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Creating an Assisted Reproductive Technologies Registry in Canada: Rationale and Viability

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The Current State

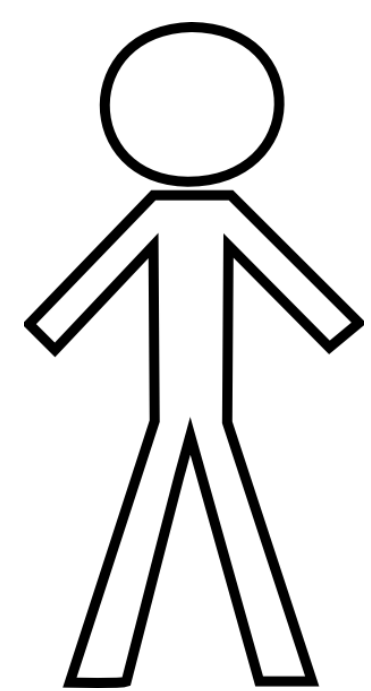
- Canada does not have a federal, public registry
- Ten jurisdictions prohibit anonymous gamete donation (7 European nations, 2 Australian states, New Zealand)
- **Linked** registries (e.g. Denmark – IVF/ birth/ cancer)
- **Private** registries (e.g. Donor Sibling Registry)
- **Public** registries (e.g. U.K. HFEA)
- A **combined** approach (e.g. Canada – provincial centralized birth registry, BORN, and federal independent registry, CARTR)

The Problem

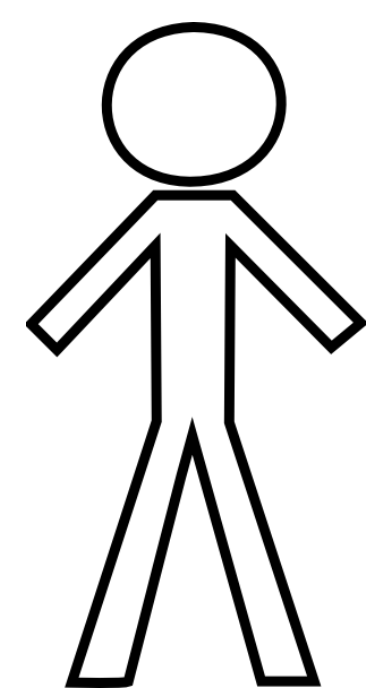


CLINICS

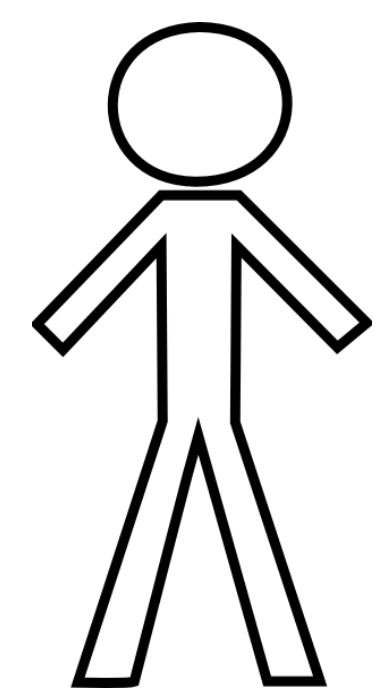
Cost of data collection



PARENTS OF
DONOR
CONCEIVED
CHILDREN



DONOR
CONCEIVED
CHILDREN
Right to know
Health Conditions



DONOR
Right to privacy

- Data protection and privacy of data stored
- Accuracy of data collected when not mandatory
- Inability to access large volume of health information

Methodology

- Scoping study of global literature
- Answer questions about registry's scope and regulation
- Address ART registry conception and design on a global level
- Determine purpose and justification for creating an ART registry
- Identify the type of information collected by major ART registries and how they address stakeholders' interests

10,245 unique records

- QuickLaw: 433
- LegalTrac: 786
- PubMed: 1,694
- SCOPUS: 7,332

5,188 eligible for screening

594 articles retained for data extraction

Study 1: rationale for registries

Study 2: registry use and impact

Preliminary Findings

WHY ESTABLISH REGISTRIES?

