



# What do Patient Organisations want their Role to be?

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# Consultation Methodology

- Survey with EPF members (36 orgs – 11 replies)
- Survey with non-member patient organisations (400 orgs – 30-3 replies)  
Translated in 7 languages
- Workshop with reps of patient organisations, parents, patients (9 p.)

Diversity of respondents:

Respondents from SW, SL, DE, PL, GR, LUX, FR, UK

20 diseases represented



## PRIOR TO CT

- Conveying **Patients' Needs and Demands** on to Decision-Makers
- Ensuring a **Patient-Centred Trial Design**
- Generating Patients' **Trust**
- **Finding** Suitable Patients
- Obtaining True **Informed Consent**



## DURING THE CT

- **Supporting** the Patients
- Ensuring the Patients are **Respected**
- Intermediate for **Communication**



# POSTERIOR TO CT

- **Assessment** of Results
- **Taking Action** for the Well-being of Patients
- **Sharing Outcomes** and **Good Practices**



## CONCLUSIONS

- Strengthened role of POs in CT → empowerment of current and potential patients participating

*“Empowered children and parents in clinical trials mean that they are involved all stages of the trial and from its planning, have the status of co-researchers and receive all necessary information and support to make informed decisions.”*



## MODEL OF EMPOWERMENT\* – Key points

- Involvement of children, parents / their reps at the beginning and throughout the CT in planning and decision making
- Co-operative working with researchers, supported by a clear understanding of each other's roles
- Providing information and support for the involvement and empowerment of children, parents / their reps, including clear communication about the trial itself
- Monitoring and evaluation of the experience of involvement and empowerment from the perspective of all the actors
- Evaluation of the trial's results and impact, identifying how they meet the outcomes expected by children and parents.

*\*Adapted from Value+ Model of Patient Involvement*

*<http://www.eu-patient.eu/Documents/Projects/Value+%20Toolkit.pdf>*