

INTEGRATE-HTA

Scoping: Involving stakeholders right from the start



**Dr Louise Brereton, Mrs Jacqui Gath & Mr George Wood
On behalf of the INTEGRATE-HTA project team**

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Purpose of the presentation

To share:

1. The rationale for stakeholder involvement in scoping and throughout the project
2. Ways in which stakeholders were involved throughout the project
3. The value of stakeholder involvement in the INTEGRATE-HTA project
4. Lessons learned about stakeholder involvement in HTA

Stakeholders

- Individuals or groups with an interest in the topic (in this case, palliative care)
- Lay people – i.e. patients caregivers, ex-caregivers and members of the public with an interest in palliative care
- Professionals – i.e. commissioners, practitioners including those with experience of home based palliative care and academics with an interest in palliative care
- Stakeholders aged 18 years and over played a key advisory role throughout the project



Rationale for stakeholder involvement (researcher view)

- Policy requirement in several countries
- Give stakeholders a 'voice' in HTA & allow them to influence decision making in the project.
- Assists understanding from stakeholder perspectives
- Potentially leads to an HTA that better meets stakeholder's needs
- Morally & ethically right

Rationale for stakeholder involvement (professional view)

- Allows professionals to influence the research agenda
- Potentially leads to findings that are more likely to be put into practice

Rationale for stakeholder involvement (lay stakeholder view)

- Desire to improve things
- Brings pragmatism and the real-world lived experience to the research
- Adds 'emotion' to the description of experiences
- Patients and carers can prioritise needs

Stakeholder involvement in scoping

Stakeholder Advisory Panels (SAPs) set up in each country.
132 stakeholders (82 professionals & 50 'lay' people)
provided information and advice across the seven
countries.

Two approaches were used:

- 1) Qualitative research approaches
- 2) Stakeholder consultation



Qualitative research approaches

Country	Methods	Stakeholders involved
Italy	Individual, face-face/telephone interviews using EUnetHTA core model as a framework.	7 lay & 8 professional stakeholders
Germany	Focus groups and face-face interviews using nominal group technique and categorical coding procedure informed by a Grounded Theory approach.	8 lay & 7 professional stakeholders
The Netherlands	Interactive evaluation using face-face interviews with subsequent case reconstruction using constant comparison.	2 lay & 12 professional stakeholders
Lithuania	Face-face , audio-taped interview & 2 focus groups. Transcribed & Thematic analysis.	9 professionals , including 3 who represented patient organisations.

Consultative approach

Country	Methods	Stakeholders involved
England	Stakeholders acted as 'research advisors' and took part in individuals or small group face-face / telephone discussions using an adapted version of the EUnetHTA core model.	20 lay & 34 professional stakeholders
Norway		5 lay & 5 professional stakeholders
Poland		8 lay & 7 professional stakeholders

Findings of the scoping exercise

Four common themes were identified across the seven countries – these themes included 23 issues that were common to 3 or more countries:

- 1. Knowledge and understanding;** e.g. training for professionals & family carers; recognition of patients with palliative care needs, nature, benefits & harms of palliative care, reduce stigma
- 2. Organisational dependent availability and access;** e.g. improve equity of access & availability of palliative care geographically/to groups in a timely manner – over or under treatment issues
- 3. Attitudes and clinical decision-making;** e.g. Communication & information giving is important
- 4. Continuity of care (outcome which is dependent of the three above pre conditions);** e.g. Improve the organisation & co-ordination of palliative care
Reduce hospitalisation and increase home care, Withdrawal of treatment & the transition from active to palliative care is an area of concern

Key issues selected as the focus of the palliative care case study

1. Family carer support
2. Home care

Selection of key issues was based on

- SAPs
- A review of review level evidence undertaken at the same time as stakeholder consultation

Most evidence relates to specialist palliative care – notably home based models of palliative care.

Home based palliative care could be divided into reinforced & non reinforced models (i.e. services with and without an additional element of caregiver support respectively)(Gomes et al 2013).

Stakeholder involvement throughout the project

Scoping (Step 1 & 2 of the INTEGRATE-HTA model)	Stakeholders assist in identifying HTA questions and comment on the project scope to ensure questions address relevant and important issues in palliative care.
Evidence Assessment (Step 3 of the INTEGRATE-HTA model)	Stakeholders assist by providing information and/or considering the evidence and how this relates to their experience of palliative care.
HTA Conclusion (Step 5 of the INTEGRATE-HTA model)	Stakeholders (decision makers and lay people) assist in considering the project findings and the implications of these in light of their experience of palliative care.

The value of stakeholder involvement

- identified priorities in palliative care which led to the focus on home care provision and family carer support early in the project;
- assisted development of the logic model;
- informed gaps in the effectiveness evidence;
- validated/confirmed findings for patient preferences and moderators of treatment effect, giving additional insights into these;
- provided expert opinion to assist economic modelling to predict the potential cost impact of additional carer support;
- informed the assessment of sociocultural aspects which focused on user-professional relationships and decision making.

Conclusions and lessons learned

- Stakeholder involvement is invaluable throughout HTA & increases legitimacy of HTA.
- Various approaches can be used to involve stakeholders throughout the HTA process but a number of methodological, ethical and practical issues need to be considered.
- In addition to assisting in identifying priorities, stakeholder advice can complement and enrich traditional forms of evidence to provide additional insights into the evidence base without creating heavy workload demands for researchers or stakeholders.
- Stakeholder information can enhance understanding of the technology, its application and its implications for practice and further research.

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Reading

- Abelson, J., Giacomini, M., Lehoux, P., & Gauvin, F. P. (2007). Bringing 'the public' into health technology assessment and coverage policy decisions: from principles to practice. *Health policy*, 82(1), 37-50.
- Gomes, B., Calanzani, N., Curiale, V., McCrone, P., & Higginson, I. J. (2013). Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. *Cochrane Database Syst Rev*, 6(6).
- Mitton, C., Smith, N., Peacock, S., Evoy, B., & Abelson, J. (2009). Public participation in health care priority setting: a scoping review. *Health Policy*, 91(3), 219-228.
- Oliver, S. (2006). Patient involvement in setting research agendas. *European journal of gastroenterology & hepatology*, 18(9), 935-938.
- Oliver, S., Liabo, K., Stewart, R., & Rees, R. (2014). Public involvement in research: making sense of the diversity. *Journal of health services research & policy*, 1355819614551848.
- Sharma, T., Choudhury, M., Kaur, B., Naidoo, B., Garner, S., Littlejohns, P., & Staniszewska, S. (2015). Evidence informed decision making: the use of "colloquial evidence" at nice. *International journal of technology assessment in health care*, 1-9.





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