



UNIVERSITY  
OF MANITOBA

# Translating to the Community (T2C): A social epigenetic study of FASD



T2C Community-Clinic-University  
Partnership

Dr. Brenda Elias, Director

Colleagues:

Dr. Geoff Hicks

Dr. Ana Hanlon-Dearman

Dr. James Davie

Garry Munro (CNTHC)

Betty Head (CNTHC)

Swampy Cree Tribal Council Communities

Manitoba FASD Clinic

Expansion to Reunion Island (France)

Michael Kobor, Paul Pavlidis (UBC)

Abraham Fainsood (Hebrew University)



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LIQUOR & LOTTERIES



# Learning Objectives

- Learn about social bio-repository elements to advance new diagnostic tools and realign community-clinical processes.
- Learn about the participatory research processes to design a social bio-repository.
- Discuss opportunities and challenges in developing social bio-repositories.

# Fetal Alcohol Spectrum Disorders

- Umbrella diagnostic term
- Neurodevelopmental, recently viewed as a whole body disorder
- Effects include physical, cognitive, memory, behavioural & learning difficulties
- 428 comorbid conditions, spanning across 18 of 22 ICD-10 chapters
  - congenital malformations, deformities, and chromosomal abnormalities
  - mental and behavioural conditions
- Premature development of diseases (e.g., auto-immune conditions, early onset dementia, metabolic conditions)
- Life-long disability
- Shortened life-expectancy

## Fetal Alcohol Spectrum Disorders



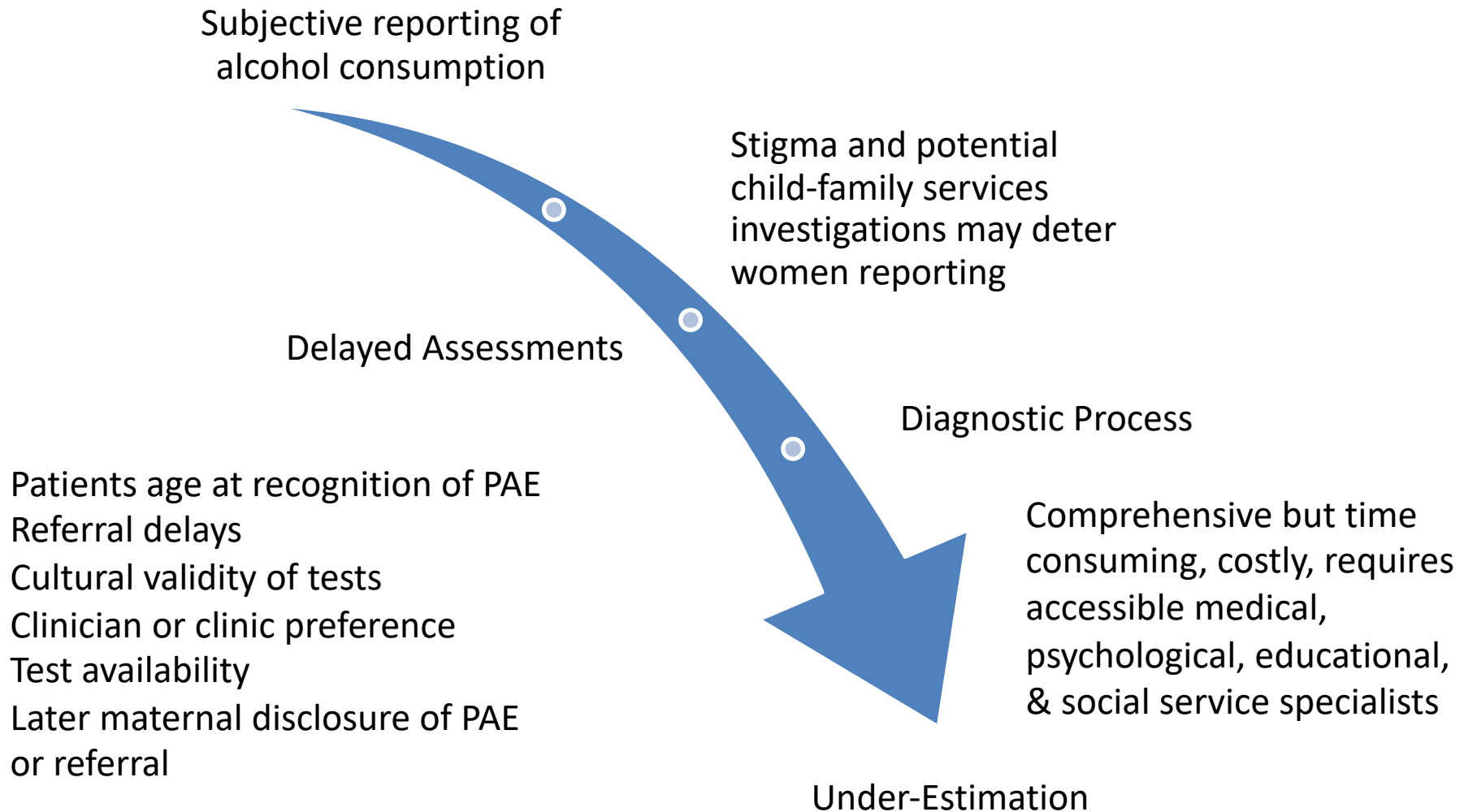
Emily Travis, left to right, Myles Himmelreich, and C.J. Lutke  
Led a ground breaking study of early onset chronic disease

