



Meaningfull patient involvement in Research and Innovation

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www.eu-patient.eu
www.patientpartner-europe.eu

Meaningful Patient Involvement In Research

Patient meaningful involvement in R&D aims to:

- ❑ Ensure that the way **research** is designed, undertaken, evaluated and disseminated **reflects the needs and views of the patients**
- ❑ **Integrate researchers'** theory expertise with **patients' real-world knowledge** and experiences of the condition
- ❑ Ensure that research doesn't just measure outcomes considered important by professionals
- ❑ Strengthen **trust and acceptance** of research results
- ❑ Promotion of research results by patient organisations because of sense of ownership of the process (**enhanced visibility**)



Produce results that can be used to effectively improve practice in health care for the benefit of the patients

Levels of patient involvement and the research cycle



Representativeness



It relates to...

- geographical scope
- constituency
- consultation mechanisms
- independency

Issues around involvement of patient organisations

- Representativeness
- Mandate



It relates to...

- Mission & Objectives:
 - Provide information
 - Provide services to patients (counselling; self-help groups; home assistance, etc)
 - Advocacy for treatment
 - Advocacy for broad variety of patients' issues

It impacts on what the organisation can contribute

Issues around involvement of patient organisations

- Representativeness
- Mandate
- Governance



It relates to...

- consistent management, cohesive policies, guidance, processes and decision-rights for a given area of responsibility. Diverse scenario:
 - Existence of a Board with elected Board members/governance policies and procedures/supervises organisations' management
 - Board = Management/no separation
 - No elected Board/ad hoc leadership based on subjective criteria

It impacts on: Decision-making – Functioning - Representativeness

Issues around involvement of patient organisations

- Representativeness
- Mandate
- Governance
- Human resources



It relates to...

- staff
- volunteers

It impacts on: scope and sustainability of contribution of the patient organisation

Issues around involvement of patient organisations

- Representativeness
- Mandate
- Governance
- Human resources
- Resources



It relates to...

- capacity
- finances
- assets

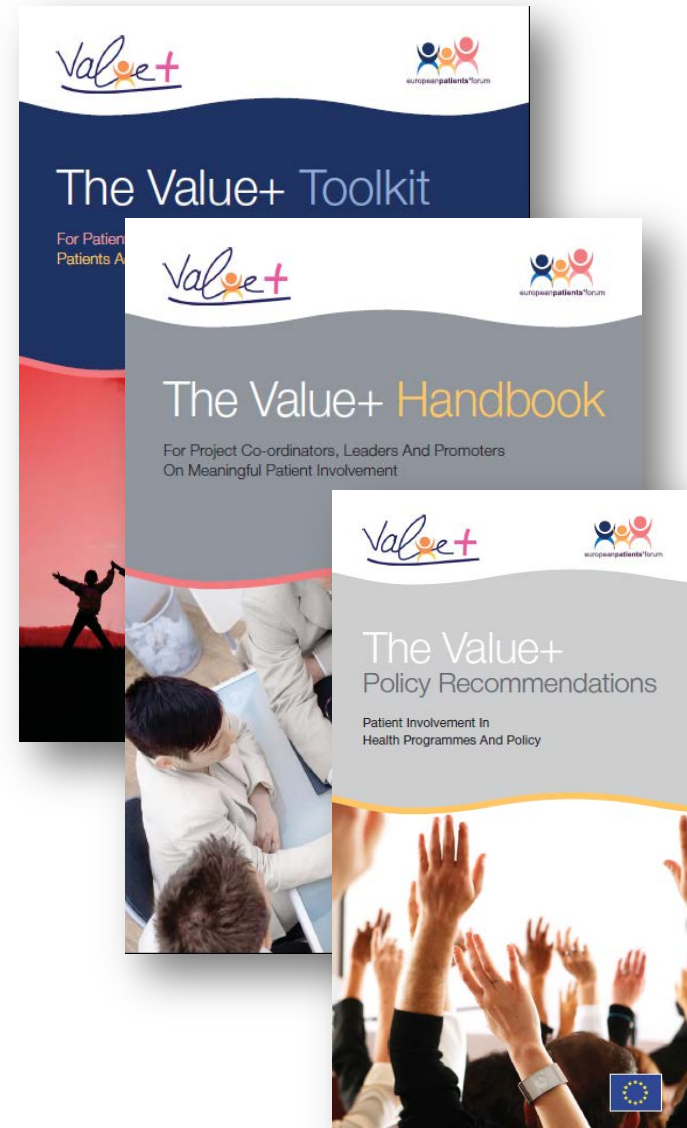
It impacts on: capacity to perform and compliance to projects' eligibility criteria and administrative requirements

- ❑ European Aids Treatment Group: Designing Research Protocols In Co-op With Industry, Involved In Several Regulatory Committees
- ❑ AFM France: Raises And Funds > 100 Million A Year For Research Into Rare diseases
- ❑ French Association For Research On Trisomy 21:to promote more research on Down syndrome at European and international levels.
- ❑ Croatian Patient Organisation KUZ: developed an information guide on clinical research for Croatian patients and citizens

- Value+, Respect (EPF)
- Eurogenguide (Genetic Alliance UK)
- PatientPartner (Dutch Genetic Alliance)
- Treat-n-MD (AFM FR, VSN NL and others)
- EUROVISIONNET (Retina Suisse)

Series of Tools:

- ❑ to enable patients to become more involved in EU funded projects including research projects (**Value+ Toolkit**)
- ❑ for **project promoters** and **coordinator** to acquire more skills to enable them to facilitate in practice (**Value+ Handbook**)
- ❑ a series of **policy recommendations** looking at linking research project outcomes with patient – centred policy development
- ❑ a **database of patient organisations** in all EU Member States



- ❑ European Network Patients Partnering in Clinical Research
- ❑ Guidelines for partnering (for all stakeholders)
- ❑ Recommendations to EC/national policy makers
- ❑ Thematic website for best practices, literature, links on active involvement in clinical research
www.patientpartner-europe.eu

Other resources

- www.invo.org.uk (INVOLVE UK)
- www.ema.europa.eu (Patient and Consumer working party)
- www.peopleinresearch.org
- <https://www.clinicaltrialsregister.eu/>
- www.nihr.ac.uk (Clinical research networks)

Questions

- What makes a research project attractive to your organisation? What kind of project would you take part in and why? /why not?
- What role would you like to play?
- What would the benefits for your organisation and or patients need to be for you to consider to take part?
- What measures can you take as organisation to make yourself more known to researchers in your condition's research field? How can researchers find you?
- What help do you need and who should provide this?