

POPULATION DATA BC

"Just Give Me My Data"

Researcher Access to Privacy Sensitive Data

Jim Mintha

Population Data BC
University of British Columbia

April, 2018

















POPULATION DATA BC SERVICES











POPULATION DATA BC

A brief history



REGISTRATION

AND PREMIUM BILLING

BC MINISTRY OF HEALTH

HOSPITAL SEPARATIONS

BC MINISTRY OF HEALTH

CONTINUING CARE

BC MINISTRY OF HEALTH

PHARMACARE

BC MINISTRY OF HEALTH

BIRTHS, STILLBIRTHS AND **DEATHS**

BC VITAL STATISTICS

(BCLHD)

CLAIMS AND INJURY FILES WORKSAFEBC

BC CANCER REGISTRY

BC MINISTRY OF HEALTH **INCOME BAND**

MENTAL HEALTH

MARRIAGES

BC VITAL STATISTICS

INSTRUMENT

HUMAN EARLY LEARNING PARTNERSHIP

EARLY

DEVELOPMENT

INSTRUMENT

HUMAN EARLY LEARNING

PARTNERSHIP

MIDDLE YEARS

DEVELOPMENT

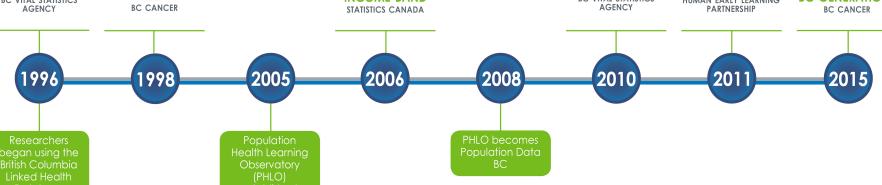
PERINATAL DATA REGISTRY

PERINATAL SERVICES BC

PERMANENT RESIDENTS

CITIZENSHIP AND IMMIGRATION CANADA

BC GENERATIONS





DATA HOLDINGS & POPULATION COVERAGE



British Columbia has

4.6 MILLION residents

We hold data on **ALL** of them **100% coverage**

For some people we have

A LOT OF DATA for other people VERY LITTLE

HOW MUCH DATA

we have on a person depends upon their

LIFE EXPERIENCE

Data holdings relate to, for example:

Hospital stays



Citizenship



Education/early childhood



Pregnancy & childbirth



Visits to a Doctor



Disease registries



Medications



Workplace injuries



Births, marriages & deaths



ER visits





DATA SOURCES

Internal data holdings for linkage 19 datasets from 2 Federal and 6 Provincial sources

HEALTH CARE & HEALTH SERVICES



7 DATA SETS

Medical Services Plan (BC MINISTRY OF HEALTH)

PharmaCare
(BC MINISTRY OF HEALTH)

Hospital Separations (BC MINISTRY OF HEALTH)

Home & Community
Care

(BC MINISTRY OF HEALTH)

Mental Health
(BC MINISTRY OF HEALTH)

BC Cancer Registry
(BC CANCER)

Perinatal Data Registry (PERINATAL SERVICES BC)

POPULATION & VITAL STATISTICS



5 DATA SETS

MSP & Premium Billing (BC MINISTRY OF HEALTH)

Vital Statistics Births
(BC VITAL STATISTICS
AGENCY)

Vital Statistics Stillbirths
(BC VITAL STATISTICS
AGENCY)

Vital Statistics

Marriages
(BC VITAL STATISTICS

AGENCY)

Vital Statistics Deaths
(BC VITAL STATISTICS
AGENCY)

OCCUPATIONAL



2 DATA SETS

WorkSafeBC Claims
WorkSafeBC Firm
Level files
(WORKSAFEBC)

CHILDHOOD



2 DATA SETS

Early Development
Instrument
(HUMAN EARLY LEARNING
PARTNERSHIP)

Middle Years
Development
Instrument
(HUMAN EARLY LEARNING
PARTNERSHIP)

DEMOGRAPHIC & LIFE COURSE



3 DATA SETS

BC Generations Project (BC CANCER)

Permanent Residents (CITIZENSHIP & IMMIGRATION CANADA)

Income Band (STATISTICS CANADA)



Legislative Permission:

• Freedom of Information and Protection of Privacy Act (FOIPPA) in British Columbia, Section 35 says:

"A public body may disclose personal information in its custody or under its control for a research purpose, including statistical research..."