# ? Prevalence ?

- While alcohol exposure is the cause of FASD, not all individuals prenatally exposed to alcohol develop FASD.
- Worldwide prevalence ranges from 1% to 5%.
- Prevalence is underestimated



# Drivers of Under-Estimation



# Diagnostic Challenges



**Full suite of diagnostic criteria cannot be assessed at infancy**

**Age at diagnosis, 3 to 11 years, difficult to assess in later years**

**No diagnostic test for adults**

**Definitive neurodevelopmental profile not yet established**

**Lacking established approach to assess PAE as a risk for co-morbid conditions**

# Our quest for improved understanding and diagnostics

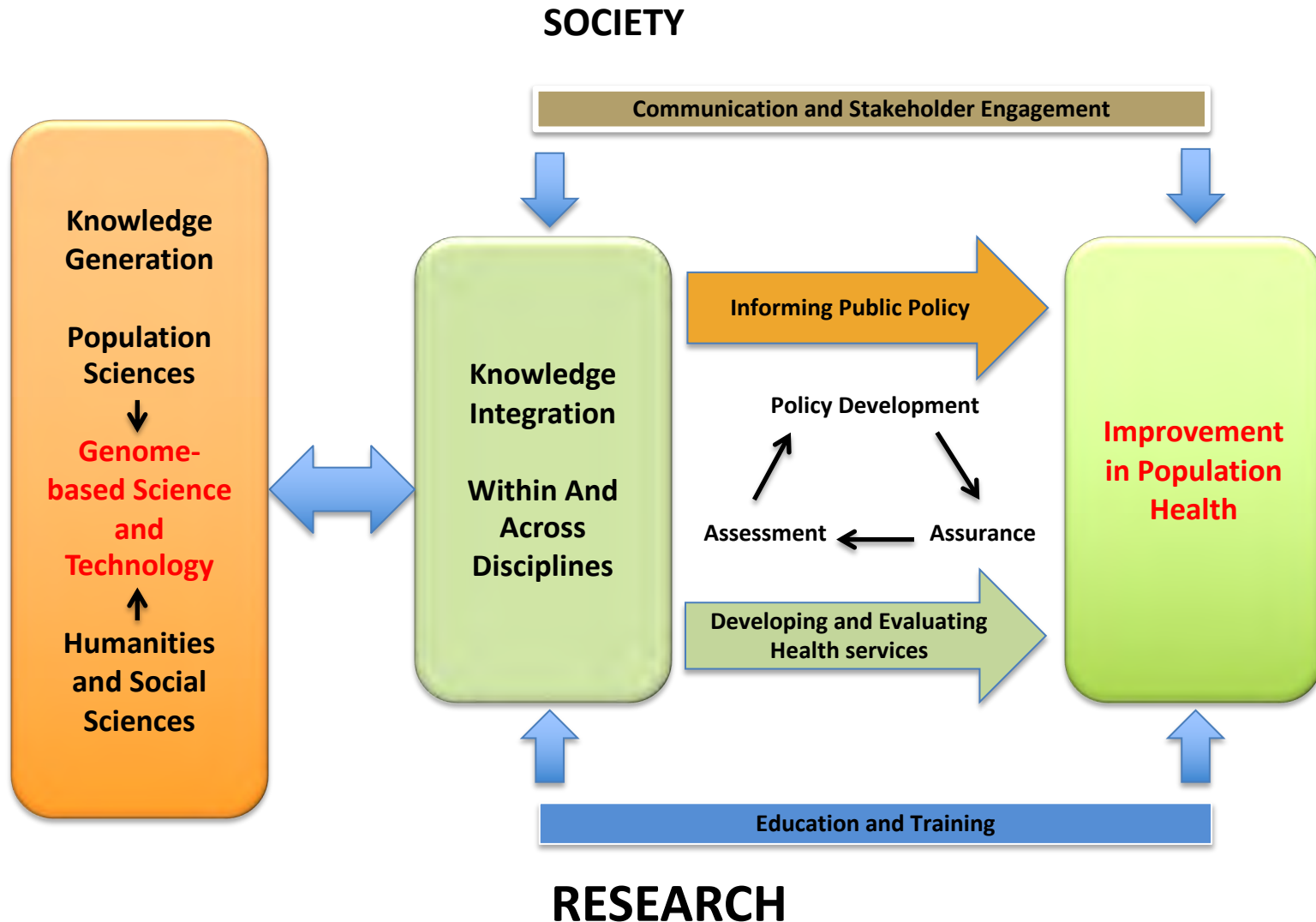
- Beyond alcohol exposure, genetic & epigenetic influences may play an important role in its determination.
- Social nutritional factors can contribute
- Such complexity requires the emerging area of public health genomics



