

Assessing the needs for patient involvement and best practices in EU projects

Rainald von Gyzicki

Kim Wever



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Outline workshop 1

- Identification of the aspects that are important for involvement in EU projects
- Identification of the needs that you have to be meaningfully involved in an EU project?
- Presentation of FP7 project PatientPartner as a best practice.
- Sharing of best practices and identifying what a best practice should be.

Outline workshop 2

- How can your needs be met and which stakeholder can play which part?
- Which recommendations can you make to facilitate the future involvement of patient organisations in EU projects?
 - Which of these recommendations have the first priority?

Introduction

- Aspects : in what part of an EU project do you want to be involved: e.g. organisational level ?
- Needs: what do you need to be able to get involved in (certain aspects of) an EU project? e.g. in terms of accessibility, money
- Best practices: What does a project need to look like to make meaningful involvement of patient organisations possible ?

Assignment 1

- In what aspects of a EU project do you, as a patientorganisation, feel it is most important to be involved to have a meaningful involvement?
 - Write one aspect per person on a post-it
 - Explain this aspect to the members of your group
 - Group the aspects of 2 groups together
 - Report the findings to all in a plenary discussion lead by facilitator

Assignment 2

- What do you, as a patient organisation, need to be meaningfully involved in an EU project ?
 - On project level
 - On policy level

An example of a best practice FP7 project PATIENTPARTNER



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An example of a best practice FP7 project PATIENTPARTNER

- FP7 Project, May 2008- May 2011
- Coordinated by the Dutch Genetic Alliance :
An umbrella organisation for rare and hereditary diseases in the Netherlands
- Cooperation between 3 patientorganisations (VSOP,GIG,EGAN) and one policy body (EFGCP)

An example of a best practice FP7 project PATIENTPARTNER

- Objective : stimulate active involvement of patient organisations in therapy and drug development (in clinical trials)
- Project is based on identifying the patients needs for partnering in the clinical trials context.
- Project is driven by the patient's perspective

Patients organisations can get involved in a number of ways

- Through taking part in our survey on their involvement in clinical trials → identification of best practices and learning from experiences
- Through getting involved in the European Network for Patients Partnering in Clinical Research (ENPCR) → dialogue, mutual learning

Patients organisations can get involved in a number of ways

- By sharing their experiences, needs, motivations on their current and future involvement in clinical trials in an interview.
- By taking part in a dialogue between patient organisations, researchers and pharmaceutical companies in our workshops → making recommendations for patient partnership in clinical trials

Patient organisations will

- Be informed about the results via mailinglists and our website www.patientpartner-europe.eu →feedback
- Be asked to test drive our patient guide for involvement in clinical trials → empowerment
- Be asked to implement the recommendations within their own goals in therapy and drug development. →impact

Assignment 3:

- What should a best practice look like to make meaningful involvement of patient organisations possible?
- Do you know any examples of best practices?

Assignment 4

Define recommendations on:

- How your needs for being meaningfully involved in EU projects can be met?
- Which stakeholder should play which role in meeting these needs?

Which 3 recommendations have the highest priority and why?

THANK YOU FOR YOUR INPUT



Get Involved

"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has"

-Margaret Mead