Consent, Privacy and Research Biobanks: commentary from the public’s perspective

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Disciplines of Genetics / Surgery (Ophthalmology),
Memorial University of Newfoundland
Professional background

- MSc (UBC) 1965 – Drosophila genetics
- Memorial University (1978 - present)
  - initial funding from CNIB (research asst)
    - Ocular Genetics Clinic with Dr Gordon Johnson (St John’s / rural clinics)
    - review of CNIB records
    - Cancer Genetics from 1982
- PhD (MUN) 1991-5 – Cancer Genetics
- Lecturer (1988), Professor (2002)

Genetics Research with Families in Newfoundland and Labrador
Newfoundland as a unique population

- coastal settlements (*outport*)
- large family size
- descendants lived in same area
- religious segregation, and geographic isolation

*genetic isolates / founder effect*
To obtain consent and continued participation

- Over 50% of NL population lives in rural communities of less than 2500 - must go to the population to inform and to conduct research
- Explain potential value of research, provide feed-back, screening recommendations, itinerant teachers, genetic testing
- Individual sessions, letters, group meetings, newsletter
Hereditary non-polyposis colon cancer

Types of tumour; age of onset
- clinical screening recommendations
Identification of gene; mutation
- genetic testing
‘The public’ is made up of individuals and families

including the affected and unaffected members of NL families involved in research on hereditary eye diseases and hereditary cancers
‘Informed’ Consent

- Consent is readily (and repeatedly) given when information has been provided - knowledge translation before, during and after the research
- Some become aggravated with repeated request for consent – because they say that they have provided consent already
- Increasingly difficult to recontact as population moves for economic reasons
Perspective of family

- 1979 – infant born with severe eye disease → pedigree studies
- 1980-85 – rural clinics to see family members
- 1985 -2009 – molecular studies
- 2009 – gene/mutation identified

‘Thank you for persisting’
‘Is there is any other research you would like us to take part in?’
Perspective of NL families

- Willingness to participate in genetics research that will help
  - themselves
  - their family
  - other families
Education of the population
Funding for KT

- Important to maintain or increase the level of funding for knowledge translation so that individuals will understand and continue to participate in biobank research.
Options for consenting

- Consent for each project
- Broad initial consent with appropriate governance
- Opt out model
Genetics Research in Newfoundland and Labrador: Implications for health care

A presentation and discussion with
Dr. Jane Green, PhD, Discipline of Genetics, Faculty of Medicine, Memorial University

Wednesday, October 7, 2009, 7 to 8 pm
Fogo Island Health Centre, Activity Room
...Fogo

Twillingerate

Moreton’s
Harbour....

All around the circle