INTEGRATE-HTA

Scoping as a means to systematically involve stakeholders in Health Technology Assessment (HTA)

Gert Jan van der Wilt, Louise Brereton, James B Chilcott, Kristin Bakke Lysdahl, Dario Sacchini & Kati Mozygemba

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The project aims to develop methods for a
• comprehensive
• patient – centered and
• integrated assessment for complex healthcare technologies

Recognized that scoping conducive to achieve these goals

Pilot to test methods on case study of palliative care
Purpose of the panel session

To share with you:

• What do we mean by scoping
• How to do a scoping exercise
• What kind of results do you get
• How these results relate to HTA
• Why you want to do a scoping exercise
Structure of the panel session

- Rationale of the panel session / subject
- Results of a scoping exercise five European countries
  - England
  - Norway
  - Italy
  - Germany
  - The Netherlands
- Relation of the results with HTA
- Discussion
Rationale of a scoping

**Scoping** is a process to indentify key issues of concern at an early stage in assessment

- Stakeholder involvement is crucial throughout the various stages of health technology assessment (HTA)
- Stakeholder involvement can lead to an HTA that better meet people's needs and is more likely to be put into practice
- Little is known as to how this can be achieved in a systematic, culturally sensitive way
Scoping exercise

Systematic review

Building research agenda

Interpretation

Transition management

Step 1

Step 2

Step 3

Step 4

Step 5

Continuous action and reflection

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## Stakeholder consultation

<table>
<thead>
<tr>
<th>Country</th>
<th>Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>Individual or group, face-face meetings using the EUnetHTA core model.</td>
</tr>
<tr>
<td>Norway</td>
<td>Individual, face-face meetings using the EUnetHTA core model.</td>
</tr>
<tr>
<td>Italy</td>
<td>Qualitative individual, face-face / telephone interviews using EUnetHTA core model as a framework.</td>
</tr>
<tr>
<td>Germany</td>
<td>Qualitative focus groups and face-face interviews were conducted (using nominal group technique and categorical coding procedure informed by a Grounded Theory approach).</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>Interactive evaluation using qualitative face-face interviews and subsequently case reconstruction using constant comparison.</td>
</tr>
</tbody>
</table>

Other participating countries: Poland, Lithuania
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Stakeholder Advisory Panels (SAPs) in England

Louise Brereton, James B Chilcott
(presenter: Marcia Tummers)
# Participants

<table>
<thead>
<tr>
<th>Stakeholders characteristics</th>
<th>Professionals</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>9 Male &amp; 25 Female</td>
<td>10 Male &amp; 10 Female</td>
</tr>
<tr>
<td>Age range (mean)</td>
<td>28-66 (48.3) 33 responses</td>
<td>32-89 (66.15)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>31 White, 2 African, 1 Mixed – White and Black Caribbean</td>
<td>19 White &amp; 1 Asian-Indian</td>
</tr>
<tr>
<td>Religion</td>
<td>19 Christian, 12 ‘None’, 3 not asked</td>
<td>13 Christian, 1 Hindu, 3 ‘None’ 3 non-response</td>
</tr>
<tr>
<td>Experience</td>
<td>Palliative / specialist palliative care &amp; end of life care (nursing, medicine education, Rehabilitation, community nursing, Research into end of life care in the community Nursing home / dementia care)</td>
<td>2 Patients; 1 both a patient and carer; 2 carers; 2 ex-carers; 6 family members; 2 friend / close other &amp; 5 members of palliative care group</td>
</tr>
<tr>
<td>Years of experience in palliative care – Range (mean)</td>
<td>3 months-43 years (18.8 years based on 31 responses)</td>
<td>1-16 (8.86) based on 15 responses – 8 were currently involved with palliative care services</td>
</tr>
</tbody>
</table>
Examples of key issues raised (1)

Availability & Accessibility of Palliative Care

• Increase availability of palliative care services for all groups as the focus has been on patients with cancer & rural areas are under served.
• Increase accessibility of palliative care services (e.g. to ethnic minorities, people with non-cancer diagnoses, those with mental health problems or learning disability and those in nursing homes).
• Ensure timely access to palliative care / specialist support services.
Examples of key issues raised (2)

