

LE COMMISSAIRE À LA SANTÉ ET AU BIEN-ÊTRE



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Integrating ethics into policy decision making: Consultation on the ethical issues of prenatal screening for Down syndrome in Quebec



Public Health Ethics: A Tool for Deliberation and for the Development of Healthy Public Policies -
JASP, November 24, 2010

Ghislaine Cleret de Langavant, Deputy Commissioner responsible for Ethics



Outline

- The Health and Welfare Commissioner
 - Mission statement
 - methodological approach
- Consultation on the ethical issues of prenatal screening for Down syndrome in Quebec
 - Consultation stages
 - Results
- Consultation Forum: Contributions and challenges



The Health and Welfare Commissioner



The Health and Welfare Commissioner

- Evaluate
- Consult
- Inform
- Recommend



The Consultation Forum

- > 27 members, consisting of:
 - 18 persons from the different regions of Quebec
 - 9 persons with specific expertise in health and social services

- > The Commissioner appoints members for 3-year mandates



The Consultation Forum: Mandate

- > To provide the Commissioner with new perspectives on the issues that the Commissioner submits to it
- > To help carry out the Commissioner's mandate
- > The Forum's conclusions are included in the Commissioner's reports, which are sent to the Minister and tabled at the National Assembly.



Methodological Approach:

Appraising performance

Ethical deliberations



Some completed and ongoing work

- > Consultation on the ethical issues in prenatal screening for Down syndrome (or trisomy 21) in Québec (2009)
- > Appraisal report on performance in primary care (2009)
- > Appraisal report on performance in chronic disease care and services (2010)
- > **Advisory opinion on rights and responsibilities (December 2010)**
- > Appraisal report on performance in perinatal and early childhood care (2011)
- > Appraisal report on performance in mental health care and services (2012)



The nature of policy decisions

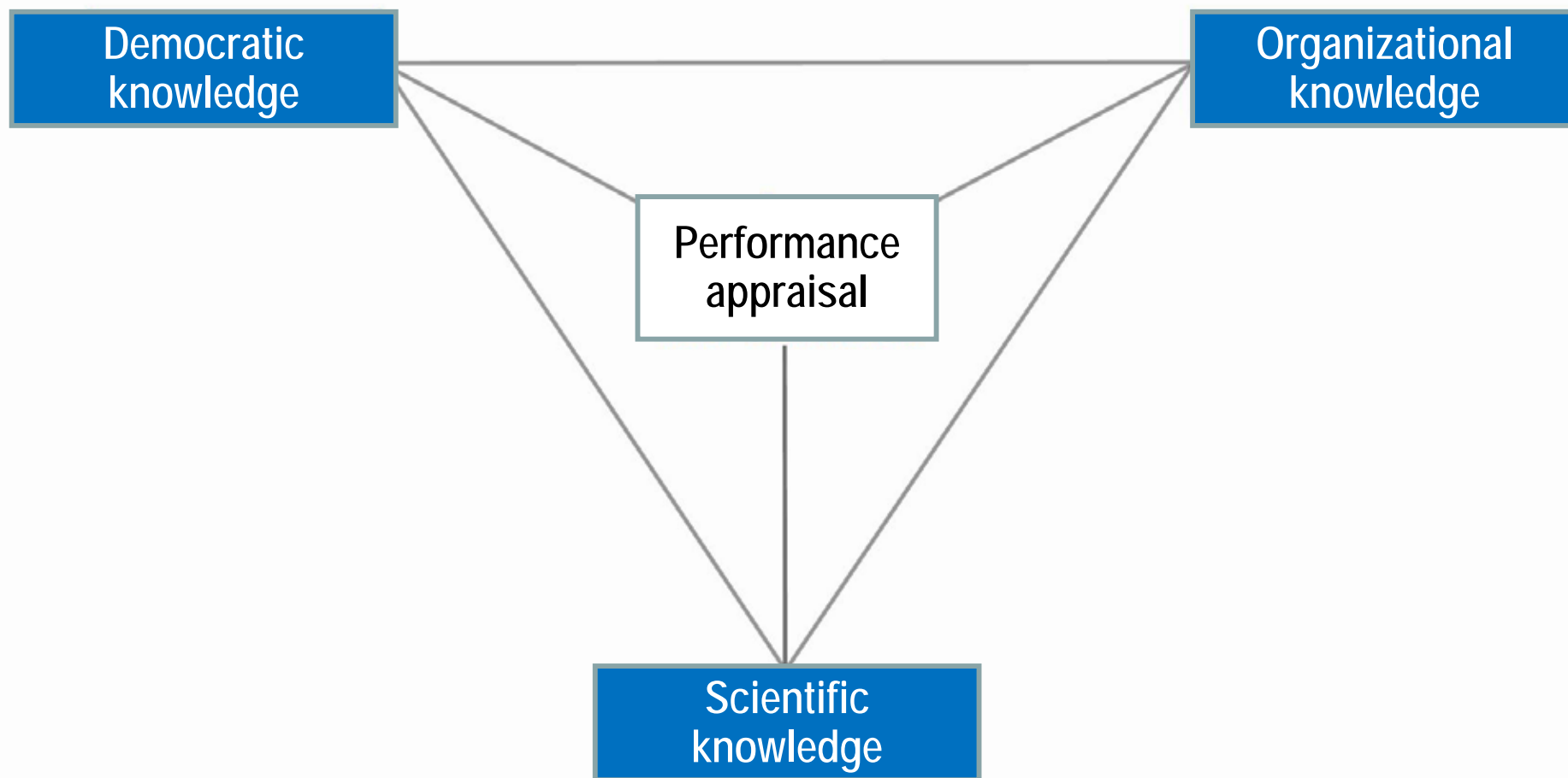
- Science needs to inform not only about potential action but also about **realizable** action according to the **context** (**sensible** vs. **rational** decisions)
- Need to account for:
 - the tensions between social values and the potential consequences of the actions taken
 - the nature of the risks, the interests involved, the distribution of advantages and disadvantages between social groups, and cultural and policy factors



