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Working for people living with brain disorders

The added value of patient partnership to ND research

Patients and researchers may view things differently...



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Knowledge

- Through experience
- Personal
- Complementary
- Don't waste it

Experiential knowledge



Learned knowledge



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Added value:

Relevance of research question

Significance of research

Prioritisation of research



Target resource

Generate a research agenda for the future



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Full partners in the research process

- Protocol design - what has been missed?
- Outcome measures – patient relevant (OMERACT)
 - different; more appropriate
 - Suggest investigations/assessments
 - Implications for quality of patient education
- Perspective on HTA



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The role of the patient framing SRA

- Avoid tokenism
- Concerns about
 - Technical knowledge
 - Clarity of role
 - Value of contribution
 - Ability to contribute
 - Exposure to difficult facts
 - Fear looking foolish



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Organisation, structure & process.

- Patients add value from start to end
- Contracts
- Training
- Confidentiality – both parts
- Relationships
- Membership of committees
- Membership of steering groups



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Conclusions:

It is practical to include patients in the research process.

Science is improved by patient involvement.

Patient participation will inform and improve clinical practice.



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