

# Training NF Researchers to Work with Patient Representatives

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12/4/2017



Response Evaluation In Neurofibromatosis Schwannomatosis  
INTERNATIONAL COLLABORATION

# Why actively involving patients in health research?

- ❖ Ethical argument  
In a democracy patients have the right to speak for them selves
- ❖ Content argument  
Experience based knowledge makes research outcomes more relevant and fitting better with the context of daily life
- ❖ Political argument  
Legitimacy and chances for implementation increase
- ❖ *Empowerment of patients and researchers*



Slide from Maarten de Wit,  
PhD



- Reciprocal relationships
  - Roles and decision-making authority of all parties are defined collaboratively and clearly stated
- Co-Learning
  - Help patients understand research process and help researchers learn about patient-centeredness/patient engagement principles
- Partnerships
  - Patient contributions are appropriately valued
- Transparency, Honesty, and Trust
  - Inclusive decision-making, open communication



# **PATIENT ENGAGEMENT IN REINS: LESSONS FROM OTHER GROUPS**



# Groups with Patient Representatives

Group	Year Founded	First Year PRPs Included	Type of PRP Involvement
OMERACT Outcome Measures in Rheumatology	1992	2002	Identify, Analyze, Design, Research, Publish
GRAPPA Group for Research Assessment of Psoriasis and Psoriatic Arthritis	2003	2012	Identify, Analyze
HOME Harmonizing Outcome Measures for Eczema	2008	2008	Analyze
GASTROS Gastric Cancer Trial Reporting Outcomes Standardization	2015	2015	Identify, Analyze

# Patient representatives add value throughout the research cycle

## Planning Process

- Identify new conceptual domains
- Prioritize research questions
- Help plan methods for outcome validation studies and clinical trials that encourage participation and minimize burden to subjects



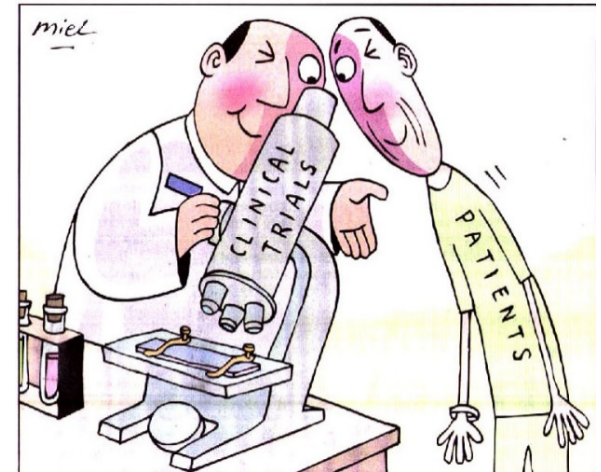
# Patient Representative Contribution to Conducting/Analyzing Research

## Outcome Selection Process

- Review literature to select potential outcome measures
- Participate in working groups to compare potential outcome measures
- Participate in Delphi panels or consensus conferences to determine final recommendations

## Outcome Creation or Validation Studies

- Generate and/or assess items for inclusion in new outcome measures
- Assist with recruitment and outreach for studies; conduct and analyze interviews or surveys



# Patient representative contribution to endpoint dissemination

## Researchers/Clinicians

- Help present findings at scientific conferences
- Co-author scientific manuscripts



## Patients/Public

- Identify best ways to share findings to patients, family members & community at large
- Help present findings at lay events (ex. patient forums)







# **BRINGING BEST PRACTICES TO REINS: IDEAS AND RECOMMENDATIONS**

# Organizational Methods to Facilitate Patient Involvement

- Document commitment to patient engagement in official mission statement, operational procedures, etc.
- Recruit patient representatives using a clear selection process to assess potential contribution and set expectations
- Give patient representatives full participation and voting rights
- Have a dedicated patient representative liaison
- Inclusive conference design (ex. pre-orientation, financial support for patient representative attendance, personalized schedules/travel arrangements to accommodate health needs)

# Organizational/Group Methods to Facilitate Patient Involvement

- Education
  - Educational materials can range from simple handouts (ex. glossaries) to short talks/webinars to more intensive workshops
  - No topic is too technical or complex for patients to contribute to
  - BUT, idea is not to turn patients into scientists
- Solicit continuous feedback on education and engagement practices