SECURE DATA STORAGE and ARCHIVING

Data protection and privacy

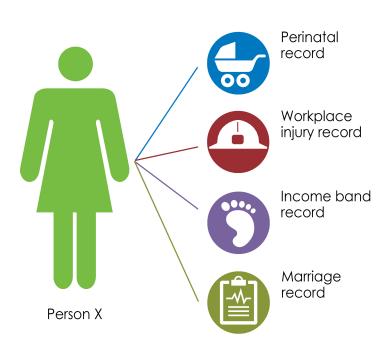
Our mandate: to meet and exceed all relevant legal, ethical and legislative guidelines for data protection and privacy

The tenets of individual privacy and data protection are embedded in all aspects of operations, and include externally audited:

- Physical measures
- Technical measures
- Procedural measures

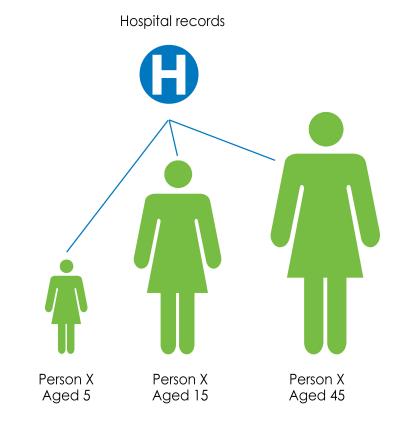


DATA LINKAGE



Linkage allows information on an individual from **One data source** to be **linked** to information on

the **Same** individual from **another data source**.

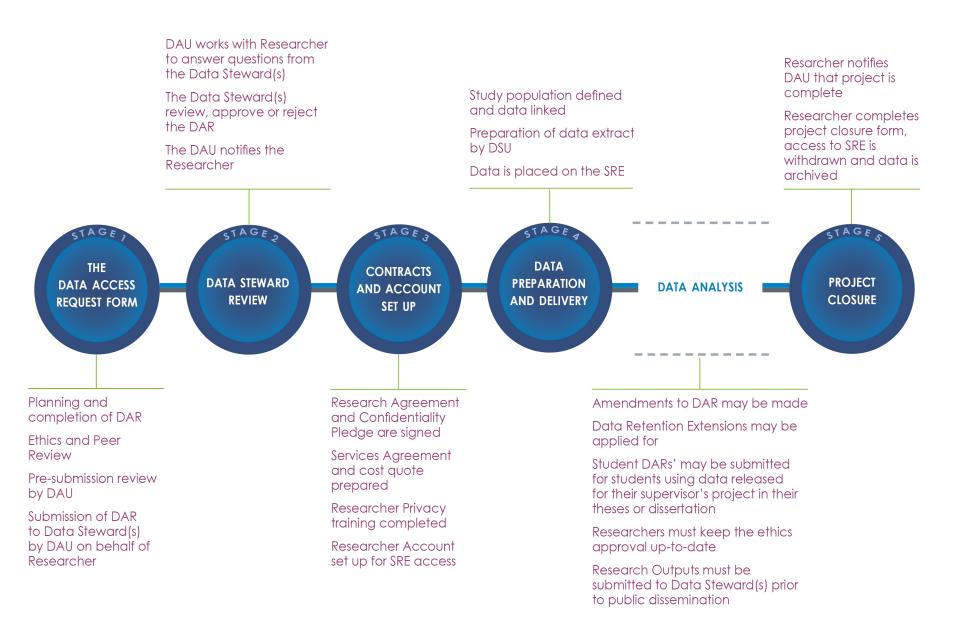


Linkage can also be used for **longitudinal analyses** within the **same data source**,

even when identifying information is recorded inconsistently,
incompletely or has changed over time.



