

Ways of integrating patients' and families' perspectives in European projects

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Background and Aim

Despite the importance placed on patient and public involvement (PPI) globally, involvement methods remain inconsistently reported. Clarity on current methods is required to ensure patients' time is used valuably and successfully contributes to the research process. The aims of this study were to compare how PPI activities are integrated into current EU-funded projects and to clarify current challenges and facilitators to PPI practices.

Method

Exploratory study of PPI activities in ongoing European projects focussing on palliative care for adult patients – purposively sampled for their PPI activities. Representatives completed an open-ended questionnaire detailing the recruitment, aims, composition, challenges and facilitators of PPI groups. Responses were analysed using summarising content analysis.

Search strategy: all EAPC projects with a PPI group were contacted, 4 out of 6 completed the questionnaire; a further project, which was added by hand search, was included due to its thematic proximity (treatment and care choices with cancer).

Results

Aims

- advise and input to the project to contribute to a better quality
- co-create material/e-learning/training
- support dissemination

similar aims

Composition of the groups

- international PPI group for the whole project, meeting regularly online
- national PPI group per involved country, regular meetings on national and international level
- one local PPI group per participating clinical centre, regular local meetings

different structures

Involvement of PPIs

- provide feedback from a patient/user perspective
- participate in project meetings and committees
- provide solicited and unsolicited advise
- co-create information material for patients and families
- contribute to manuscripts as patient authors
- provide feedback on study material
- support in study recruitment

differs depending on context, develops over time and depends on individual preference rather than project requirements

Recruitment Strategies

- social media posts
- newsletters
- personal outreach
- organizational partnerships (e.g. with patient organizations, European professional associations, existing PPI boards)

Shared challenges in approaching PPI:

- partial inexperience of researchers with PPI, which required additional training and resources from the consortium
- lack of face-to-face interaction to support the growth of personal relationships
- define the scope and area of responsibility (e.g. in project planning), as this depends partly on the group and the interests of the individuals



Specific tools/working strategies

- patient/user centric approach
- invite input and initiatives to meetings
- guidelines to outline the purpose of the group and the meetings
- tools to guide researchers in their collaboration with PPI (e.g. to jointly define, evaluate and adapt roles)

Notable facilitators for PPI :

- flexibility of rolls, tasks, methods
- establishing trust with PPI members
- ongoing support to reflect on roles and tasks (e.g. through involvement matrices and PPI logs)
- addressing concerns about international online meetings
- technical and translation support for online meetings

Conclusion

Although the reported aims of the groups are similar, the engagement of patients and families across projects differed, from limiting activities to one aspect of the project to including them in the overall design. PPI requires flexibility and continuously defining roles and methods in collaboration with all involved. Exchanging challenges and facilitators among researchers offers benefits in learning together how best to organize and conduct PPI at European level.

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Conflict of interest

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