The body etched, exposures, our ancestors within, our mother's mother's energy, our blood memory

# The Public Health Genomics Enterprise (Bellagio Model)

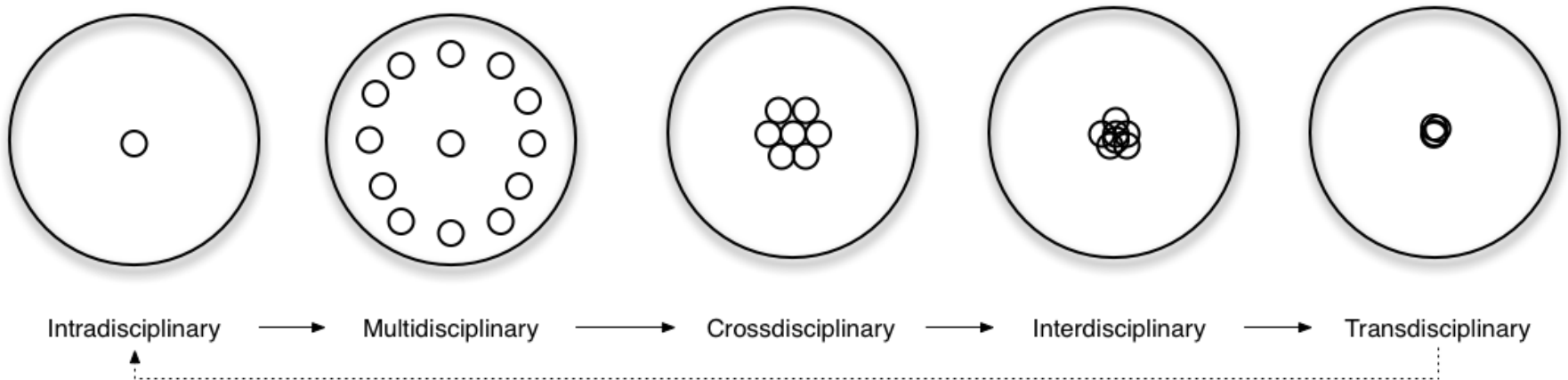
Source: Bellagio Statement. Genome-based Research and Population Health, Report of the expert workshop held at the Rockefeller Foundation Study and Conference Center, Bellagio, Italy, 14-20 April 2005





Brenda Elias Photo Credit: In Edmonton, designer mice have a role too!