THE DATA ACCESS PROCESS





THE DATA ACCESS PROCESS

Stage 4: Data preparation and delivery



WHAT HAPPENS?

Study population defined and data linked Preparation of data extract by DSU Data is placed on the SRE



DATA PROTECTION and PRIVACY

External audits and reviews

PRIVACY IMPACT ASSESSMENT

Developed, reviewed and approved by:

- UBC Office of the University Counsel
- BC Office of the Chief Information Officer
- BC Office of the Information and Privacy Commissioner

AUDITS

- Completed Systems and Security Audit in 2007 by BC Ministry of Health
- Expanded Systems and Security Audit in 2009 by Grant Thornton
- Detailed review of security and privacy controls and technical testing in 2014 by Deloitte

SITE VISITS

- David Flaherty, Former Privacy Commissioner for BC
- BC Office of the Chief Information Officer
- BC Office of the Information and Privacy Commissioner
- Data Stewards

POLICIES & PROCEDURES

- Extensive privacy policies and procedures, regularly revised and updated
- Information Security Policies confirmed by Grant Thornton to be fully compliant with ISO/IEC 27002 requirements



SECURE DATA STORAGE & ARCHIVING

Data protection and privacy

Procedural measures



Only named researchers have access to data



Data can only be used for requested purpose



Confidentiality pledges for research team



Pre-publication transcripts are reviewed by Data Steward(s)



Mandatory privacy training for researchers



Data is destroyed upon closure of project



DATA PROTECTION and PRIVACY

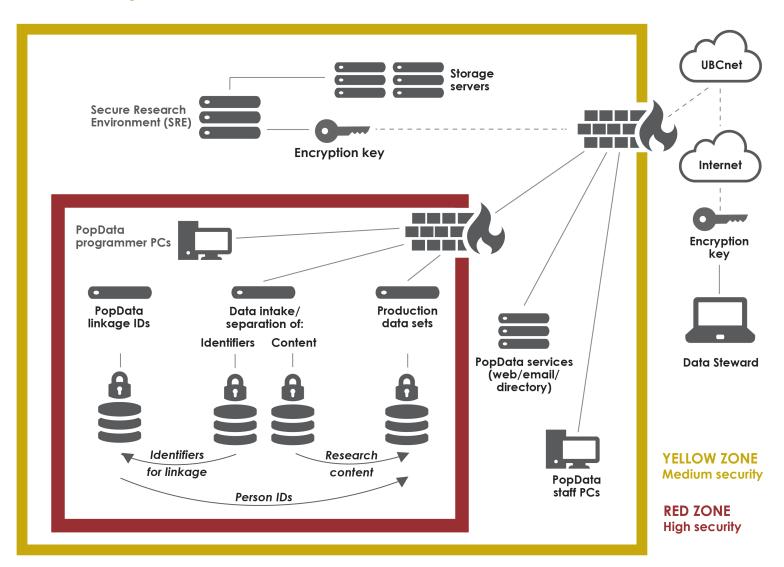
Physical measures





DATA PROTECTION and PRIVACY

Network security





Receiving data on an encrypted CD

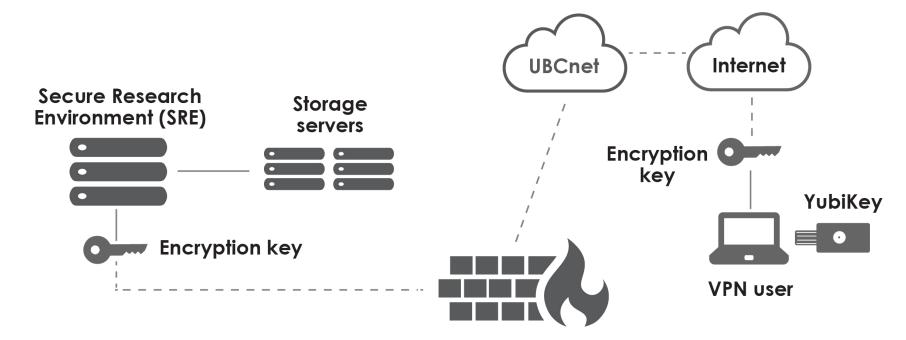








The Secure Research Environment



The SRE provides:

