Health technology assessment in genetics and the role of AETMIS in policy making

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AETMIS
Objective

• What kind of partnerships between Public Health Genetics and stakeholders should be encouraged?

• What impact do scientific advisory bodies have on policy making?
Overview

• HTA

• HTA in genetics

• AETMIS genetics unit

• Discussion
  Partnerships and impact on decision-making
Health Technology Assessment (HTA)
HTA as an aid to decision-making

Science

Decision-making

\{ micro, meso, macro \}

Battista & Jacob, 1994
Definition of HTA

“HTA is a multidisciplinary field of policy analysis. It studies the medical, social, ethical et economic implications of development, diffusion and use of health technologies.”

INAHTA
- medical and surgical procedures
- instruments, devices, medications
- modalities of health care delivery and service organization
- techniques supporting the system’s infrastructure and organization

AETMIS
HTA steps

- Framing the question
- Collecting evidence
- Critical analysis of evidence
- Synthesis of evidence
- Contextual analysis
- Formulating recommendations

Assessment

Appraisal
HTA in Genetics
Evaluative Framework

Blancquaert, Bouchard, Chikhaoui, de Langavant, 2001
Methodological challenges

• Summarizing information
  – multiple dimensions
  – high level of uncertainty

• Integrating context and multiple stakeholders’ perspectives in appraisal and formulation of recommendations
Methodological challenges

• Requires interdisciplinary teamwork

• Calls for openness, reflexivity and transparency
  – Openness to issues beyond traditional HTA
  – Reflexivity with respect to one’s own values
  – Transparency with respect to the reasoning underlying the appraisal
AETMIS

Agence d’évaluation des technologies et des modes d’intervention en santé

Québec
AETMIS

• CETS 1988 - AETMIS 2000
• Board of Members
• Mission
  – Advice to Minister of Health and Social Services
  – Knowledge transfer
  – Promotion of evidence-based culture
  – Training

⇒ Advisory body, at arm’s length
AETMIS Genetics Unit

1996-1999  Context
2000-2001  Activities
2002-2004  Impact
1996-1999

• **Context**
  – scarce resources
  – no official integration of molecular biology
  – low priority on political agenda

• **AETMIS Genetics Unit activities**
  – multidisciplinary advisory committee
  – 4 reports on molecular diagnosis/screening for:
    - myotonic dystrophy
    - Duchenne muscular dystrophy
    - hereditary tyrosinemia
    - fragile X syndrome
1996-1999 impact

• **AETMIS**
  - developing methodology & building interdisciplinary team
  - establishing collaborations & building credibility

• **Partners**
  - no ‘instrumental’ impact on policy
  - request for health technology assessment reports
  - impact on laboratory practice (and institutions)
  - moving genetics upwards on the policy agenda
2000-2001

• **Context**
  – funding agencies’ emphasis on applicability and evaluation
  – exacerbated concerns with oversight mechanisms

• **AETMIS Genetics Unit activities**
  – requests for informed opinions on technology transfer process and on oversight mechanisms
  – requests to participate in research projects
  – requests for collaboration (HTA, Public Health)
2000-2001 impact

• AETMIS
  – broadening of scope of activities
  – opportunities to share methodology

• Partners
  – increasing awareness of evidence-based culture in genetics community
2002-2004

• **Context**
  – knowledge transfer
  – evidence-based policy
  – national HTA strategy

• **AETMIS Genetics Unit activities**
  – Symposium on HTA in genetics and policy-making in Canada
  – APOGEE-Net, a network to assist policy-making in genetics
2002-2004 impact

• AETMIS
  – active role in knowledge transfer
  – alternative sources of funding

• Partners
  
  – Action Plan for the organization of genetic services in Québec
Discussion
Impact on decision-making

• Impact occurs at different levels of decision-making (micro, meso, macro)

• Knowledge utilisation:
  – instrumental (problem-solving)
  – strategic
  – enlightenment (problem-framing)
Partnerships and impact

- Partnerships and impact
  - context-driven
  - consolidated over time, from micro to macro
  - are a function of credibility and trust
Partnerships and impact

• Credibility depends on
  – methodological rigor
  – thorough contextual analysis

• Trust depends on
  – transparency and reflexivity
  – critical distance with stakeholders
  – institutional independence
Challenge

Independence versus Service relationship

- institution at arm’s length
- editorial independence

- policy-makers identified as ‘client’
- public funding: accountability & efficiency
Challenge

Independence versus Service relationship

➔ Negotiations with policy-makers:

• balanced perspective  
• methodological rigor  
• relevance for micro & meso

• scope of HTA  
• timelines  
• priorities
Conclusion

• Solid partnership at micro level:
  – essential to build credibility and trust
  – groundwork for relevance and impact at macro level

• Paradoxical effect of close collaboration with policy-makers?
  Evidence-based policy *versus* evidence-based medicine