

First experiences with the POWER model

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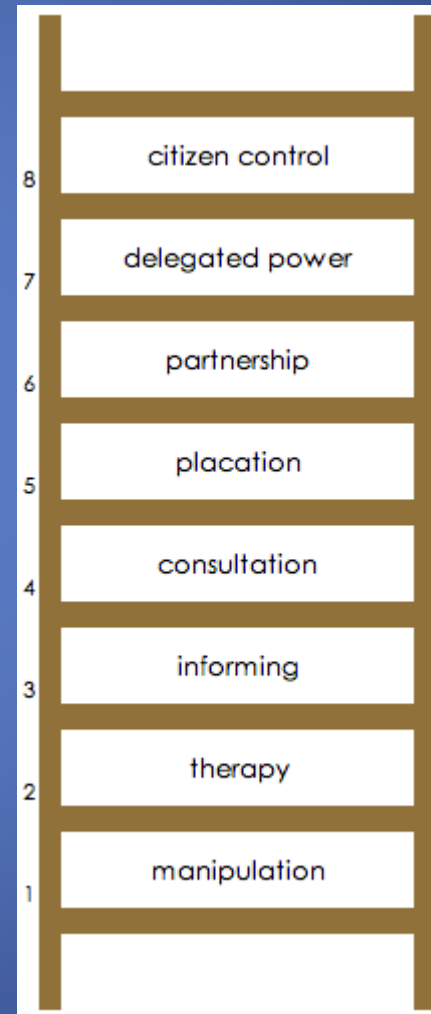


POWER model:

- **P**atient participation in **O**utcome measure **WE**ighting for **R**are diseases
- A model for researchers to involve patient representatives in trial design:
 - setting the right circumstances for an equal discussion
 - choosing and prioritizing outcome measures

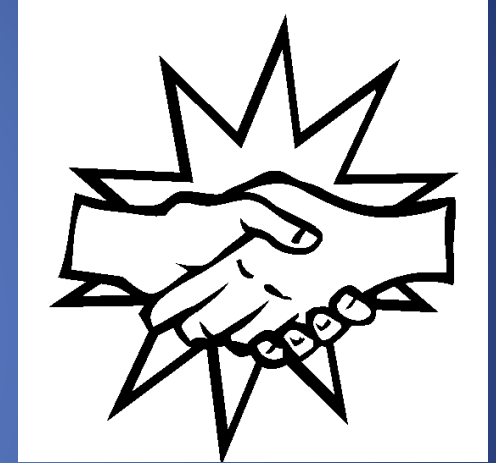
Models as a basis:

- FIRST model
(Hewlett et al., 2006)
- Dialogue model
(Elberse et al., 2012)
- Evaluation framework
(Rowe & Frewer, 2000)
- Participation ladder
(Arnstein, 1969)



The POWER model has 4 steps:

1. Creating the right circumstances
2. Preparing the consultation
3. Consultation phase
4. Follow-up



In the consultation phase, patient representatives and other stakeholders discuss the prioritization of outcome measures as equal partners

Evaluation in SPACE trial

SPACE trial: efficacy of pyridostigmine in Spinal Muscular Atrophy (SMA) patients
(January – December 2017)

Focus group with 3 trial participants:

- Discussion on outcome measures
- Consensus round
- Evaluation of POWER-model

Evaluation of POWER-model

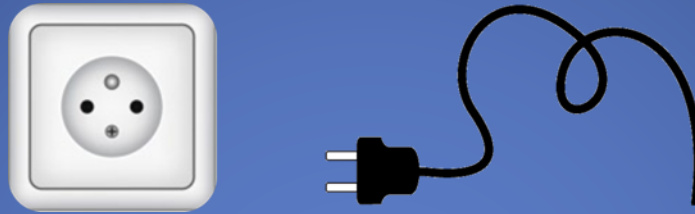


Evaluation of POWER-model

- Stop the progress of the disease
- Increase strength
- Fatigue

5 hours was only just enough!

*Patients and researchers were happy with the model,
patients felt that they were heard*



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Thank you for your attention!

