# Centre for Victorian Data Linkage

Registry SIG

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Mark Sipthorp, Technical Manager

Nicholas Ivkovic, Content Manager

Kenneth Cheng, Client Service Manager

Centre for Victorian Data Linkage

# A brief history of data linkage in Victoria

2009

- The Centre for Victorian Data Linkage was established as the Victorian node of the Population Health Research Network
- Undertakes data linkage in Victoria on a project by project basis in response to requests from government and researchers

2016

- The CVDL develops the Victorian Linkage Map and a de-identified dataset of individual's service history for research and analysis
- Enables identification of individuals across 20+ health and human services data sets and births and deaths data

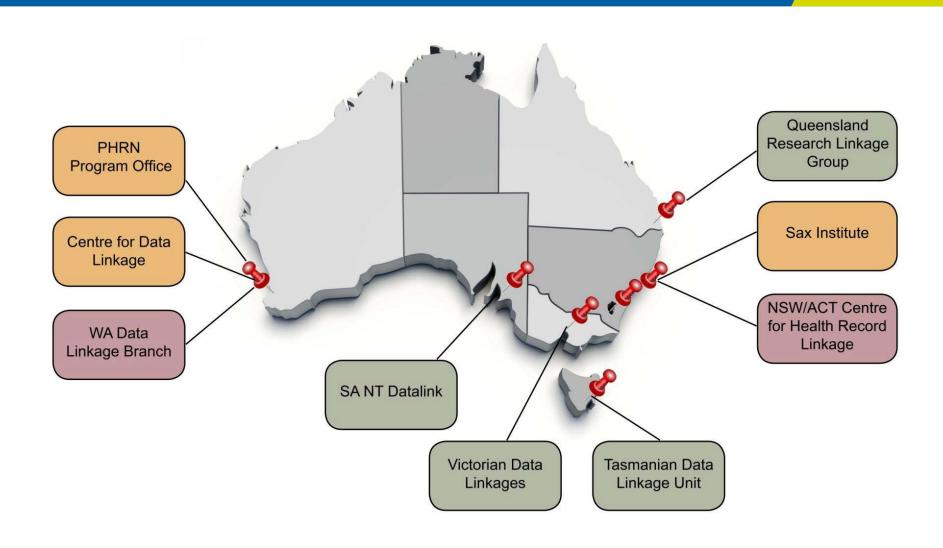
2019

- The VLM now includes 30+ health and human services data sets with up to 25 years of records
- Additional datasets from other Departments are being added as part of the Victorian Social Investment Integrated Data Resource (VSIIDR)
- CVDL's accreditation in October 2018 as an national integrating authority allows linkage of Commonwealth data.

# **Population Health Research Network**

- The Population Health Research Network (PHRN) was established in 2009 as Australia's first data linkage network.
- Established with backing of the Australian Government as part of the National Collaborative Research Infrastructure Strategy (NCRIS).
- The key role of the PHRN is to improve the way that linked health and health-related data is made available to approved researchers to enhance Australia's ability to research, analyse and monitor health trends and health needs.
- The PHRN is a national network coordinated by the Program Office in Perth, Western Australia
- Data linkage units now operate across every state and territory in Australia, including the CVDL in Victoria.

# Population Health Research Network data linkage locations



# Who is involved in linkage in Victoria?

**Centre for Victorian Data Linkage** – Manages governance of linkage projects and undertakes linkage and content integration.

**Data custodians** – stewards for data collections, responsible for collection, use and disclosure. Their authorisation is required for release of linked datasets.

Researchers/policy analysts – use the linked data for analysis and research after going through an appropriate application and approval process.

**Ethics Committees** – Researchers external to government must gain ethics committee approval for linkage projects

# Government uses linked data to support policy design and decision making

Supporting evidence based practice by developing predictive models, for example a model and tool to identify those risk factors most likely to lead to substantiaton of children reported to child protection.