Cost effectiveness of palliative care

- Determine the best way to fund palliative care services.
- Determine whether palliative care services are good value for money.
- Identify ways to measure the direct and indirect costs and cost effectiveness of palliative care services.
Examples of key issues raised (3)

Family (Lay) Carers / caring

• Improve assessment of carer’s needs.
• Provide training and support for family (lay) carers.
Lesson learned

- Stakeholders were willing to participate in the stakeholder advisory panels & had much advice to offer based on their experience of palliative care.
- Patients and the public as well as professionals can identify a number of key issues of relevance to palliative care.
- The EUnetHTA core model was a comprehensive guide for discussions.
- The key issues raised by stakeholders can be used to inform relevant questions for the HTA.
- None-the-less a number of methodological, ethical and practical issues need to be considered when engaging patients and the public in scoping for an HTA, especially with regard to palliative care.
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Stakeholder Advisory Panels (SAPs) in Norway

Kristin Bakke Lysdahl
## Participants

<table>
<thead>
<tr>
<th>Stakeholders characteristics</th>
<th>Professionals</th>
<th>Patients / relatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>4 female, 1 male</td>
<td>3 female, 2 male</td>
</tr>
<tr>
<td>Age</td>
<td>( \geq 50 ) years</td>
<td>Range: 27 – 81 years</td>
</tr>
<tr>
<td>Profession</td>
<td>Physicians, nurses. Clinicians and researchers/managers</td>
<td>Various</td>
</tr>
<tr>
<td>Experience</td>
<td>Wide and long, in oncology / palliative care / end of life settings</td>
<td>With different parts of palliative care services, currently involved as patients (3), or relatives/carers (2)</td>
</tr>
<tr>
<td>Residence</td>
<td>All advisors worked / lived in the same area</td>
<td></td>
</tr>
</tbody>
</table>
Example of key issues raised: Accessibility of Palliative Care Services

- Increase services to ensure equal access independent of:
  - diagnoses: non-cancer patients
  - age: the elderly patients
  - setting: patients in home care and nursing homes
- Include all aspects of services (psycho-social and existential)
- Ensure easy access to services whenever needed (open return to palliative unit)
Accessibility of Palliative Care Services
- relates to explaining / solving issues:

• Improve recognitions of palliative care and its holistic approach in the medical environment

• Increase competency, education and research
  – From “field of competency” to formal medical speciality

• Supplement palliative care within the frames of public health services with free-standing hospices?
Example of key issues raised: Overtreatment at the end of life

• Decrease aggressive interventions in end-of-life (cancer) care
• Clarification and common understanding of concepts related to withholding of treatment
Overtreatment at the end of life - relates to explaining / solving issues:

• Improve cooperation between service units
  – Include palliative care experts in multi disciplinary teams

• Patient autonomy ambivalences
  – Professionals: patient autonomy most important, but often forgotten
  – Patients: balance between need of information and relief of be spared from responsibility of decisions

• Increase implementation of Advance Care Planning (ACP)
Lessons learned

• Patients/relatives and professionals stakeholders raised a number of interrelated issues, and

• key issues raised providers information relevant within several HTA domains.
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Stakeholder Advisory Panels (SAPs) in Italy

Dario Sacchini
## Participants

<table>
<thead>
<tr>
<th>Stakeholders characteristics</th>
<th>Professionals</th>
<th>Patients / relatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>5 female, 3 male</td>
<td>5 female, 2 male</td>
</tr>
<tr>
<td>Age</td>
<td>Range: 33 – 67 yy</td>
<td>Range: 33 – 72 yy</td>
</tr>
<tr>
<td>Profession</td>
<td>Bioethics, economics, palliative care specialist, nursing, oncology, physiotherapy</td>
<td>Nurse, Secretary, Public official, Lawyer, Retired, Student</td>
</tr>
<tr>
<td>Experience</td>
<td>Range: 2 – 15 yy</td>
<td>Range: 1 – 24 months</td>
</tr>
<tr>
<td>Residence</td>
<td>All advisors worked / lived in the same area</td>
<td></td>
</tr>
</tbody>
</table>
### Key-issues - 1

