

INTEGRATE-HTA

International experiences of Patient and Public Involvement (PPI) in the INTEGRATE-HTA project.

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Aim of this presentation:

- To share experiences of PPI and things we considered in the INTEGRATE-HTA project.



Overview of this presentation:

- Background to the project:
 - i. Health Technology – definition,
 - ii. Health Technology Assessment,
 - iii. The INTEGRATE-HTA project.
- Aim of PPI & methods used for PPI in the project.
- Considerations associated with PPI in the INTEGRATE-HTA project related to governance (regulations), ethical (moral principles) and methodological (procedures used) issues.
- Impact of PPI in the project to date.
- Conclusions & recommendations.



Background

- Health Technology:



Simple or complex technologies?



Images from: <http://www.freeimages.co.uk/galleries/medical>

- Health Technology Assessment:

e.g. the work of NICE in England

“The systematic evaluation of properties, effects, and/or impacts of health technology. It may address the direct, intended consequences of technologies as well as indirect, unintended consequences.”



Purpose of INTEGRATE-HTA

- Develop new methods to assess complex health technologies and test these in palliative care.
- We are especially interested in models of service delivery in palliative care for people with life limiting illnesses.



Integrate-HTA

WP1: Project management

WP2: Dissemination, external communication,

WP6: Integrating different issues

WP3: Assess :
Economics (costs), Effectiveness
(does it work), Ethics, Legal &
Socio-cultural issues

WP4: Assess :
Patient preferences &
Factors that effect
(Moderators) of treatment
effect issues

WP7: Apply
methods to
palliative care
(c/o people
with life
limiting
illness)

WP5: Assess :
Context & implementation

WP8: Apply methods to other complex technologies

Patient and Public Involvement (PPI) in the project.

- PPI in seven European countries to identify key issues in palliative care that will inform the project plans (scope).



- Patients/ex-patients; family carers/ex-carers; family members and members of public organisations or groups with an interest in or experience of palliative care.



Country		Methods	
England		“Research advisor” approach (n=33)	Face-face discussions with individuals or small groups. Adapted version of the EUnetHTA core model.
Norway			
Poland			
Italy		Qualitative research approach (n=19)	Individual, face-face / telephone interviews using EUnetHTA core model as a framework.
Germany			Focus groups and face-face interviews using nominal group technique and categorical coding procedure informed by a Grounded Theory approach.
The Netherlands			Interactive evaluation using face-face interviews and subsequently case reconstruction using constant comparison.
Lithuania			Face-face , audio-taped interview & 2 focus groups. Transcribed & Thematic analysis.

Governance (regulation)

- Research regulations vary in the countries involved which influences:
 - a. how informants are recruited
 - b. the data collection allowed about informants' ethnicity.
- Level of patient involvement, roles & relationships differ with methods used
 - a. 'research advisor'
 - b. qualitative research.



Ethical considerations

- Ethics requirements vary in each country – we had to overcome uncertainty about ethical requirements for PPI.
- Enabling patients at the end of life to take part in the project presents a number of unique challenges - e.g. recruitment and retention, ability to make decisions for oneself (autonomy).



Methodological considerations

- Views on the ‘best’ methods for PPI consultation vary internationally – no ‘gold standard’ approach.
- Although clear methodologies exist when using qualitative research approaches, this is not the case when engaging PPI representatives as research advisors.
- Identification of topics & priorities for HTA proved challenging but 23 similar issues arose.



Methodological considerations

- Validation of findings with PPI representatives who have life limiting illnesses is challenging.
- Assessing the impact of PPI on the project & identifying the added value of international patient and public involvement.



Impact of PPI on the INTEGRATE-HTA project to date

- Assisted in the development of comprehensive project plans (the project scope).
- Relationships with PPI representatives established.
- Learning opportunities for all involved in the project.



Conclusions

- Positive experiences of PPI in palliative care internationally – very willing stakeholder group.
- The methodological, ethical and governance challenges that exist when undertaking PPI are enhanced with an international project.

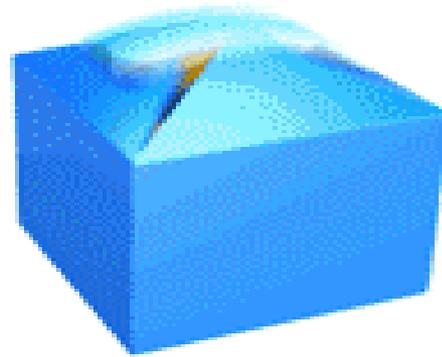


Recommendations

- Planning PPI at the bid stage is important.
- Need methods for PPI as advisors and to address the merging of findings from different PPI methods.
- The Public Involvement Impact Assessment Framework Guidance (Piaf) (Popay et al 2014) assists research teams to consider a number of PPI issues and to assess of the impact of public involvement in their research.
- Tools such as the GRiPP checklist (Staniszewska et al 2011) can assist transparency in PPI reporting.



Thank you for your attention



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This project is co-funded by the European Union under the Seventh Framework Programme (Grant Agreement No. 306141)

