



Collaborating for Success

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Collaborating for Success

- Successful Collaborations
- Patient Involvement in HTA
- Elements of Success?

- Views are my own

Collaboration

The process of two or more people or organizations working together to realize or achieve something successfully.

Collaboration is very similar to, but more closely aligned than, cooperation.

Most collaboration requires leadership, although the form of leadership can be social within a decentralized and egalitarian group.

Wikipedia

Successful collaboration



Successful collaboration



PPL Therapeutics

Ministry of
Agriculture



Ethics and Legal underpinning

Elements of success

- Identifying a problem
- Thinking widely about what might work
- Cross-sectoral working
- Developing a prototype
- Refining the model with all stakeholders - reflecting on what works well/challenges
- Engaging the public

Collaboration vs decisions?

Managing expectations

Topic	Buzz	Reality?
Research	Co-Production	Informed research Partnerships in research networks
Service design	User led commissioning	Multi-stakeholder input
HTA for resource allocation	Patient-centered	Fair to all service users patients involved
Managed entry (access) agreements		Patient group safe harbour, facilitator of stakeholders

HTA



Clinical research

What does the treatment effect mean in real life?

Who will benefit most from this medicine?

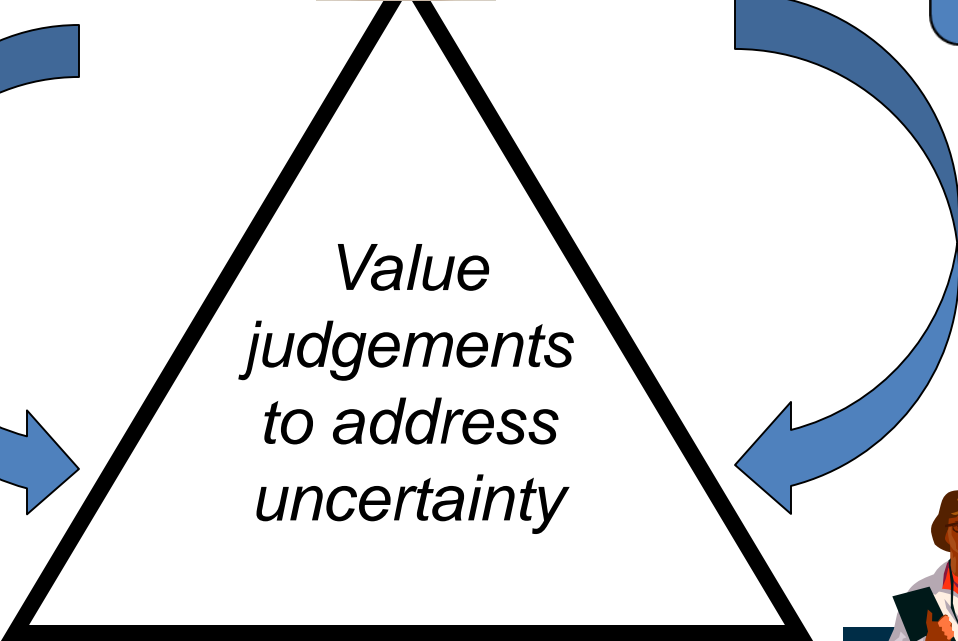


Genetic Alliance UK
Supporting. Campaigning. Uniting.

What are the long-term effects of treatment?



Organisation of Managed Access Agreement



Value judgements to address uncertainty

Patient-Based Evidence
- Qualitative Evidence Synthesis, Preference Studies

Reimbursement recommendation





Theorized Goals of Public and Patient Involvement in HTA
Final Report from the OHTAC Public Engagement Subcommittee. April 2015

Elements of success

- Honesty about what can be achieved, limitations, challenging behaviours
- Commitment to enable all stakeholders to be effectively involved
- Recognition of burden on patient groups vs uncertainty about value of input
- Review and feedback about sustainable approaches as views and processes evolve (including social, ethical, legal reflection)
- Consistency across all Member States (EUnetHTA guidance on participation?)
- Building relationships (trust)
- Leadership

Values for Patient Involvement in HTA	Quality Standards for Patient Involvement in HTA
<p>Relevance Patients have knowledge, perspectives and experiences that are unique and contribute to essential evidence for HTA.</p> <p>Fairness Patients have the same rights to contribute to the HTA process as other stakeholders and have access to processes that enable effective engagement.</p> <p>Equity Patient involvement in HTA contributes to equity by seeking to understand the diverse needs of patients with a particular health issue, balanced against the requirements of a health system that seeks to distribute resources fairly among all users.</p> <p>Legitimacy Patient involvement facilitates those affected by the HTA recommendations/decision to participate in the HTA; contributing to the transparency, accountability and credibility of the decision-making process.</p> <p>Capacity building Patient involvement processes address barriers to involving patients in HTA and build capacity for patients and HTA organizations to work together.</p>	<p>General HTA process</p> <ol style="list-style-type: none">1. HTA organizations have a strategy that outlines the processes and responsibilities for those working in HTA and serving on HTA committees to effectively involve patients.2. HTA organizations designate appropriate resources to ensure and support effective patient involvement in HTA.3. HTA participants (including researchers, staff, HTA reviewers and committee members) receive training about appropriate involvement of patients and consideration of patients' perspectives throughout the HTA process.4. Patients and patient organizations are given the opportunity to participate in training to empower them so that they can best contribute to HTA.5. Patient involvement processes in HTA are regularly reflected on and reviewed, taking account of the experiences of all those involved, with the intent to continuously improve them. <p>For individual HTAs</p> <ol style="list-style-type: none">6. Proactive communication strategies are used to effectively reach, inform and enable a wide range of patients to participate fully in each HTA.7. Clear timelines are established for each HTA with advance notice of deadlines to ensure that appropriate input from a wide range of patients can be obtained.8. For each HTA, HTA organizations identify a staff member whose role is to support patients to contribute effectively to HTA.9. In each HTA, patients' perspectives and experiences are documented and the influence of patient contributions on conclusions and decisions is reported.10. Feedback is given to patient organizations who have contributed to an HTA, to share what contributions were most helpful and provide suggestions to assist their future involvement.

For more information, please see the resources available on the HTAi Interest Sub-Group for Patient/Citizen Involvement in HTA at www.htai.org/index.php?id=545