- Secure storage and backup
- Centralized location for access and processing of research data
- A range of software for use in data analysis
- Security standards that meet Data Steward(s) requirements



Trade Offs:





Researcher Perspective:





The Costco Advantage:





PopData / Data Provider Perspective:





Security & Privacy Controls:

- Firewalled and restricted environment
- Two factor authentication
- Outputs limited and controlled
- Access can be turned off
- Data is encrypted on disk
- Secure backups
- Access can be restricted to Canada
- Audit controls
- Proper project closure



Sweetening the deal:





Taking Care of the Hassles:

- We take care of encryption
- We do the backups (offsite too)
- Hardware support
- Software upgrades
- Anti-virus
- Sharing within the team
- Project Archiving
- Many tools to choose from:





The Secure Research Environment

Software

- ACG John Hopkins 11.0.1
- ArcGIS Desktop 10.5.0.6491
- Epi Info 7.2.1
- GeoDa 1.8.14
- HLM 6.08
- JoinPoint 4.4.0.0
- MATLAB 2016b
- MLwiN 2.18

- MPlus 7.4
- MS Office 2013
- MS Project 2013
- MS Visio 203
- Python 2.7.11
- Python 3.5.1
- R 3.3.2
- Rstudio 1.0.136

- SAS 9.4 TS Level 1M3
- SAS Entertainment Guide 7.13
- SaTScan 9.4.2 64-bit
- SPSS (IBM) Version 23
- SPSS Python Essentials Plugin
- SPSS Integration Plugin for R
- Stata 14.2
- WinBUGS 1.4.3

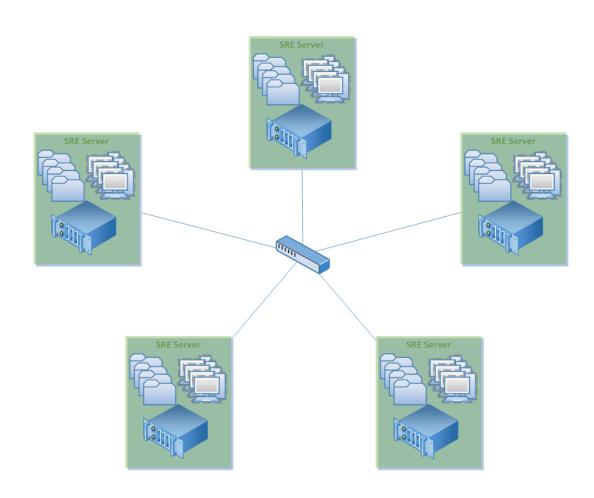
Utilities

- Adobe reader DC 15.023.20056
- Cygwin
- MS Visual FoxPro 9.0 SP2
- Notepad ++ 7.2.2
- Putty 6.07

- TextPad 7.6.2
- 7zip 16.04
- Java plugin Ver 8 Update 121
- Cute PDF Writer 3.1



SRE Architecture





Secret Ingredient:





SRE Architecture

- HP servers running Debian Linux
- KVM for virtualization
- Custom scripts for spinning up VMs from gold image
- Backing image with overlays
- 10Gbe network
- Login scripts mount the project R: drive



SRE Machines:

Regular Machines:

- Windows 7 (transitioning to Windows 10)
- Two virtual CPUs
- 16GB memory

Fast Machines:

- 32GB memory
- Quad-core Intel i7



File Space:

- Each project has its own share
- Read only folder for the Data
- Separate private home directory for each project member
- Import and Export directories for each user
- Shared working directory
- 500GB initial quota, no hard quota, extra is charged

