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

Louise Brereton¹, Gert Jan van der Wilt², Wija Oortwijn³, Kati Mozygemba⁴, Kristin B Lysdahl⁵, Dario Sacchini⁶, Wojciech Leppert⁷, Elizabeth Goyder¹, Christine Ingleton⁸, Clare Gardiner⁹.

¹ScHARR, University of Sheffield, Sheffield, England. ²Department of Primary and Community Care, Radboud University Medical Centre, Nijmegen, The Netherlands. ³ECORYS Nederland B.V. Rotterdam, The Netherlands. ⁴Department of Health Services Research, University of Bremen, Bremen, Germany. ⁵Institute for Health and Society, University of Oslo, Oslo, Norway. ⁶Institute of Bioethics, Università Cattolica del Sacro Cuore, Rome, Italy. ⁷Department of Palliative Medicine Department of Palliative Medicine, Poznan University of Medical Sciences, Poznan, Poland. ⁸School of Nursing & Midwifery, University of Sheffield, Sheffield, England. ⁹School of Nursing, University of Auckland, New Zealand.
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?

• 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

WP5: Assess:
Context & implementation

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

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

www.integrate-hta.eu
References
