



# populationdata<sup>BC</sup>

A PLATFORM SUPPORTING RESEARCH ON  
HUMAN HEALTH, WELL-BEING AND DEVELOPMENT.

## *EXPLORING THE LIMITS OF DE-IDENTIFICATION*

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# OVERVIEW

- Situation and context matter – here the main focus is research
- De-identification is:
  1. Not mandatory
  2. In context, and only one of a whole suite of data protection tools
  3. Slippery in a changing context

## WHY DE-IDENTIFICATION?

- Moral imperative



## WHY DE-IDENTIFICATION?

- Legal imperative



## WHY DE-IDENTIFICATION?



HORSES FOR COURSES...

# WHY DE-IDENTIFICATION?



## DE-IDENTIFICATION MINIMIZES AND/OR PREVENTS ABILITY TO

- Identify an individual
- Link data sets, and/or
- Infer sensitive information about someone

*But the term means different things to different disciplines*

# IDENTIFIABLE

*Names*  
*Birthdate*  
*Postal code*  
*Personal Health number*  
*Etc.*

# DE-IDENTIFIED

*Aggregate*  
*“safe”*

## PRIVACY IS NOT BINARY



**Data availability** |

**Legal allowance** |

**Social license**

**IDENTIFIABLE**

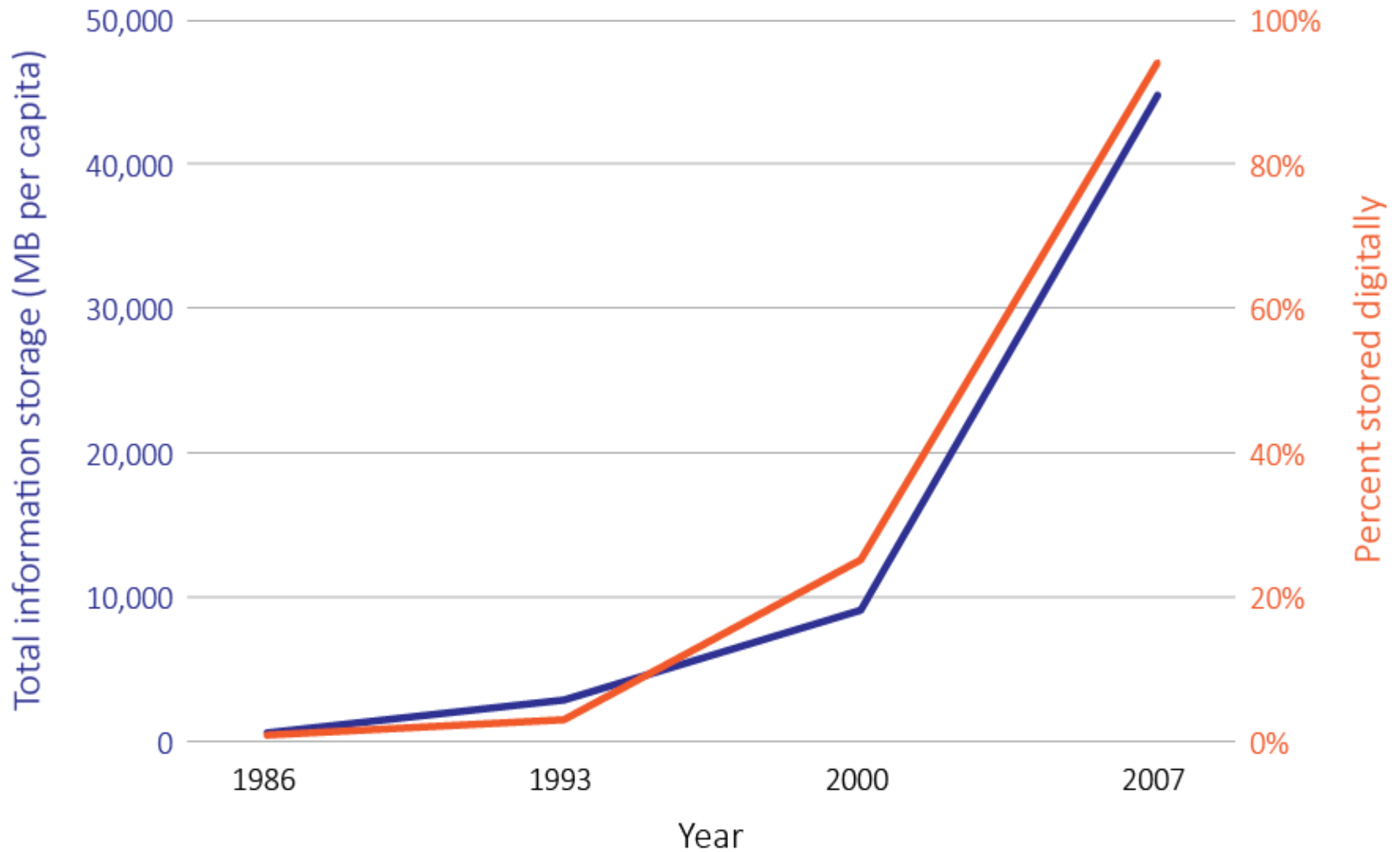
**DE-IDENTIFIED**

**IDENTIFIABLE**

**?**

**DE-IDENTIFIED**

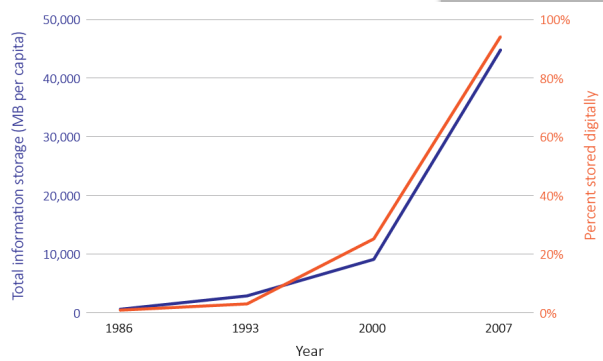
## MORE DATA – and it's DIGITAL!



IDENTIFIABLE

?

DE-IDENTIFIED



## CHALLENGES TO DE-IDENTIFICATION

- Determination of “de-identified”
- Impossibility of that except within a specific context (data and motivation)
- Can’t predict future technologies and future data
- Increasing dimensionality of ALL data requests
- Increasing implications of data use regardless of presence in the data.



**facebook**



**amazon**





# WHAT IS THE SOLUTION?

Legislation



The collection, linking  
and use of data in  
biomedical research  
and health care:  
ethical issues

NUFFIELD  
COUNCIL ON  
BIOETHICS



Voices for **Data**

Public engagement for a new model to access research resources



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## CONTACT INFORMATION

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