<table>
<thead>
<tr>
<th>Issues</th>
<th>EunetHTA domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Providing palliative care services for all diseases with poor</td>
<td>Health problem and current use of the</td>
</tr>
<tr>
<td>prognosis</td>
<td>technology</td>
</tr>
<tr>
<td>• Need to offer the same service as well as in other countries</td>
<td>Safety</td>
</tr>
<tr>
<td>like in England</td>
<td></td>
</tr>
<tr>
<td>(Patients)</td>
<td></td>
</tr>
<tr>
<td>• Psychological damages due to terminal illness</td>
<td></td>
</tr>
<tr>
<td>• Providing more patient’s awareness about his/her prognosis</td>
<td></td>
</tr>
<tr>
<td>• Loss of consciousness/relationship skills due to opiates</td>
<td></td>
</tr>
<tr>
<td>• Lack of legally authorized staff to move patients within hospices</td>
<td></td>
</tr>
</tbody>
</table>
## Key-issues - 2

<table>
<thead>
<tr>
<th>Issues</th>
<th>EunetHTA domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Families)</td>
<td>Safety</td>
</tr>
<tr>
<td>• Economic damages due to temporary suspension from work</td>
<td></td>
</tr>
<tr>
<td>• Social/relational damages: h24 family involvement</td>
<td></td>
</tr>
<tr>
<td>• Psychological damages: waiting for relative’s death</td>
<td></td>
</tr>
<tr>
<td>• Symptoms Control: pain and suffering during the switch of therapy</td>
<td>Clinical Effectiveness</td>
</tr>
<tr>
<td>• Need to homogenise national health reimbursement</td>
<td></td>
</tr>
<tr>
<td>• Increasing funds for palliative care services</td>
<td>Costs, economic evaluation</td>
</tr>
<tr>
<td>• Increasing number of hospices in Southern Italy</td>
<td></td>
</tr>
<tr>
<td>Issues</td>
<td>EunetHTA domain</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-----------------</td>
</tr>
<tr>
<td>• Unequal access to palliative care due to a patchy distribution all over the country</td>
<td></td>
</tr>
<tr>
<td>• Unequal access to palliative care due to inhomogeneous eligibility criteria</td>
<td></td>
</tr>
<tr>
<td>• Anticipating request time for palliative care (not limited to 3 months of survival prognosis) to avoid loss both of patient’s autonomy and possible clinical benefits</td>
<td></td>
</tr>
<tr>
<td>• Modulating information to patients from a quantitative and qualitative point of view</td>
<td>Ethics</td>
</tr>
</tbody>
</table>
## Key-issues - 4

<table>
<thead>
<tr>
<th>Issues</th>
<th>EunetHTA domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Extending home care and nursing care</td>
<td>Organisational aspects</td>
</tr>
<tr>
<td>• Setting up a network between hospital and hospice</td>
<td></td>
</tr>
<tr>
<td>• Increasing number of “ad hoc” health professionals</td>
<td></td>
</tr>
<tr>
<td>• Improving quality of life (e.g. providing music in the rooms)</td>
<td></td>
</tr>
<tr>
<td>• Implementing personalized palliative care service pathways</td>
<td></td>
</tr>
<tr>
<td>• Training the relative’s role about palliative care administration</td>
<td></td>
</tr>
<tr>
<td>• Increasing staff training to communicate and inform patients</td>
<td></td>
</tr>
<tr>
<td>• Reducing bureaucracy</td>
<td></td>
</tr>
<tr>
<td>• Increasing number of staff and volunteers that can move patient</td>
<td></td>
</tr>
<tr>
<td>during the day</td>
<td></td>
</tr>
<tr>
<td>• More public information about palliative care</td>
<td></td>
</tr>
<tr>
<td>• Homogenizing procedures for request home care/ hospice palliative</td>
<td></td>
</tr>
<tr>
<td>care</td>
<td></td>
</tr>
</tbody>
</table>
### Key issues - 5