Greater variety is needed in sources of knowledge



Performance appraisal components





Consultation



Screening program proposed by the MSSS

- Prenatal screening of all pregnant women, regardless of their age
- Free and informed consent after receiving complete, non-directive information
- Screening approach chosen: serum integrated screening (serum markers in the mother's blood in the 1st and 2nd trimesters of her pregnancy and a dating ultrasound in the 1st trimester)



Services currently offered in Quebec

- > For the last 20 years, the public health and social services system has offered prenatal diagnostic testing for Down syndrome to women 35 years of age and older.
- > Prenatal screening services for Down syndrome have been offered irregularly and in different forms in the public and private sector.



Screening and diagnosis

- > The screening assesses the *probability* that a pregnant woman is carrying a foetus presenting with T21: non-invasive
- > The diagnosis *determines* whether a foetus does or does not present with an anomaly. The risk of losing the foetus is assessed at 0.6%-1%.



Consultation stages

1. Literature review (January 2008)

2. Consultation in three phases:

- Position papers and hearings: persons concerned with the screening (Feb.-May 2008)
- Online consultation: wider outreach (June 2008)
- Deliberative sessions of the Consultation Forum: persons not directly concerned (June-Sept. 2008)



Results/Conclusions



Position papers and hearings

- The equitable availability of quality services
- Women reclaiming control over their pregnancies
- Human dignity and the acceptance of difference



The equitable availability of quality services

- Equity in the service offered
- Need to change the status quo
- What's being done elsewhere in the world



Women reclaiming control of the maternity experience

- Facilitate free consent
- Facilitate informed consent
- Importance of assistance and support



Human dignity and accepting differences

- Accepting differences
- The “quest for the perfect child”
- Eugenics and discrimination
- Free and informed consent: a mirage?



Online consultation

- Profile of respondents
- Level of agreement with:
 - the **principle** of prenatal screening for Down syndrome
 - the **free offer** of a prenatal screening test for Down syndrome



Consultation Forum

Different options considered:

1. Withdraw existing services?
2. Maintain the status quo?
3. Improve existing services?



Response to the needs of persons with Down syndrome and their loved ones

- Social integration of persons presenting with Down syndrome
- Accessibility of specialized care and services
- Support and families' experience



Main findings from the consultation

- Persons with Down syndrome and their loved ones experience discrimination and face social integration problems.
- The screening tests are not offered consistently across the health and social services network and the private sector and are of different forms and varying reliability:



Unequal access to high-quality information

- Problems in terms of the content of the information provided before testing and how that content is presented.



