Social sciences and ethics in early HTA

What have I learned about the twin challenges of user involvement, and social and ethical issues?

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AETMIS (1994-2004)

Upstream Research (2005-…)

KT&E activities...

A personal timeline...

Downstream Research (1992-2006)

AETMIS (1994-2004)

Upstream Research (2005-…)

A personal timeline...
1st observations-Downstream research
Hypotheses about the context of use and users’ expectations

- Designers
  - Setting
  - Technology
  - Initial plan

- Users

Real world

Does the technology achieve stated goals?
Does it induce other effects?
Theory of use: planned vs. real world


(Re)production of structures

Physicians as users
Social & technical adaptation (use in context)
Teleconsultation

Constraints
Duality of structures
Opportunities

Clinical & social routines (anxiety & self-esteem)
Definition of users’ needs
1st observation—Downstream research

Technology developers’ hypotheses regarding users’ expectations and the context of use are often under-developed.

Yet, they pave the way to failures, shortcomings and unanticipated learning-by-doing.
2nd observation-Social sciences and ethics
How medical specialists appraise three controversial health innovations: scientific, clinical and social arguments

Pascale Lehoux¹, Jean-Louis Denis¹, Melanie Rock², Myriam Hivon³ and Stephanie Tailliez³
Value of technology

- Value is not to be found in the technology itself
- Rather, it is embedded in the meaningful activities that it helps bring about Ramirez (1999)
- Value is intimately linked to a technology’s perceived ability to extend users’ competencies and range of action
<table>
<thead>
<tr>
<th>Clinical</th>
<th>Technical</th>
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<tr>
<td>Impact on clinical activities and outcomes</td>
<td>Technical assets and comparison with technological alternatives</td>
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<tr>
<td>Structural</td>
<td>Human</td>
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<tr>
<td>Impact on work processes and health care structures</td>
<td>Response to clinicians’ and patients’ values, expectations and constraints</td>
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<tr>
<td>Clinical</td>
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<td>Reducing risks and complications associated to current practices</td>
<td>Real-time feedback</td>
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<td>Effectiveness, safety and patient outcomes</td>
<td>Precision, performance and simplicity</td>
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<td>Precision, early diagnosis, improved detection rate</td>
<td>Modularity, flexibility, interoperability and adaptability</td>
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<td>Objectivity, predictability, improved clinical decision-making</td>
<td>Providing more biomedical information</td>
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<td>Proactive care/responsiveness</td>
<td>Technical improvements reducing side effects</td>
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<td>Support research</td>
<td>Completeness of the solution</td>
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<tr>
<td>Reach a greater number of patients</td>
<td>Accuracy of databases</td>
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<td>Feedback to caregivers</td>
<td>Paperless environment</td>
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<td>Compliant patients</td>
<td>Transportability</td>
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Implications

- Clinical and technical improvements are, in principle, unlimited; they fuel each other.
- Structural valuable features are often in direct contradiction with those in the other categories.
- How do we sort out which technologies bring a more (or less) valuable response to health care needs?
2nd observation—Social sciences and ethics

We continuously mobilize, explicitly or tacitly, social and ethical claims to justify why a given technology is valuable or not.

But, our ability to reason the “big picture” remains limited.
3rd observation - User involvement in technology development
Clinicians as technology designers?

- Innovation policies increasingly foster collaborative ventures between industry and clinicians

- Clinicians can, in principle, identify and articulate **clinical needs** and provide relevant input regarding the **context of use**
Design process

Problem-setting

Problem-solving

Design and user involvement strategies

Needs and issues prioritized
Two contrasting problem-solving strategies

- **Problem-driven processes**
  - Significant efforts are devoted to documenting and analyzing the problem the technology is supposed to solve

- **Solution-driven processes**
  - Mostly seek to further develop a technological solution (Kruger & Cross, 2006)
<table>
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<th>Problem-setting</th>
<th>Labor decision support software</th>
<th>Home telehealth monitoring</th>
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<tr>
<td>Needs and issues prioritized</td>
<td>Birth-related injuries wrongly perceived as unpredictable</td>
<td>Growing clinical needs Healthcare system challenges</td>
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<th>Problem-solving</th>
<th>Solution-driven design</th>
<th>Problem-driven design</th>
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<td>Design and user involvement strategies</td>
<td>Late and low user involvement</td>
<td>Early and high user involvement</td>
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1. The way a technology design team engages in problem-setting is influenced by its initial hypothesis regarding the needs and issues its innovation is supposed to address.

2. Subsequently, the type of design process it will deploy (e.g., problem- vs. solution-driven) conditions the scope of user feedback it may gather and respond to (Lehoux et al., in press).
Implications

- A solution-driven process may support focused R&D activities, but it narrows down the scope of user feedback that may be gathered:
  - It emphasizes usability over relevance

- While clinical needs and health systems needs may at times be synergistic, there are situations in which they are conflicting
3rd observation-User involvement

Health services and policy research expertise would bring a valuable, early contribution to technology development
Can “early HTA” help address the twin challenges?

Social/ethical issues
- Secondary Research
  - Reviews (qual, quant or mixed)
  - Quantitative
  - Qualitative
- Primary research

User involvement (patients, public, clinicians, decision-makers, etc.)
- In HTA
  - Agency-level
  - Report-level
- In technology development
  - +/- structured process
What (I think) I have learned

- Public and/or patient involvement is not a substitute for a proper analysis of ethical and social issues.

- User involvement is not sufficient for designing health technologies that are (more) relevant from a healthcare system standpoint.
What (I think) I have learned

- Clear need to flesh out/validate technology developers’ hypotheses about valuable goals and features
- And to spell out what health system needs and challenges are

Two video clips on Hinnovic.org
What (I think) I have learned

“Downstream” research
- Arrives too late to:
  - Realign substantially technology design assumptions
  - Address relevance

“Upstream” research
- Arrives too early to:
  - Tap on learning-by-doing
  - “Rank order” user preferences
What health technologies do we need to overcome the challenges of healthcare systems?