<table>
<thead>
<tr>
<th>Issues</th>
<th>EunetHTA domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Develop a real culture on palliative care and end-of-life</td>
<td>Social aspects</td>
</tr>
<tr>
<td>• Need of a better application of the Italian legislation on palliative care (L. 38/2010), especially for what that concerns the set up of new hospices</td>
<td>Legal aspects</td>
</tr>
<tr>
<td>• Decrease health tourism within country (among regions)</td>
<td></td>
</tr>
<tr>
<td>• Major public knowledge and awareness about Italian Legislation on palliative care</td>
<td></td>
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</tbody>
</table>
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Stakeholder Advisory Panels (SAPs) in Germany

Kati Mozygemba
Research Question

- What are important aspects (outcome measures) for the benefit assessment of palliative care?
Data collection

2 focus groups
(4 relatives, 7 professionals (incl. 1 person volunteering), based on Improved Nominal Group Technique

4 interviews with patients
### Participants

<table>
<thead>
<tr>
<th>Stakeholders characteristics</th>
<th>Professionals</th>
<th>Patients / relatives</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td>6 female, 1 male</td>
<td>5 female, 3 male</td>
</tr>
<tr>
<td><strong>Age range</strong></td>
<td>40-69 years</td>
<td>40-69 years</td>
</tr>
<tr>
<td><strong>Profession</strong></td>
<td>- Pastor (1)</td>
<td>Various</td>
</tr>
<tr>
<td></td>
<td>- Nurse (3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Physician (2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Social worker (1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Editor (1)</td>
<td></td>
</tr>
<tr>
<td><strong>Experience</strong></td>
<td>Years of experience: 5 – 18 years</td>
<td>different parts of palliative care services</td>
</tr>
<tr>
<td></td>
<td>Outpatient hospice (2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Inpatient hospice (1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Outpatient specialist palliative care (1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Palliative care unit (2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Liaison palliative care (1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Others (2)</td>
<td></td>
</tr>
<tr>
<td><strong>Residence</strong></td>
<td></td>
<td>Northern part of Germany (city and small towns)</td>
</tr>
</tbody>
</table>
Examples of key issues raised

1. Defining the intervention palliative care

- Especially professionals had difficulties to define the intervention

- Two cultural different traditional lines of PC in Germany lead to different understandings of palliative care

  A) focusing on palliative medicine as professionalized and specialized medicine

  B) focusing on hospice and palliative care rooted in a civic movement
Examples of key issues raised

1. Defining the intervention Palliative Care

Benefit for HTA on Palliative Care

Our research suggests that

- using “bubbles” (e.g. WHO-definition) does not present every day experience

- pre-defined definition could hide cultural differences of

  - ideas of the intervention, and

  - important outcomes (e.g. medical effectiveness vs. trustful relationship with patients)
2. Professional Cultures in Palliative Care

**Palliative care as an *attitude* contains e.g.**
- holistic care
- egalitarian team work,
- close and trustful relations to patients and their relatives.

**Palliative medicine is associated with e.g.**
- specialized,
- hierarchic,
- fragmented (hospital) care and nursing homes.
Examples of key issues raised

2. Professional Cultures in Palliative Care

Benefit for HTA on Palliative Care

Knowing that, we

- understand differences in team structure and service delivery

- understand fears of sticking to a different service culture and losing PC as holistic approach
Examples of key issues raised:

3. Professionals’ idea of benefit assessment

- Skepticism against benefit assessment as a whole because of the association with
  - economic functionalization,
  - standardization and
  - fracturing the holistic approach into single intervention parts that can be defined and payed easily

- Fear of force to adapt a holistic approach that is useful in the sense of helping (dying) people – “reasonable disutility”
Examples of key issues raised

3. Professionals’ idea of benefit assessment

Benefit for HTA on Palliative Care

Our experience shows that,

- researchers must carefully explain their understanding of benefit assessment, because benefit assessment is culturally associated with economic and medical assessment.
Lessons learned for scoping in HTA

- Different understandings of the intervention can lead to different outcome measures.
- Professional cultures could represent different ways of service delivery.
- Stakeholders could be skeptical about benefit assessment, because it is associated with economic benefit.
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Scoping exercise in The Netherlands

Gert Jan van der Wilt
## Participants

<table>
<thead>
<tr>
<th>Stakeholders characteristics</th>
<th>Professionals (n = 12)</th>
<th>Patients (n = 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>6 female, 6 male</td>
<td>1 female, 1 male</td>
</tr>
<tr>
<td>Profession</td>
<td>Specialist palliative care providers (n = 5)</td>
<td>Retired</td>
</tr>
<tr>
<td></td>
<td>Generalist palliative care providers (n = 2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nurses (n = 2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Chaplain / spiritual care giver (n = 3)</td>
<td></td>
</tr>
<tr>
<td>Experience</td>
<td>Nursing home (n = 1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hospice (n = 1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Elderly care medicine (n = 1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pain and palliative medicine (n = 1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pain management (n = 1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>General practice (n = 2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Home care (n = 2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Spiritual care (n = 3)</td>
<td></td>
</tr>
<tr>
<td>Residence</td>
<td>All participant worked / lived in the vicinity of Nijmegen</td>
<td></td>
</tr>
</tbody>
</table>
Data analysis

Reconstructing interpretive frame method
1. Problem definitions
2. Preferred solutions
3. Empirical and ethical background theories
4. Normative preferences
Summary of the key findings

The medical staff

- Continuity of Palliative Care
  - Information transfer among medical staff
  - No protocol when treatment is still useful
  - Doctors are often not trained in palliative care

Deciding on curative/palliative intent of treatment

Declared "incurable"

Curative Treatment

Advanced care planning

Possible contributory factors:

The patient

- Acceptance /Coping
- Questioning Meaning of Life

Possible Manifestations:
- Spiritual/Religious distress
- Request euthanasia
- Purposeless curative treatment
- Decreases QoL/QoC/Well-being
- Worsening symptoms

Possible Intervention:
- Spiritual/Religious Care

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Lessons learned

Key problem
Transition from curative to palliative care

Solutions
– Interventions aimed at increasing spiritual well-being
– Continuity of palliative care
– Advanced care planning
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How do the results relate to HTA?
Implications for an HTA

**England**

**Problem**

Improve assessment of carer’s needs

**Solution**

Provide training and support for lay carers

**HTA**

Is there evidence to suggest that training and support for lay carers relieve carers and as a result improve quality of palliative care?
Implications for an HTA

Norway

Problem

Avoid hospitalisation and overtreatment at the end of life

quality of life / side effects

Solution

Advanced care planning

HTA

Is there any evidence to suggest that advanced care planning improves the quality of life at the end of life?
Implications for an HTA

Italy

Problem

Continuity of palliative care / organisation of palliative care

Solution

Setting up a network between hospital and hospice

HTA

Is there evidence to suggest that a network between hospital and hospice improves the quality of palliative care?
Implications for an HTA

**Germany**

**Problem**

Different understandings of palliative care

- focusing on palliative medicine as professionalized and specialized medicine
- focusing on hospice and palliative care rooted in a civic movement

![Diagram showing Context, Mechanism, and Outcome]
Implications for an HTA

**Germany**

**Problem**

Different understandings of palliative care

- focusing on palliative medicine as professionalized and specialized medicine
- focusing on hospice and palliative care rooted in a civic movement

**HTA**

Selection of end-points may unwittingly favour either of the two palliative care models!
Implications for an HTA

The Netherlands

Problem
- Transition from curative to palliative care

Solution
- Acceptance of life / addressing meaning of life questions

Relevant questions
- Is there evidence to suggest that spiritual interventions improve patients' acceptance or coping with facing death?
Take home message

A scoping exercise

• Maps key issues is an area
• Can inform an HTA
• Increases ownership of the findings
• Increases legitimacy by respecting stakeholder perspectives
• May make effective implementation of HTA recommendations more likely