By bridging sciences and societal partners we are stronger together in creating new approaches and perspectives to make a positive difference

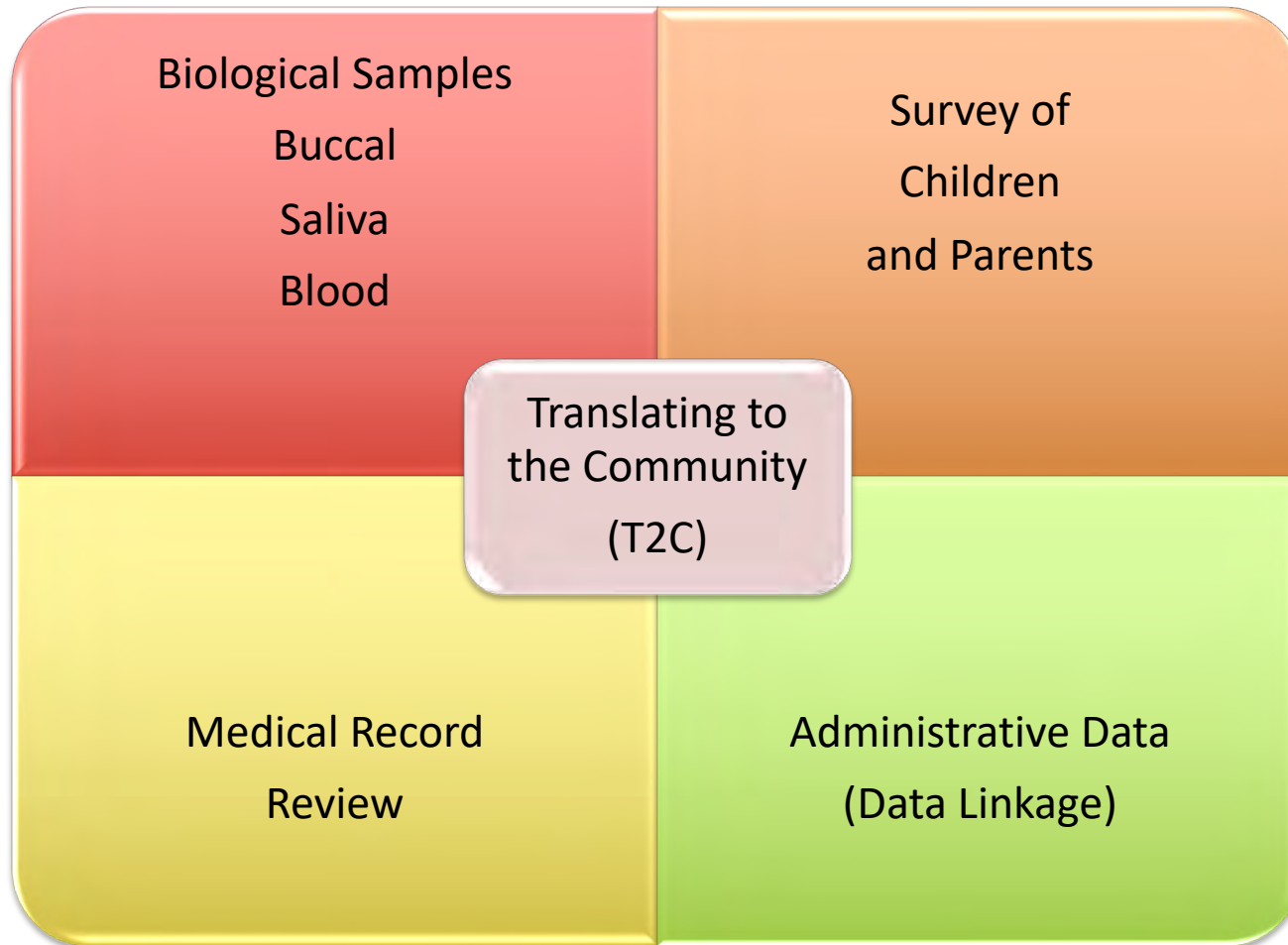


# Community Grounded Social Epigenetics (CNTHC)



Indigenous, Humanities and social sciences link to genomic and population sciences