# Group/Individual Methods to Facilitate Patient Involvement

- Supporting integration of new group members
- Technology support (GoToMeeting, Dropbox, Doodle polls)
- Setting communication norms
  - Be patient
  - No opinion is a bad opinion. But (polite) disagreement is encouraged.
  - Interactive and encouraging moderation style
  - Pre- and post- conference preparation
- Willingness to change in response to patient representative input

# Potential Barriers to Effectively Engaging Patients

- Logistical and financial challenges
  - Financial barriers
  - Scheduling of phone conferences and in-person meetings
- Limits on engagement due to health problems/caretaking responsibilities
- Difficulty identifying and involving diverse partners

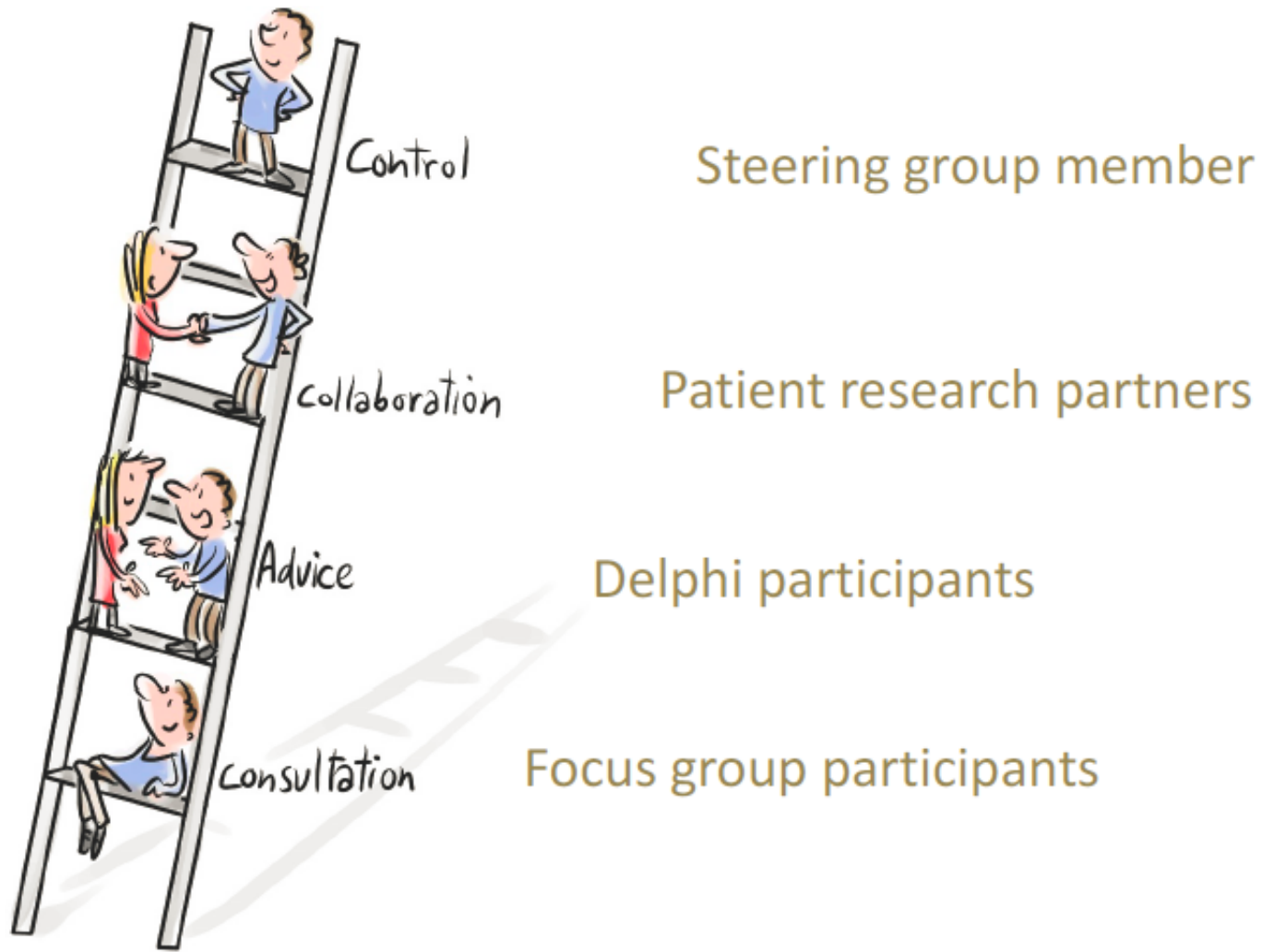


# **PATIENT ENGAGEMENT IN REINS: LOOKING TO THE FUTURE**

## Action Items for REiNS

- Develop educational materials with patient representatives
- Develop informational material about REiNS to give to larger patient/family population (blog posts, handouts, posters, social media, etc.)
- Brainstorm financial solutions
- Track contribution of patient input to REiNS and communicate this back to patient representatives and advocacy organizations
- Consider larger variety of ways patients can contribute to REiNS

