

Patient participation

1. Does it help to make better choices?
2. How much influence do you give patients?
3. How do you organize it?
4. Side effects?

Better choices (1)?

Patient perspective is different:

- Patients needs met?
- Risks?
- Time consuming?
- Invasive?
- (Privacy/ethics?)
- Patients involved?

Better choices (2)?

1. Patients do want to make a good judgement
2. Scientific knowledge is limited
3. **All necessary information for patients must be written down in the lay summary**
4. It is hard for scientists to

Better choices (3)

I believe better choices can be made if applicants write lay summaries extended with format patients have to answer.

Epilepsy panel

- 14 project proposals
- Panel: 2 patients/1 parent
- Letter to ZonMw:
 - Time consuming 45 min. per proposal
 - Because lay summary did not answers questions patients were supposed to answer
 - So proposals had to be studied in English
- Suggestion: patient evaluation form sent to applicants/ better put it in the call

Influence patients

- Judgement scientific board and patient panel in TR1 equally important
- Selection round 2 made by scientific board
- Definite selection:
Cofunding health fund decides on judgement of scientific board and patient panel

Worked out well.

Epilepsy panel

- 14 pre-proposals judged by panel
- Scientific board decided 3 pre-proposals to be worked out in definite full proposal
- Patient panel judged these full proposals
- Scientific board and patient panel choose same project
→ taken over by Dutch Epilepsy Fund

Organisation?

- Dutch Epilepsy Fund has contacts with patients
- 14 pre-proposals were read (7 hours)
- Working dinner (pre-proposals (4 hours)
- Telephone conference (full proposals 1 hour)
- Pretty time consuming for selection of 1 full proposal

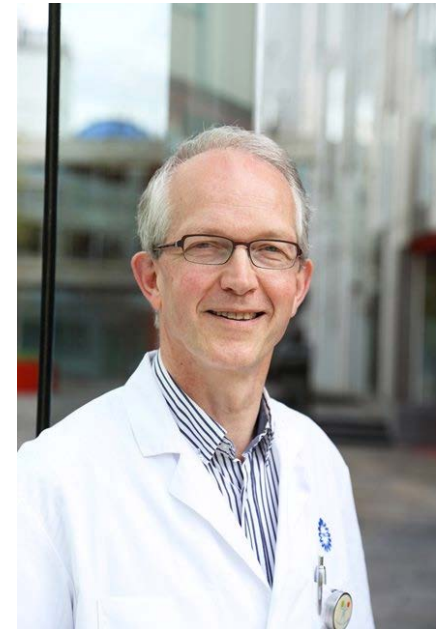
Side effects (1)

GRANT FOR FRANS LEIJTEN AND GEERTJAN HUISKAMP UMC UTRECHT

Tuesday 10 June 2014

Frans Leijten and Geertjan Huiskamp, both from the dept. Neurology & Neurosurgery, have received a grant from NWO.

The grant has been awarded by ZonMW Translational Research and Dutch Epilepsy Fund for the grant entitled: From computational models of epilepsy to clinical protocols.



Side effects (2)



Patient stories:

Naomi

Dagmar

Tamara

Doctor's story:

Frans Leijten