# Community-Population & Genome-Based Sciences



## Community-Clinic-University Partnership



Figure 1: Social Bio-Repository Schematic of Translating to the Community (T2C): A Social Epigenetic Study of FASD

## Groups (1,2,3)

1. Child diagnosed with FASD
2. Child prenatally exposed to alcohol and no FASD diagnosis at this time
3. Child has an unknown alcohol exposure (suspected) but exposure may have occurred, and no FASD diagnosis at this time

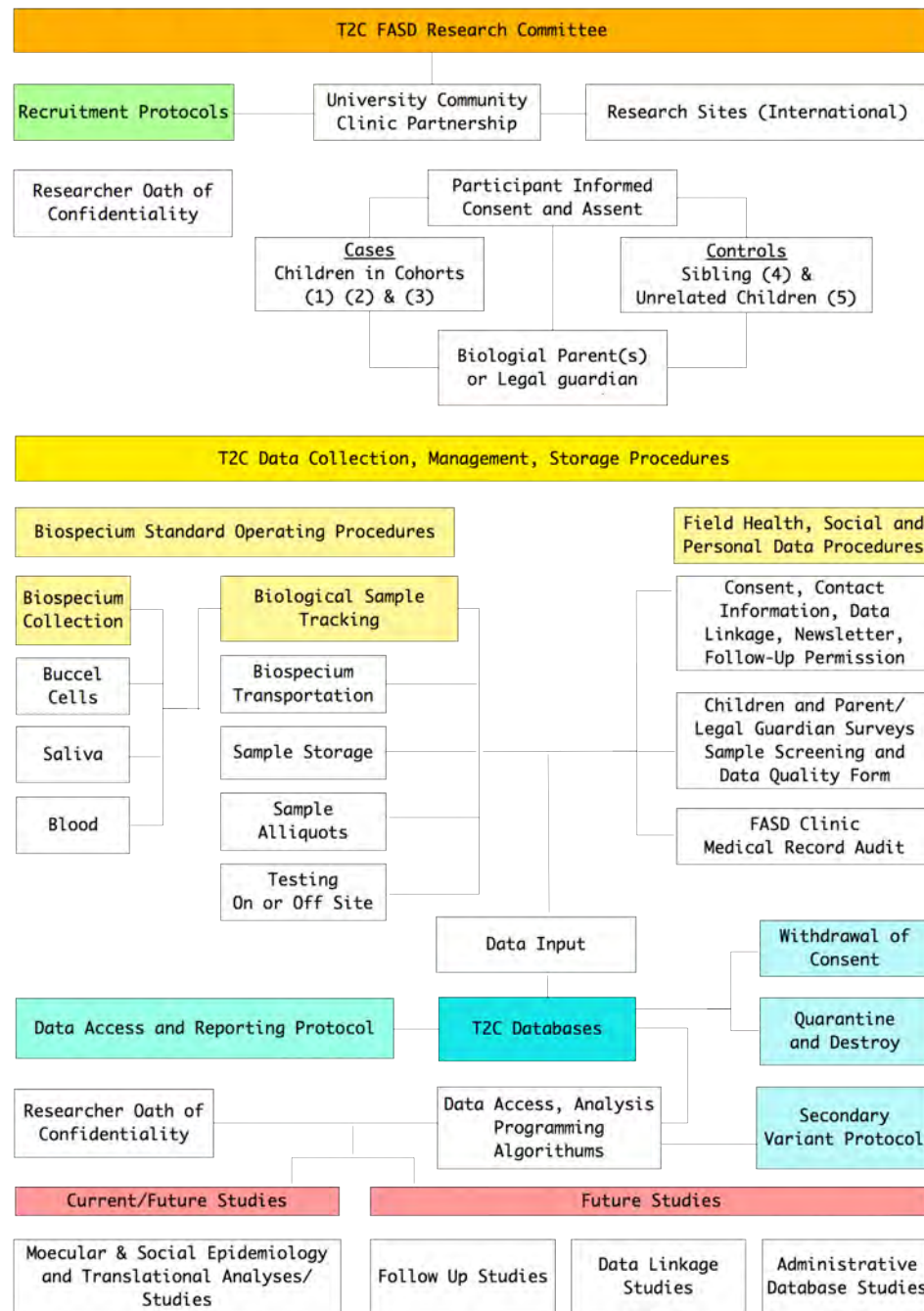
## Groups (4,5)