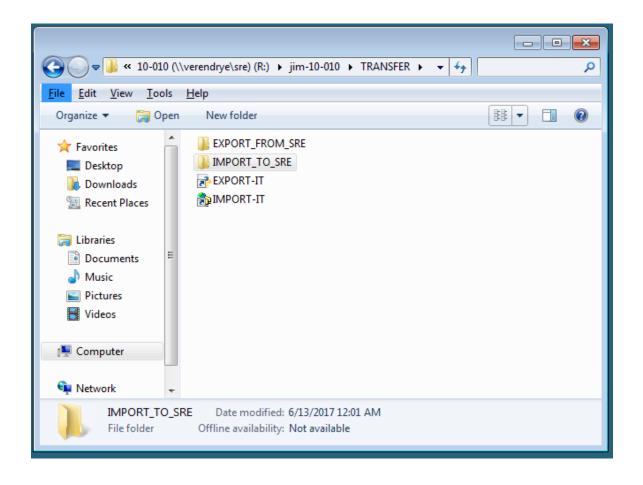


Importing and Exporting:





Yellowfolders:





Restrictions:

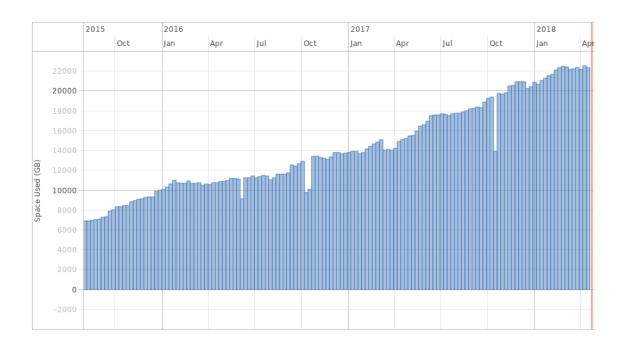
- Size
- File type
- Small cell size (<=5)
- Archives
- Binaries
- Native stats program file types





Problems / Issues:

- Camping out on Fast machines
- Data growth
- Specialized software



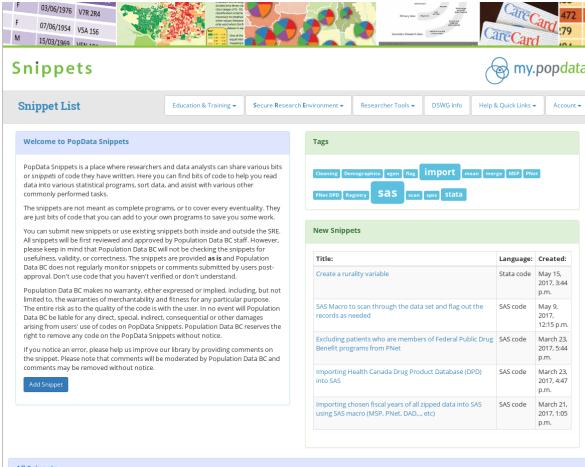


Tools for Researchers:





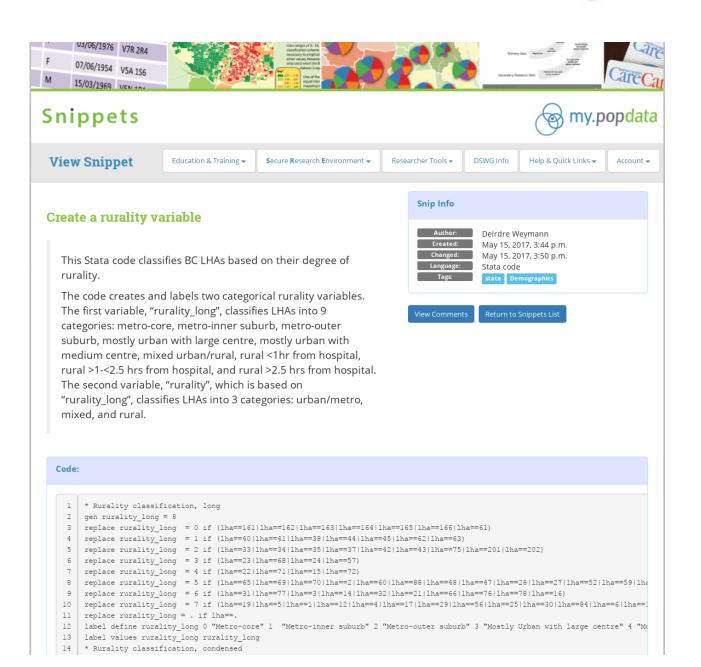
Snippets:



