

ADVENTURER EXPLORER TRAILBLAZER REBEL PIONEER CREATOR DEFENDER ADVENTURER EXPLORER TRAILBLAZER

REBEL PIONEER CREATOR DEFENDER ADVENTURER EXPLORER TRAILBLAZER REBEL PIONEER CREATOR DEFENDER ADVENTURER EXPLORER TRAILBLAZER REBEL PIONEER CREATOR DEFENDER

# Manitoba Centre for Health Policy

## What Are We Doing Here: Large Databases and the Human Touch

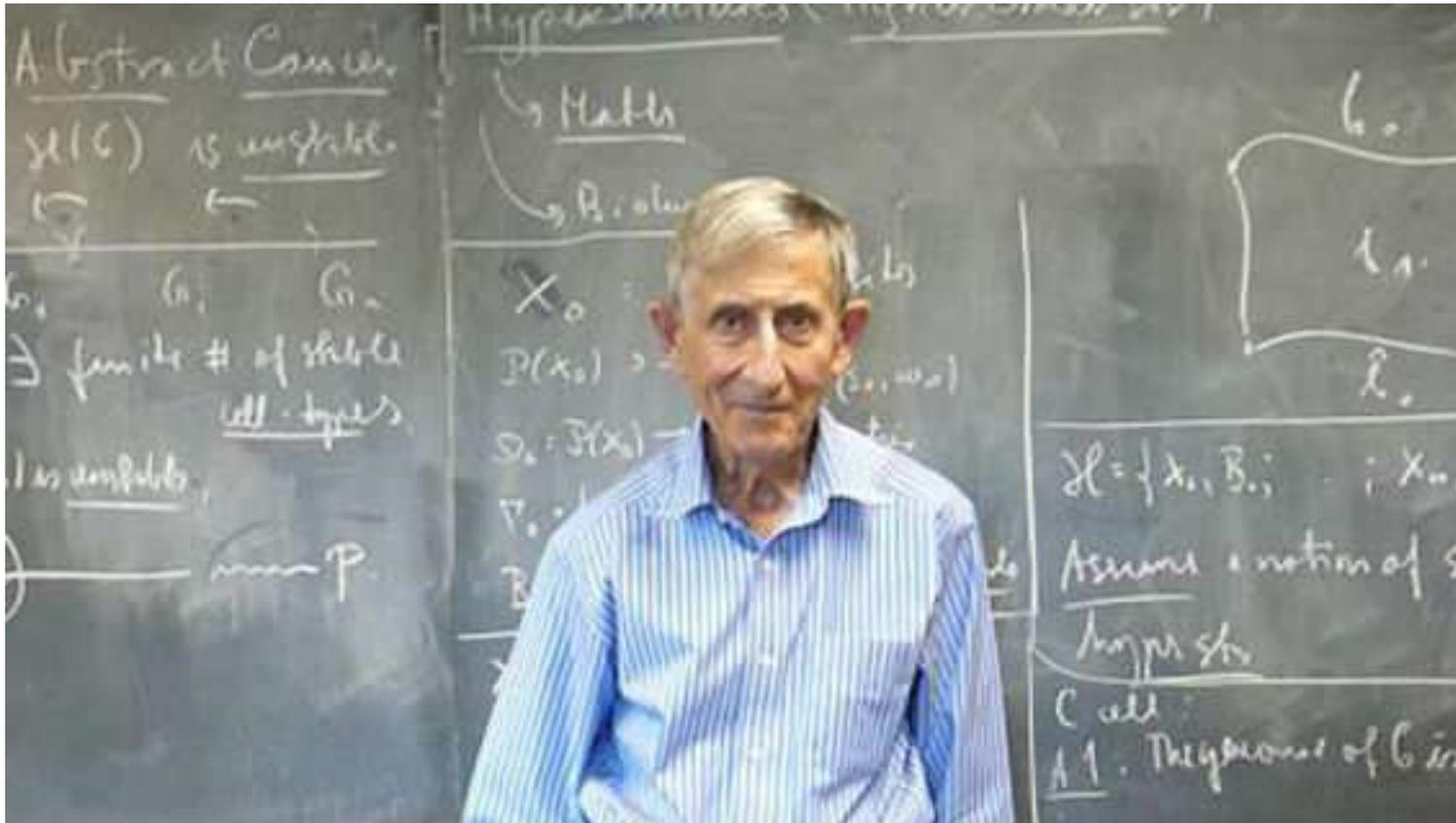
Les Roos

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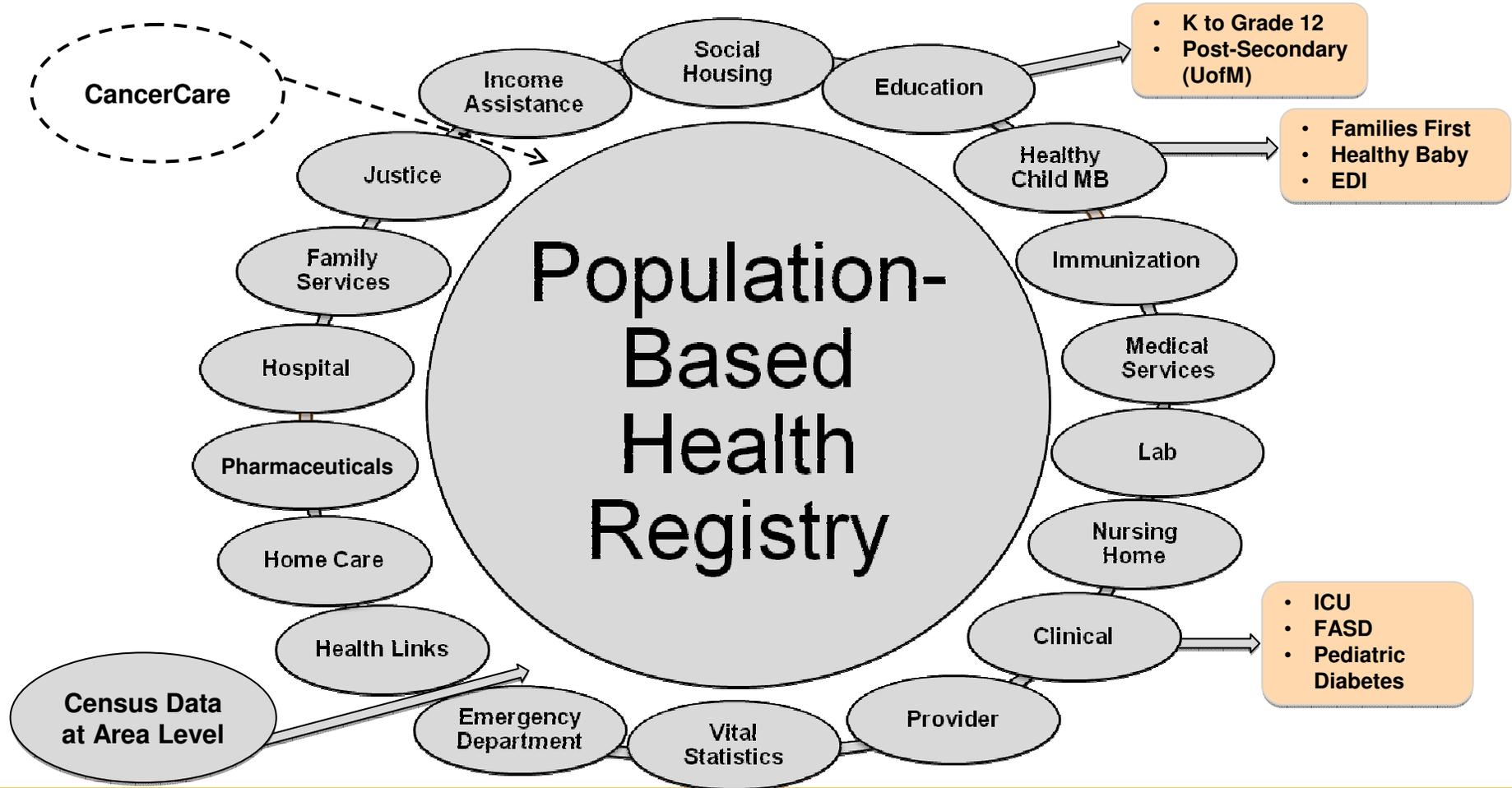
“...the majority of revolutions are tool-driven”

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**“Just a little of that human touch”**

# MCHP Houses the Anonymized Population Health Research Data Repository



## Repository

Large N

Interventions can be studied

Time

Space

Individuals and Families

## Collaborative Model

- 1) Permits use
- 2) Facilitates expansion—Data Sets come in one by one
- 3) Time consuming

## Challenges of Linked Data

Each Site has different problems – Access,  
Quality, Relationships

Around the world, researchers complain

A Population Registry should be a core aspect of repository

Quality and number of elements are critical

Used across studies

Provide flexible denominators

Data Management is critical

Documentation (such as Concept Dictionary) increasingly necessary.

Start 'small' - collect papers, appendices, and notes on Web-site.

## Manitoba Data Challenges

Stats Canada Linkage (Resolved!)

Cancer Care Linkage (20+ years – Resolved!)

Marital Status (a Core Measure)

Non Standard Measures (Small Area, Not Individual) <a general problem>

## Human Touch

Communications to Constituencies

Persistence (Preferably Smiling)

Patience

Paperwork

## Lessons 1:

Save the rants for your partner/spouse

## Lessons 2:

1) Try hard to abide by rules.

2) Save 'Sorry, I was clueless' defense for emergencies

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