Do the parents enjoy free and informed choice?



Principle of parents' free will

- The principle of the free will of parents in procreation came up several times during the consultation:
 - When the consequences of a child's birth were considered significant
 - The level of agreement with this principle was seen in the results from the online consultation
 - Limits may be imposed on this principle through socially shared values and enacted laws



Main conclusions of the consultation

- Screening must remain an individual decision
- This decision has societal repercussions that call for action by the state
- In order to avoid a systematic offer of a screening test becoming systematic screening:
 - Fair and balanced information must be given to parents
 - Support must be provided to persons with Down syndrome and their loved ones



Facilitate free and informed consent and avoid increased discrimination



Consultation Forum: Contributions and Challenges



Deliberations of the Consultation Forum

- 3-4 sessions/dossier
- Consultation guides
- Deliberations on ethical issues and acceptability
- Multiple approaches to stimulate discussion
- Independent facilitation
- External evaluation of the experience (research project)



Different approaches for different objectives

- > Ethical issues raised by prenatal screening for Down syndrome
 - > independent contribution of the Forum
- > Assessment of system's performance:
 - > perceptions of the acceptability of the recommended actions
 - > the ethical issues are integrated in the final stage of the evaluation as part of discussions of the recommendations' implications



Positive contribution of the Consultation Forum

- > Complexity and depth of the discussions
- > Confrontation of diverging rationalities
- > Discussions led by individuals with no vested interest in the issue
- > Consultation Guide: Making the dossier's issues explicit clarifies the many sides of a complex issue for the Commissioner
- > Forum members actively participate, despite the demanding nature of preparations
- > Positive feedback from members



Procedural challenges

- > The funds required to organize the sessions and prepare the members for the deliberations
- > Sufficient information vs. excessive influence
- > Complexity of the issues raised and the time set aside for deliberation
- > Record of the proceedings: in what format and how should it be validated?
- > Issues concerning procedural transparency



Methodological challenges

- > How should Forum participants' contributions be evaluated?
Relevance to members and their motivation
 - > Should the Commissioner take part in the deliberations?
 - > Should members' contributions be **a part** of an evaluation or be **kept separate**?
 - > Impact on how the information is presented and members' motivation
- Is the Consultation Forum a **means** to an end or an **end in itself**?



General challenges in integrating ethics

- > Several challenges remain:
 - > Integrating ethical deliberations into the evaluation
 - > Making the different sources of knowledge explicit (performance indicators and “procedural information”)
 - > How can we make the participation of Forum members as effective as possible while trying to maintain their independence?



Contribution of the deliberations?

- > The deliberations may represent a significant contribution to policy decision making.
- > However, they are demanding: creating appropriate conditions for the deliberations requires time, energy, funding, flexibility and creativity.



THANK YOU FOR YOUR ATTENTION !

<http://www.csbe.gouv.qc.ca/>



Required Actions



Provide parents with fair and balanced information

- The nature of the information:
 - Down syndrome and living with a child with Down syndrome
 - Abortion and mourning
 - Technical aspects (probability, false positives/negatives, etc.)
 - All the conditions that may be detected at the same time (anomalies of the neural tube: spina bifida)
- How the information is produced and communicated: by many different care givers, depending on their expertise and the nature of the information (physician, midwives, genetic counsellors, members of parent associations, etc.)
- Making the information available in a timely manner



Other required actions

- Provide support for parents, independent of their decision
- Implement follow-up mechanisms (practice standards)
- Allocate sufficient resources to the program
- Ensure a transparent process
- Assess the current needs of persons with Down syndrome and their loved ones
- Sensitize people to the contributions made by persons with Down syndrome
- Train professionals and support research



THE 9 MEMBERS WITH SPECIALIZED EXPERTISE

- > Three health care and social service practitioners (medicine, nursing, social work)
- > A health and social services manager or administrator
- > An expert in assessments of health and medication technologies
- > An expert in ethics
- > A university-based health researcher
- > Two persons from industries related to health or well-being (education, economics, environment, labour)