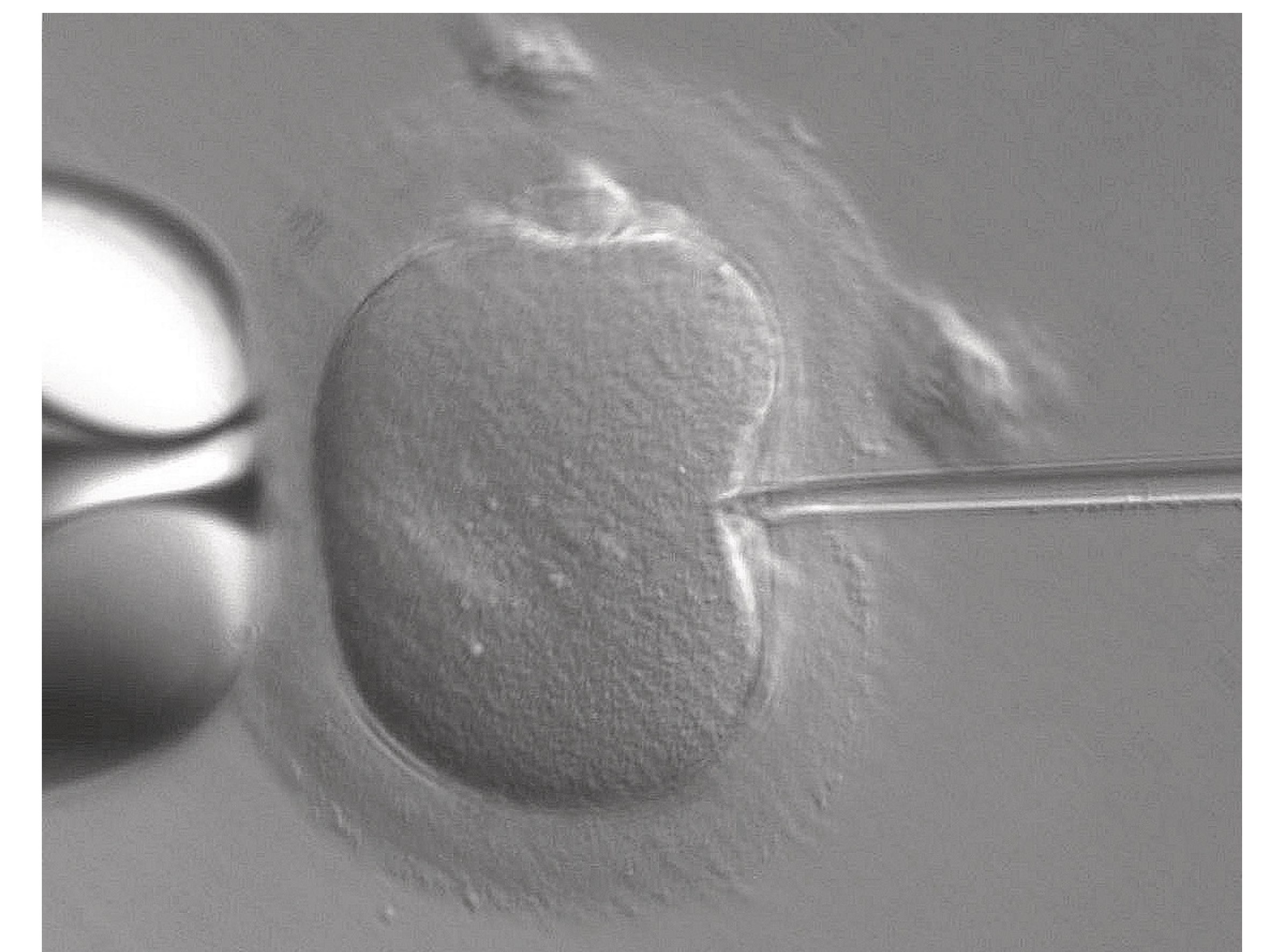
- **Compliance:** decreased in cases of voluntary registries
- **Health and safety:** medical and genetic information on diseases
- **Health research:** valuable data

HOW SHOULD THEY WORK? HOW ARE THEY USED?

- **International use:** IVF utilization, comparative studies, trends
- **Governance:** provincial/ state and federal/ national
- **Stakeholders:** clinical recommendations, individual decision making

Bibliography

Vincent Couture et al, "Strengths and pitfalls of Canadian gamete and embryo donor registries: searching for beneficent solutions" (2014) 28 Reproductive BioMedicine Online 369.



A sperm cell being inserted into an oocyte (egg cell) via a capillary tube, through the zona pellucida (outer membrane of the egg cell). (CC Image courtesy of ZEISS Microscopy on Flickr.)