Realising benefits from the linked data

**Designing new initiatives** – including helping to define cohorts for new services and to facilitate outcome measurement

Informing demand modelling – supporting budget decision making by quantifying impacts on increasing investment in one service area on other service areas

Facilitate service integration and service pathway mapping – for example optimal cancer pathways project which tracks pathways of people diagnosed with cancer

# Academic and clinical research using linked data covers a broad spectrum

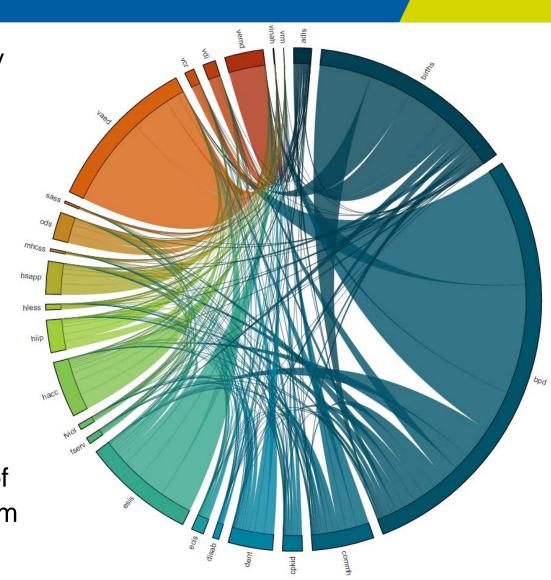
- Some projects require Victoria only data, others are multijurisdictional
- Commonly research outcomes of medical conditions (morbidity and mortality) and impact of interventions (medication, surgery)
  - Cardiovascular disease, stroke, cancer, liver disease
  - Falls and fractures, knee arthroscopy
  - Intensive care unit survivors/non-survivors
  - Heroin overdose, Paracetamol overdose
  - Road traffic accidents
- Increasingly involve broader research areas
  - Family violence outcomes
  - Mental health pathways and outcomes

# The CVDL linkage process

- In 2016, the CVDL developed the Victorian Linkage Map (VLM)
- Linked together identifiers from twenty-plus health and human services datasets with births and deaths data from the Victorian Registry of Births Deaths and Marriages.
- A linked de-identified data resource, the Integrated Data Resource (IDR) brings together the individuals' service history from the individual data sets using a linkage identifier.
- The VLM and IDR now includes over 140 million records from over 30 datasets with up to 25 years of records.
- As the included datasets primarily relate to service users, we estimate that about 40% of the Victorian population is covered.

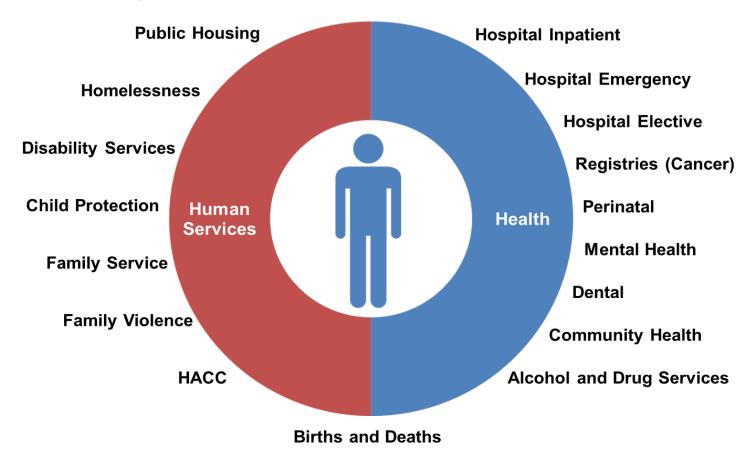
# Victorian Data Linkage Map and Integrated data resource

- A system of links created by combining personal identifiers (such as name, DOB) from each data set
- Cluster IDs are assigned to records which relate to the same individual
- Cluster IDs are used to anonymously identify content/case variables for individuals across datasets
- Integrated Data Resource of over 140 million records from 30 plus datasets