All Snippets					
All Snippets Search:					
Title:	Language:	↓↑ Author:	Last J1 Changed:	Tags:	Ţţ
Create a rurality variable	Stata code	Deirdre Weymann	2017/05/15 15:50	stata Demographics	
Creating means by sub-category	Stata code	Melissa Medearis	2017/04/05 13:49	stata mean egen	
Excluding patients who are members of Federal Public Drug Benefit programs from PNet	SAS code	Lucy Cheng	2017/03/29 09:17	PNet sas Cleaning	
Importing chosen fiscal years of all zipped data into SAS using SAS macro (MSP, PNet, DAD,, etc)	SAS code	Lucy Cheng	2017/03/21 13:56	MSP import sas	
Importing data into SPSS	SPSS code	Melissa Medearis	2017/03/22 09:10	import spss	

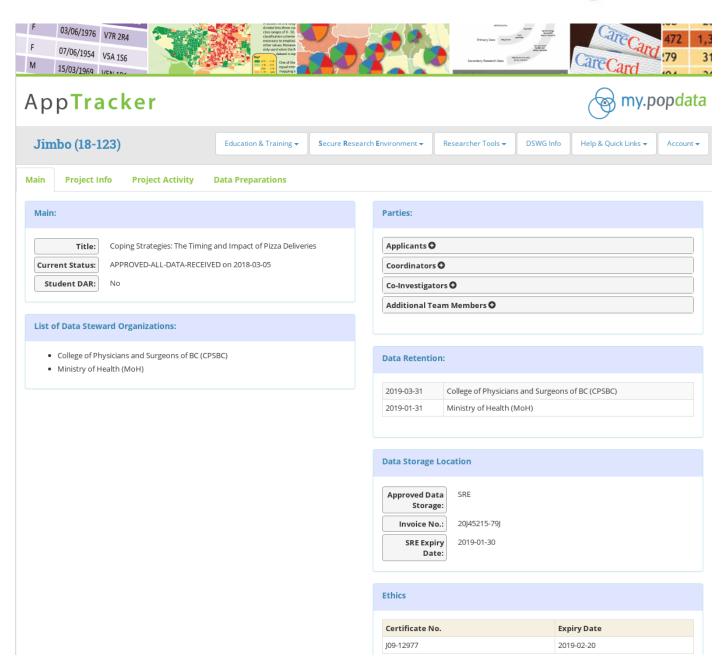


Snippets:





AppTracker:







AppTracker:

${\sf App} {\sf Tracker}$



Jimbo (18-123)	Education & Training ▼	Secure Research Environment ▼	Researcher Tools ▼	DSWG Info	Help & Quick Links ▼	Account ▼
Main Project Info Project Activity	Data Preparations					
Project Activity Summary						
Number of Amendments: 3 Number of Data Retention Extensions: 0 Number of Student DARs: 0						
2018-01-09: data-retention-extension ○						
2016-12-07: data-retention-extension ◆						
2016-01-22: data-retention-extension •						
2016-01-19: add-member ©						
2015-02-04: data-retention-extension •						
2014-10-06: add-member O						
Reference No: Type: ADD-MEMBER Description: Add Bob McKenzie (data acc Full Approved Date: Oct. 6, 2014 add-member details:	cess) and Doug McKenzie (data	a access)				
Data Steward Organization		Su	ıbmit Date	Approved Da	ate Not	tes
Ministry of Health (MoH)		0	ct. 1, 2014	Oct. 2, 201	.4	
College of Physicians and Surgeons of BC	(CPSBC)	0	ct. 3, 2014	Oct. 6, 201	.4	
2014-01-21: amendment ③						
2013-11-05: amendment O						
2013-11-04: amendment ©						
2013-09-17: data-retention-extension O						
2012-03-23: application O						