1. Biological Sibling not exposed to alcohol prenatally and does not have a neurodevelopmental condition/presentation
2. Unrelated Child (control) not exposed to alcohol prenatally and does not have neurodevelopmental condition/presentation

## Biological Parents

- Mother
- Father

## Legal Guardian

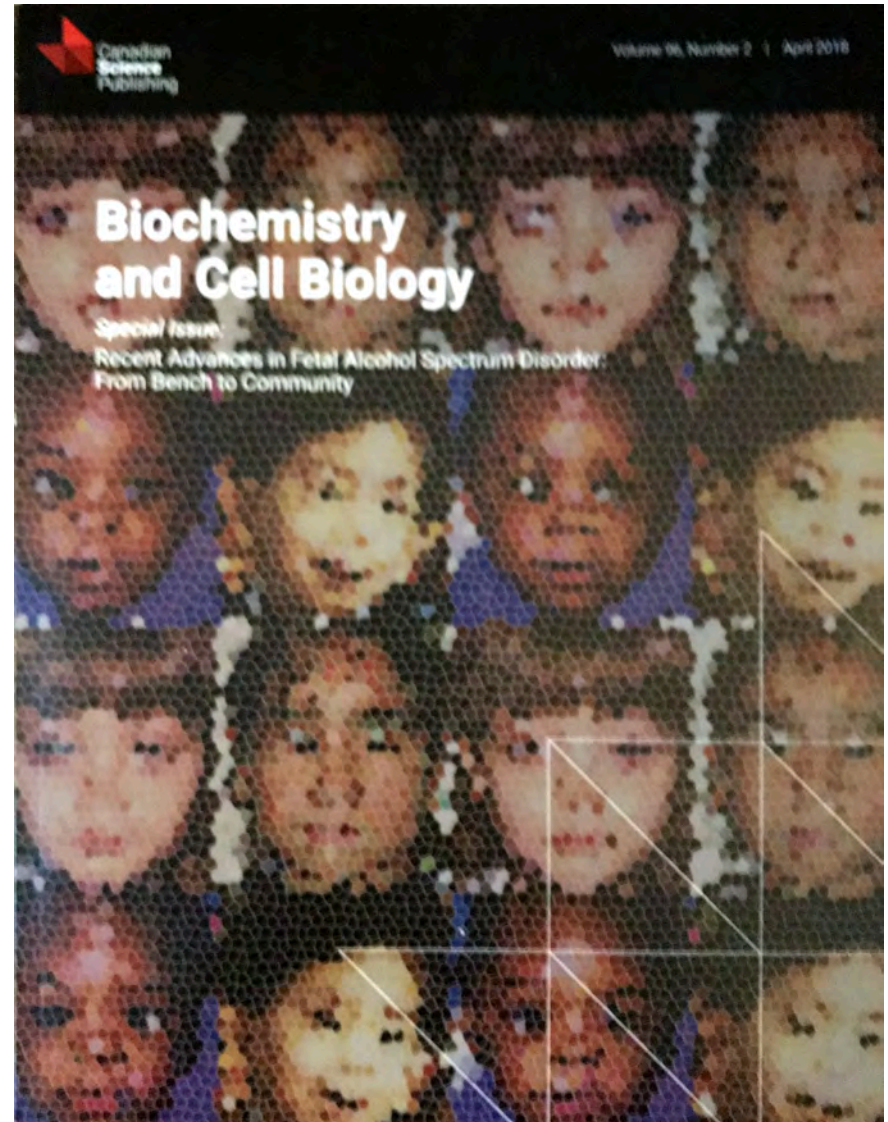


**Biochemistry and Cell Biology**  
**Special issue: Recent Advances in**  
**Fetal Alcohol Spectrum Disorder:**  
**From Bench to Community**

