ethics
- Reimbursement decisions
- Research priority setting
- Research study design
- Trial conduct
- Analysis of results and knowledge dissemination
- Etc.

New validation that the knowledge patients adds to the scientific reality.  
The wealth of knowledge of living with the condition.

# Validation of patient knowledge



- Understanding and valuing this experience based knowledge.
- Increasing value and trust in research
- Patients challenge the assumptions of the researchers
- Will help align the research with the needs of the patient
- Increase transparency and trust in research
- Lead to research with a greater impact on the care of patients.

Fits in with the development of new clinical trials, simpler, pragmatic, better reflecting realistic patient care.

# Health research & policy is changing at a fast pace

## Innovation transforms the lives of patients with serious, lifelong conditions:

- Molecular targets/pathways
- Genome sequencing,
- Translational research
- Personalized medicine
  - Small trial populations
  - Biomarkers, companion diagnostics
- Need for post-marketing data
- Health Technology Assessment, QoL, endpoints, comparators



## Window of opportunity

- trial design
- relationship between researchers, regulators, industry, patients



# Examples

- Example 1: asthma spacers



# Example 2:

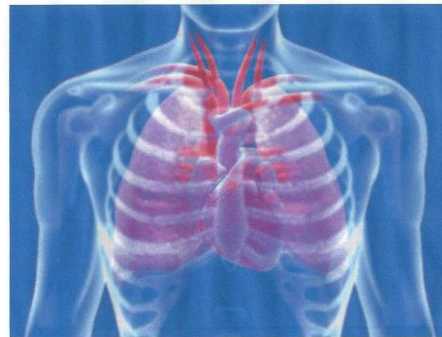
- inhalers



# Example 3

- Research agenda

Programmering wetenschappelijk onderzoek astma  
en COPD 2005-2008:  
'De maatschappelijke agenda'



J. Teerling  
J. F. Caron-Flinterman  
J. E.W. Broerse

Juni 2004



# Example 4



## EATG (European Aids Treatment Group) model

- Patients from 47 countries working together
- Development of the civil society response to the HIV/AIDS epidemic
- Represents and defends treatment-related interests of people living with HIV/AIDS
- Treatment literacy and treatment advocacy
- Treatment availability, affordability and accessibility



# Example 5

## ■ Engagement in HTA

A methodological framework for  
developing the structure of Public  
Health economic models

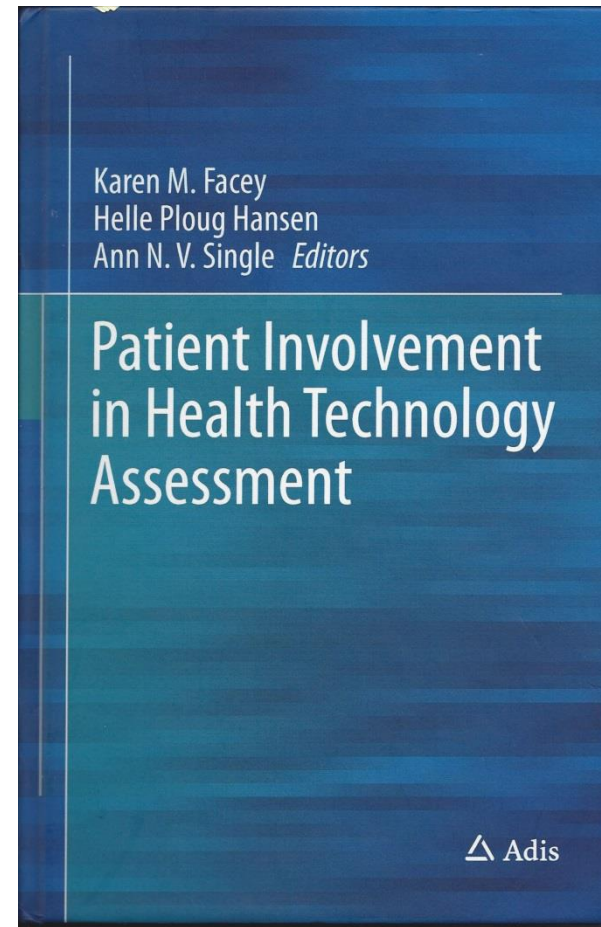
Hazel Squires

Thesis submitted for the degree of Doctor of Philosophy  
Supervised by Professor Ron Akehurst, Professor Jim Chilcott  
and Dr Jennifer Burr

January 2014



Health Economics and Decision Science



# Example 6

- Patients improved multiple sclerosis care in Italy
- At the recent Neurology Society conference this project won the Merck Prize for Neurology



# Patients as partners.

- New partnerships with industry, regulators, HTA, researchers, policy makers:
  - It will not happen overnight.
  - What can we do?
  - Training required: not just for patients
  - Working together: cooperation, co-production, co-creation, mutual understanding

# Cooperation, co-creation, mutual understanding



- Engaging new partners means:
  - Allowing others with different backgrounds and perspective to look at you work/practice
  - listening
  - think about what their questions mean for your practice
  - learn from each other
  - be willing to look at your work/practice critically
  - create mutual understanding of what you are working on.
  
- What happens if we don't engage with patients?



Thank you for your attention.

Questions?



~~WISH~~ Do



**Web:**

[www.eupati.eu](http://www.eupati.eu)

**Twitter:** @eupatients

as well as:



# The role of science and technology is changing what we know and can do dramatically



- All aspects of our lives are influenced by developments in science and technology.
- How can we use science and technology to improve lives? Adding knowledge on the real situation to the scientific knowledge will become more and more important. Better contextual knowledge.
- Patients as the go between, the linking pin between science and technology development with their contextual knowledge.
- Relating is (the next) key to innovating.

# EUPATI empowers patients with education in key areas of medicines R&D



Educate and train patients and patient advocates with objective, credible, correct and up-to-date information about:

1. Discovery of Medicines & Planning of Medicine Development
2. Non-Clinical Testing and Pharmaceutical Development
3. Exploratory and Confirmatory Clinical Development
4. Clinical Trials
5. Regulatory Affairs, Medicinal Product Safety, Pharmacovigilance and Pharmaco-epidemiology
6. HTA principles and practices

+ Patients' roles and responsibilities

# Patient involvement in medicines R&D