# Patients Can Take Different Roles in Research





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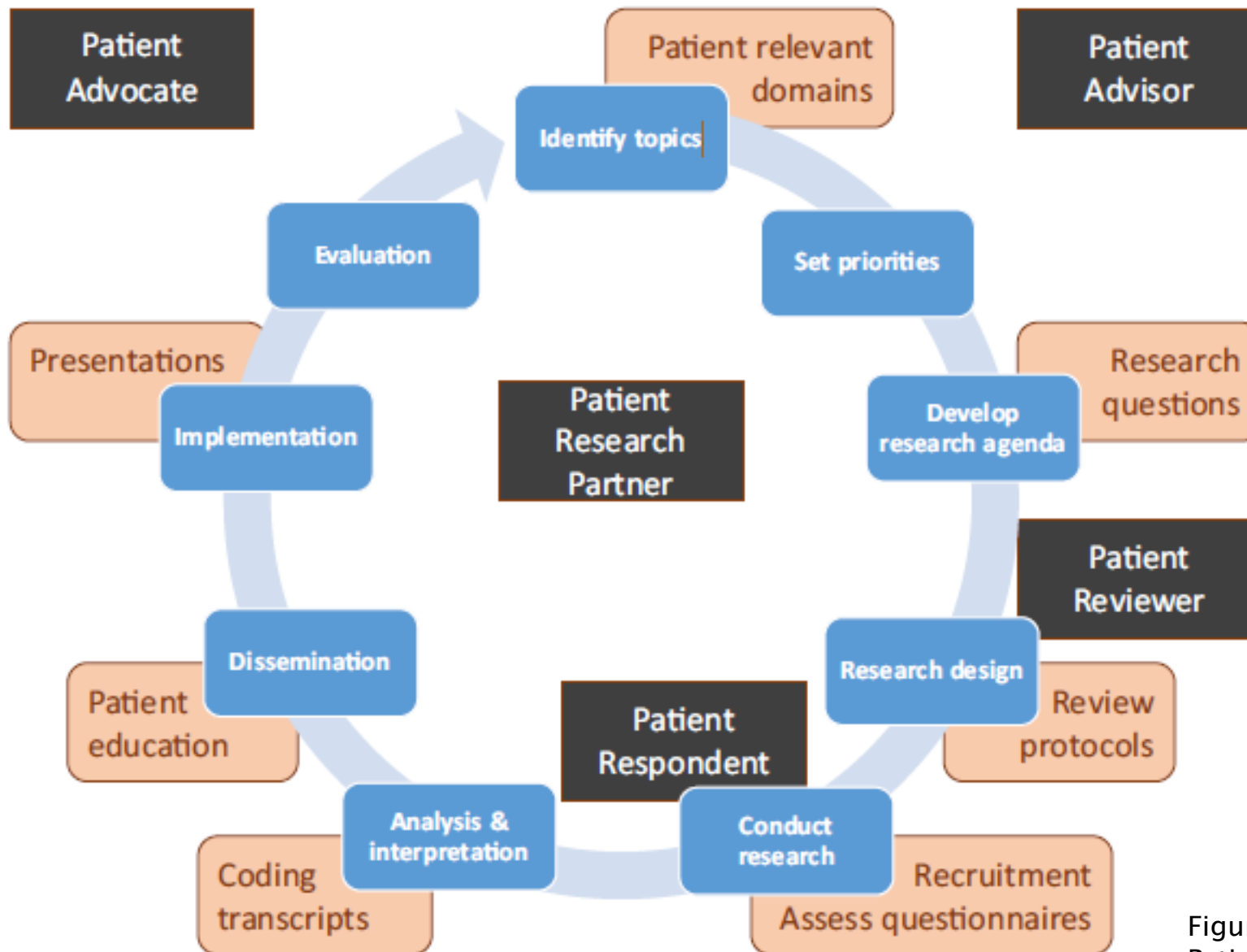


Figure 1 from Dewit et al. Patient (2017) 10:141-152