**Translating to the Community**  
**(T2C): a protocol paper describing**  
**the development of Canada's first**  
**social epigenetic FASD biobank**

Brenda Elias, Ana Hanlon-  
Dearman, Betty Head, Geoffrey G.  
Hicks

*Biochemistry and Cell Biology*,  
2018, 96(2): 275-  
287, <https://doi.org/10.1139/bcb-2017-0278>



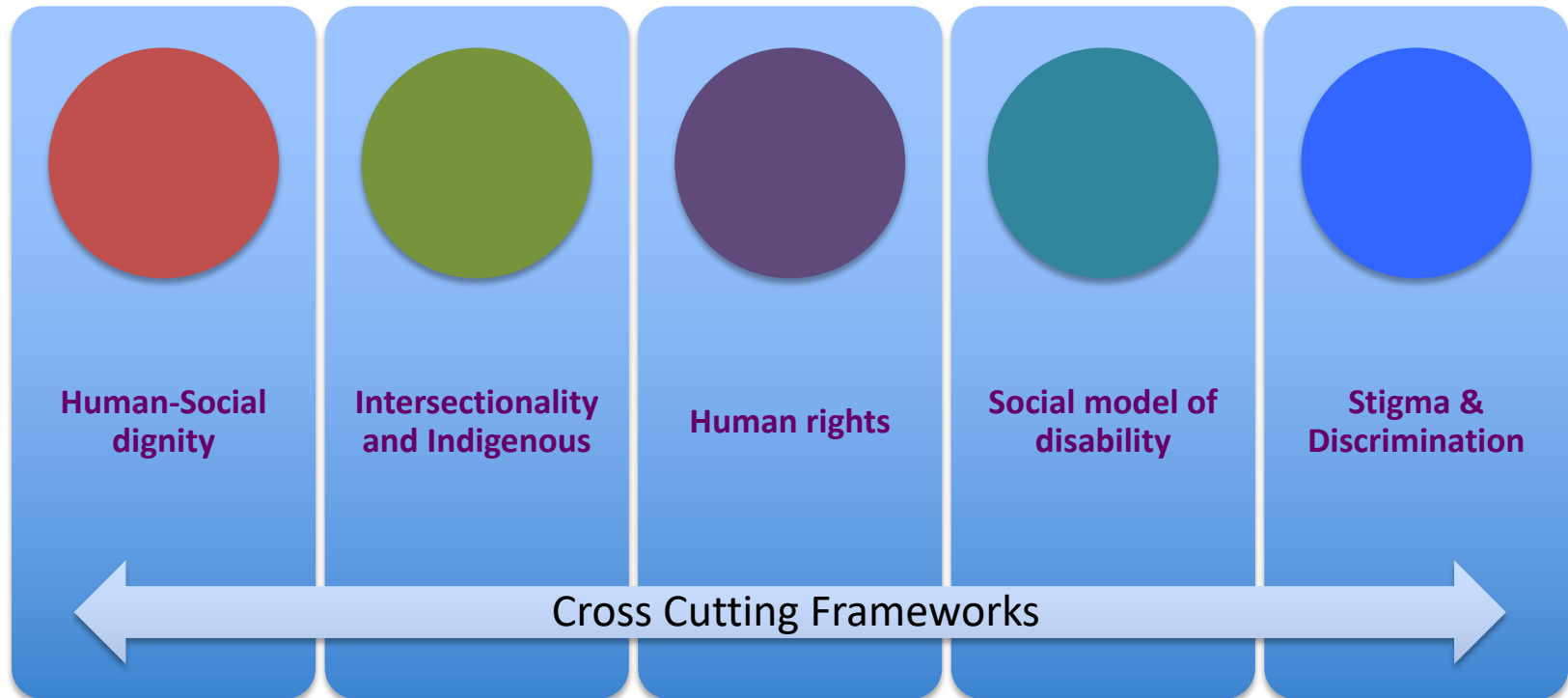


*Looking After Each Other*  
A Dignity Promotion Project

# THE SEQUEL



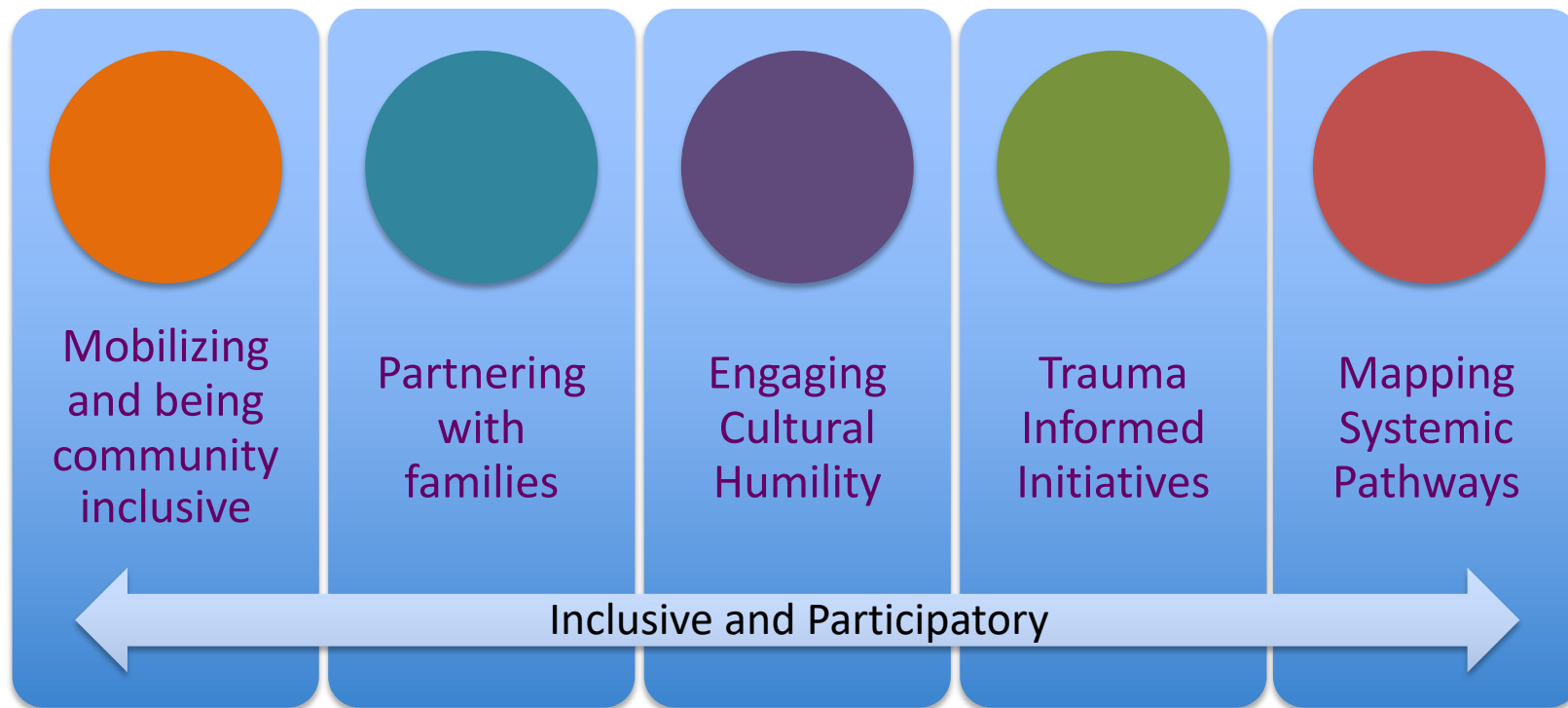
Elevating community-based humanities and social sciences





*Looking After Each Other*  
A Dignity Promotion Project

# Cross cutting initiatives



Community Partners include Aboriginal Health & Wellness Centre, FASD Life's Journey Inc., Healthy Child Manitoba, Ma Maw Wi Chi Itata Centre, Inc., Manitoba Foster Family Network, Sandy Bay Child & Family Services Inc., and the University College of the North. Cree Nation Tribal Health Centre and Swampy Cree Tribal Council Communities are new partners and research sites.



Social Sciences and Humanities  
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Artist: Jackie Travis  
Logo selected by CNTHC