MetaData Central:



DARonline



Education & Training -

Secure Research Environment →

Researcher Tools -

DSWG Info

Help & Quick Links ▼

Account ▼

METADATA CENTRAL CONTENTS

Welcome to Population Data BC's MetaData Central (MDC)! The goal of MDC is to provide the research community that Population Data BC serves (i.e., researchers, data stewards, and PopData staff) with sufficient information to facilitate informed decisions about Population Data BC's holdings. Please remember that the information that you view here is not to be reported or reproduced for any reason. You will find MDC can function as a resource for file-level summary information (e.g., inclusions, exclusions, and fields available) as well as field-level information (e.g., field descriptions, background information, and basic descriptive statistics). This information can be found by selecting one of the files currently listed on MDC below.

HEALTH CARE AND HEALTH SERVICES DATA

Discharge Abstracts Database (Hospital Separations) (April 1, 1985 onwards)

Medical Services Plan Payment Information File (April 1, 1985 onwards)

Home and Community Care (January 1, 1990 onwards)

BC Perinatal Data Registry (April 1, 2000 to March 31, 2014)

POPULATION AND DEMOGRAPHIC DATA

Consolidation File (January 1, 1986 onwards)

Vital Statistics Births (January 1, 1986 onwards)

Vital Statistics Deaths (January 1, 1985 onwards)

Vital Statistics Marriages (January 1, 1986 onwards)

Vital Statistics Stillbirths (January 1, 1986 onwards)

EARLY CHILDHOOD DATA

Early Development Instrument (EDI)

OTHER

PharmaCare (January 1, 1985 onwards)



Account ▼

MetaData **Central:**



Secure Research Environment -

Education & Training -

DARonline



Help & Quick Links ▼

my.popdata

DSWG Info

Researcher Tools -

Metadata Central Contents -> Vital Statistics Births (January 1, 2036 onwards)

Sex

Sex of Child.

Detailed Description

Sex of Child.

Background Information

None documented.

Basic Quality Issues

None documented. Code Values

M = Male;

F = Female;

0 = Other;

U = Martian

+ Show Help

Warning The information and values provided are, under no circumstances, to be reported or reproduced in any manner. The following descriptive statistics are

Below is a crude field summary which does not account for other field or record contexts. The data represented is not static and subject to revisions. The information provided is not suitable for comparison with released data, official reports or publications.

FREQUENCY_SUMMARY

Value	2036	2037	2038	2039	2040	2041	2042	2043	2044	2045	2046	2047	2048	2049	2050	2051	2052	2053	2054	2055	20
	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	
F	210,848	280,599	20,440	2,121	21,405	22,366	222,267	22,619	62,449	22,790	22,681	29,379	21,797	21,079	270,313	19,802	19,731	19,393	19,744	19,713	19,
М	212,394	231,553	261,507	272,086	22,515	23,368	233,457	234,690	23,767	24,338	24,276	23,823	122,819	21,179	21,660	20,890	220,822	20,723	230,766	20,816	20,
0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	П
U	0	15	15	0	15	0	15	0	0	15	15	0	15	15	0	0	0	0	15	15	
Total	43,242	412,154	41,948	63,207	43,922	45,734	15,726	46,309	46,216	47,130	96,958	46,202	44,618	9,059	41,973	40,692	40,553	40,116	940,512	10,530	40,

Available Summaries: c_sex - FREQUENCY_SUMMARY c_sex - PERCENTAGE_SUMMARY

Available Frequency Databases: • births2048-08-14 freq

obirths2045-10-26_freq

births2041-11-27 freq

births2037-10-10 freq



Questions?





CONTACT INFORMATION

Jim Mintha
Population Data BC
604-827-3378
jim@popdata.bc.ca
www.popdata.bc.ca













