Online Direct-To-Consumer Genetic Testing

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Online DTC Genetic Testing

- My perspective, experience, background
  - Primary care provider
  - Member of Ontario Provincial Advisory Committees
    - NBS, Prenatal Genetic Screening, CRC Screening
Online DTC Genetic Testing

- My perspective, experience, background
  - Researcher in primary care genetics
    - Knowledge translation
    - Developing practical genetics tools for practice
- Health care providers:
  - Willing to be involved in delivery of new genetics services
  - Challenged by lack of knowledge and rapid pace of genetic discovery
Health care provider comments

- Complete report highlighting major points for consideration
- Increasing public awareness and interest in genetic testing
  - Family history
  - Inherited conditions
  - Availability of GT
- Use of internet inevitable
Health care provider comments:
Concerns re online DTC GT

- Hype – DTC GT may be offering more than is delivered
- DTC GT will involve health care system
  - Potential for increased cost
  - “Raiding the medical commons”
    - “follow-up testing and treatment on the basis of PGT results of unproven clinical significance is an unjustified use of healthcare resources and constitutes a raid on the medical commons”
  - McGuire and Burke 2008
Health care provider comments:
Concerns re online DTC GT

- Involvement of health care system
  - Advice about DTC GT
    - Challenge: lack of knowledge of benefits, risks and limitations
  - Meaning of results:
    - Accuracy
      - May repeat aspects of the test
      - May act on incorrect information
Health care provider comments:
Concerns re online DTC GT

- Involvement of health care system
  - Meaning of results:
    - Clinical utility
      - HCP may not fully understand meaning of GT results
        - inappropriate referrals
        - misinterpretation of test results
        - Inappropriate decision making by pt and family
      - HCPs may change their screening and testing
Health care provider comments:
Concerns re online DTC GT

- Involvement of health care system/primary care
  - Clinical utility
    - Will knowledge of personal genome GT results make a difference to outcomes?
    - Will patients change their health and screening behaviours?
Health care provider comments: Concerns re online DTC GT

- Potential harms
  - Increased anxiety
  - Labelling effect
  - Fatalist or complacent attitude to screening
Health care provider comments: Policy options

- **Option 1: Control access to GT for more serious conditions**
  - Agree with importance of discussing benefits, risks and limitations with HCP

- **Option 2: Existing consumer protection laws**
  - FTC: consumer information sheets & talk with your HCP
  - Downloading discussion to publically funded health care system

- **Option 3: Enhance information availability**
  - Requires genetics education initiatives for public and HCP
Health care provider comments: Research questions

- Does DTC GT affect screening, health behaviours and health outcomes?
- Does DTC GT affect health care utilization (visits, other tests) and cost?