

Commentary from the Policymakers' perspective

Dr. Gregory Taylor
Director General
Office of Public Health Practice (OPHP)
Public Health Agency of Canada

PHAC Role

The Role of the Public Health Agency of Canada is to:

- Promote health;
- Prevent and control chronic diseases and injuries;
- Prevent and control infectious diseases;
- Prepare for and respond to public health emergencies;
- and,
- Strengthen public health capacity in a manner consistent with our shared understanding of the determinants of health and of the common factors that maintain health or lead to disease and injury.

PHAC Goal

The primary goal of the Public Health Agency of Canada is to strengthen Canada's capacity to protect and improve the health of Canadians and to help reduce pressures on the healthcare System.

Creutzfeldt-Jakob Disease Surveillance System (CJD-SS)

- An enhanced surveillance system established in April 1998
- Purpose: to minimize the impact of prion diseases on the health of Canadians through comprehensive, active surveillance
- Involves the collection of human biological materials
 - e.g. brain, blood, cerebral spinal fluid (CSF)

CJD-SS and Option 1

- CJD-SS early model of consent was consistent with Option 1: specific and fully informed consent for each project.
- Technological and scientific advances have led to the development of novel approaches.
- Potential uses of specimens were not envisaged
 - Techniques or tests did not even exist when CJD-SS was established

CJD-SS and Option 2

- CJD-SS recently transitioned to a layered model of consent similar to Option 2
- Separate written consent is requested for **ALL** parts of the study; *e.g.*
 - autopsy
 - genetic analysis
 - donation of biological materials for research:
 - Blood and Brain specimens
 - Cerebral Spinal Fluid (CSF)
- Most up-to-date protocols and consent forms are being presented to over 70 Research Ethics Boards (REB) across Canada

Opt-Out: Option 3

- Public Health Practice perspective
 - Trust
 - F/P/T relations
- Biobank Utility
- Legal risks?

Conclusions

- The evolution of the CJD-SS demonstrates that Option 2 is the most feasible option from a public health perspective
- Option 3: more difficult to justify

Another consideration:

- Would a functional multi-centre review model contribute to solutions?