Patient Involvement in Clinical Research

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Financial Interests

Pfizer, Advisory Board, Personal, Member of Patient advisory board
Roche, Advisory Board, Personal, Member of Patient advisory board
NOTHING ABOUT US WITHOUT US!
Principles of Successful Patient Involvement in Cancer Research
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I. A shared vision
II. Strategy, level and timing of involvement
III. Communication, understanding and relationships
IV. Resources, knowledge and skills
V. Methods and approaches
VI. Ethical and legal aspects
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1. A shared vision

- Involving patients, caregivers or patient advocates → cancer research more meaningful, relevant and valuable

- Focusing it on the actual needs and demands of the target group

- Involving patients and other stakeholders → inequality in European countries
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II. Strategy, level and timing of involvement

• Patient involvement very early in the process
• Decision-making power on the side of the patients
• Match the right persons or entities to the right project
• The appropriate timing must be decided
• Involved across the whole research cycle
• Permanent patient panels or advisory boards
• Accessibility to and participation in international or multi-centric clinical studies should be offered to all countries in an equal manner
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III. Communication, understanding and relationships

• accepting and respecting all stakeholder contributions
• building relationships based on mutual trust and empowerment of all those involved
• to understand and prioritize the motives, incentives and mutual expectations of all parties
• Thoughtfulness, openness, transparency, a team spirit and real teamwork
• Clear lines of communication and full transparency concerning goals, prerequisites, governance structures, codes of conduct, rules, decision-making processes and pathways of information
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IV. Resources, knowledge and skills

- the mind sets and dedication
- sufficient time, funding and flexibility
- all parties must have sufficient knowledge and skills
- Informed patient experts: experiential knowledge of living with their conditions and at least partial technical knowledge
- education programmes providing medical expertise, methodological expertise, systems expertise; communication or negotiation skills
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V. Methods and approaches

• use existing, validated resources and reference points wherever possible
• Funding organizations → a vital role in addressing the deficits described.
• where to find potential individuals or organizations to involve?
• sufficient level of accessibility
• noticeable differences in implementation → reduce inequalities between European countries
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VI. Ethical and legal aspects

• clearly specify, communicate and discuss underlying rules and legal issues
• rights and obligations need to be specific, reasonable, proportionate and comprehensible
• generating rules, schemes and template texts for patient sample use, data sharing/ data protection or obtaining informed consent for projects
• expose and discuss any ethical questions or dilemmas
• participating in discussions about ethical and legal aspects of projects and their research foci requires training for all project partners
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Link: