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*

INTEGRATE - HTA

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

Radboud umc

INTEGRATE-HTA

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

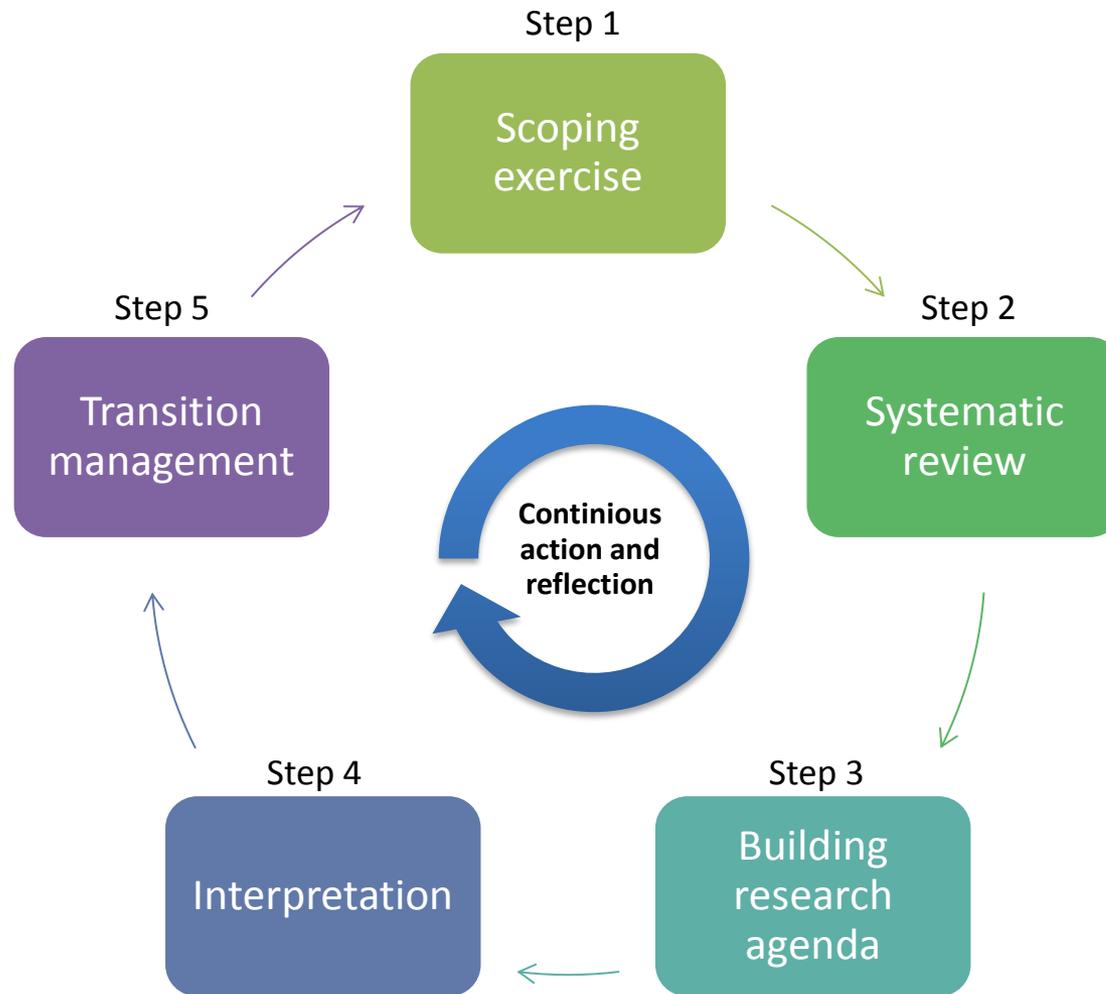- Why you want to do a scoping exercise

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

Stakeholder consultation

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

Other participating countries: Poland   Lithuania

INTEGRATE-HTA

Stakeholder Advisory Panels (SAPs) in England

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

The University Of Sheffield.

Participants

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

The University Of Sheffield.

INTEGRATE-HTA

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.

INTEGRATE-HTA

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.

The University Of Sheffield.

INTEGRATE-HTA

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.

The
University
Of
Sheffield.

INTEGRATE-HTA

INTEGRATE-HTA

Stakeholder Advisory Panels (SAPs) in Norway

Kristin Bakke Lysdahl

UiO : **University of Oslo**

Participants

Stakeholders characteristics	Professionals	Patients / relatives
Sex	4 female, 1 male	3 female, 2 male
Age	≥ 50 years	Range: 27 – 81 years
Profession	Physicians, nurses. Clinicians and researchers/managers	Various
Experience	Wide and long, in oncology / palliative care / end of life settings	With different parts of palliative care services, currently involved as patients (3), or relatives/ carers (2)
Residence	All advisors worked / lived in the same area	

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.

INTEGRATE-HTA

Stakeholder Advisory Panels (SAPs) in Italy

Dario Sacchini

Participants

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

UNIVERSITÀ CATTOLICA del Sacro Cuore

INTEGRATE-HTA

Key-issues - 1

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

INTEGRATE-HTA

Key-issues - 2

Issues	EunetHTA domain
(Families) • Economic damages due to temporary suspension from work • Social/relational damages: h24 family involvement • Psychological damages: waiting for relative's death	Safety
• Symptoms Control: pain and suffering during the switch of therapy	Clinical Effectiveness
• Need to homogenise national health reimbursement • Increasing funds for palliative care services • Increasing number of hospices in Southern Italy	Costs, economic evaluation

UNIVERSITÀ CATTOLICA del Sacro Cuore

INTEGRATE-HTA

Key-issues - 3

Issues	EunetHTA domain
• Unequal access to palliative care due to a patchy distribution all over the country • Unequal access to palliative care due to due inhomogeneous eligibility criteria • 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 • Modulating information to patients from a quantitative and qualitative point of view	Ethics

Key-issues - 4

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

Key issues - 5

Issues	EunetHTA domain
• Develop a real culture on palliative care and end-of-life	Social aspects
• 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 • Decrease health tourism within country (among regions) • Major public knowledge and awareness about Italian Legislation on palliative care	Legal aspects

INTEGRATE-HTA

Stakeholder Advisory Panels (SAPs) in Germany

Kati Mozygemba

Universität Bremen

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

INTEGRATE-HTA

Participants

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

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

Universität Bremen

INTEGRATE-HTA

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)

Universität Bremen

INTEGRATE-HTA

Examples of key issues raised
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 loosing PC as holistic approach

Universität Bremen

INTEGRATE-HTA

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"

Universität Bremen

INTEGRATE-HTA

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.

INTEGRATE-HTA

Scoping exercise in The Netherlands

Gert Jan van der Wilt

Participants

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

Data analysis

Reconstructing interpretive frame method

1. Problem definitions
2. Preferred solutions
3. Empirical and ethical background theories
4. Normative preferences

Logic model

Summary of the key findings
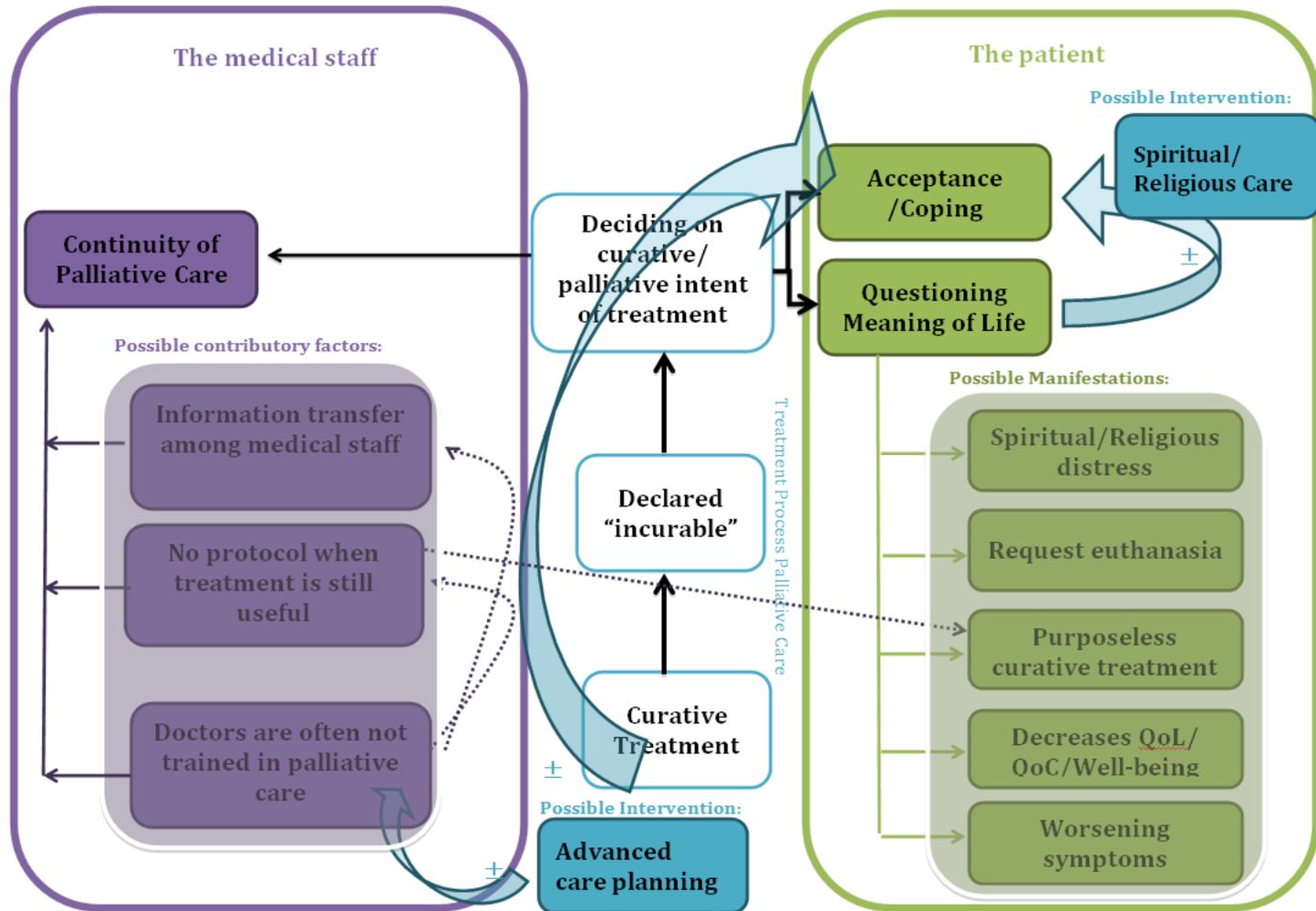
Lessons learned

Key problem

Transition form curative to palliative care

Solutions

- Interventions aimed at increasing spiritual well-being
- Continuity of palliative care
- Advanced care planning

INTEGRATE-HTA

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?

INTEGRATE-HTA

Implications for an HTA

Norway

Problem

Avoid hospitalisation and overtreatment at the end of life

$\longrightarrow$ 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?
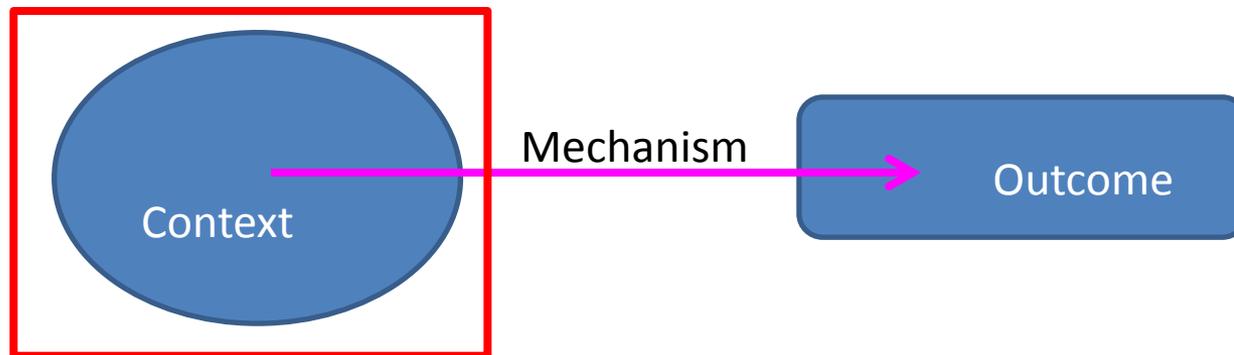
Implications for an HTA

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

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!

Universität Bremen

INTEGRATE-HTA

Implications for an HTA

Step 1

Scoping exercise

Step 2

Systematic review

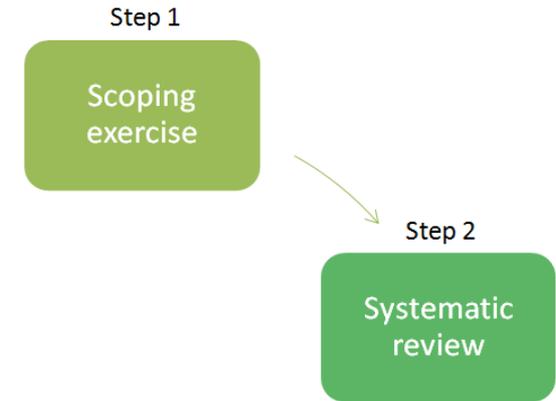*The Netherlands*

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

www.integrate-hta.eu

INTEGRATE-HTA