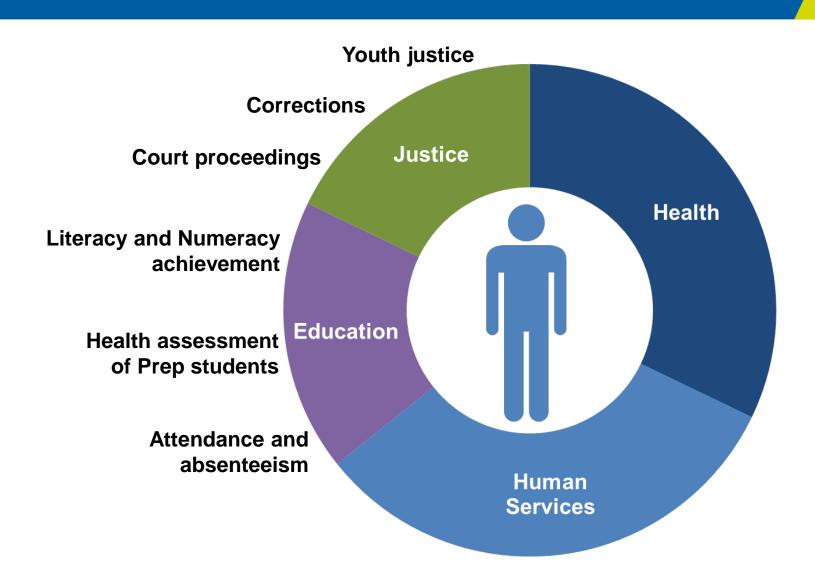


### Integrated client and services data

# **DHHS** integrated Client and Service data



# VSIIDR - whole of Victorian Government approach to integrating person level data



# CVDL processes to protect privacy

- The Privacy and Data Protection Act 2014 provides the privacy legislative framework for Victorian public sector organisations
- CVDL has developed robust practices to ensure compliance with relevant legislation and best practice linkage techniques
- This includes approval of data release by data custodians, and where required, development of a Privacy Impact Assessment and approval by a Human Services Ethics Committee
- CVDL employs data separation so that an individual's identifiers are separated from their case history information
- Access to linked data requires an assessment of disclosure risk against the ABS Five Safes Principles



The

#### 5 Safes Framework













1. Safe people Researchers can be trusted to use data appropriately and follow procedures

2. Safe projects

The project has a statistical purpose and is in the public interest

3. Safe settings Security arrangements prevent unauthorised access to the data

4. Safe data

The data inherently limits the risk of disclosure

5. Safe outputs The statistical results produced do not contain any identifying results

# **CVDL Separation Principal**

CVDL comprises three main teams:

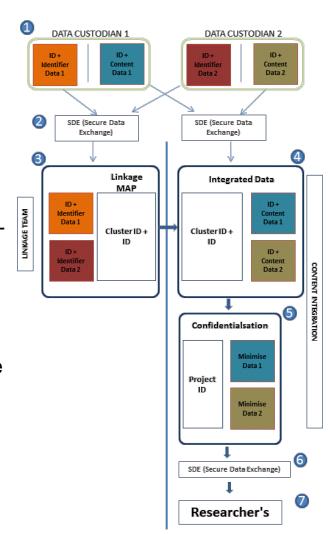
- Clients services team
- Data linkage team
- Content data integration team

To protect privacy, separate teams within the CVDL undertake data linkage and content data integration.

This separation of functions ensures that CVDL staff members do not have access to an individual's complete record (identifiers and service history).

Data custodians are requested to separate datasets into identifiers and content before they are provided to the CVDL.

They are then kept separate as they are process by the CVDL.



# Steps in linkage process

- Development of the VLM and IDR involves a number of stages, including:
  - acquiring and cleaning the datasets
  - linkage
  - integration
  - release of de-identified data to researchers and analysts.
- Most linkage projects referred to the CVDL continue to have a bespoke element rather than a simple content extraction from the IDR. For example:
  - Linkage of additional datasets such as clinical registries
  - Linkage of a particular research cohort

### Preparing datasets

- Most of the datasets included in the VLM and IDR are administrative datasets generated from DHHS services activity, either directly provided or funded.
- Provision of some datasets is relatively automated, while others involve manual transfer processes.
- The CVDL uses in-house SAS programs to perform most cleaning and standardization tasks on incoming datasets and has built a library of routines which are used with the data arrives.
- The quality and completeness of the datasets provided to the CVDL for linkage purposes varies.
- Where available, data custodians provide name, data of birth and sex as identifiers. Some funded agencies providing services on behalf of DHHS only report identifying data to DHHS in SLK-581 format

# Data linkage

- The CVDL currently uses the DataFlux product to undertake linkage to create the VLM.
- The VLM does not currently include a linkage spine of high quality datasets which form the basis for linkage.
- Links are made from any dataset to any other dataset in the VLM using the Dataflux software.
- The CVDL currently uses deterministic data linkage with some fuzzy matching to allow slight variation in the linkage variables such as names and dates
- The CVDL linkage team runs the Dataflux software over the datasets in the VLM to assign Linkage Identifiers for records that are identified as belonging the same individual

#### Data integration and release

- The CVDL Content Integration team uses the Linkage ID to extract the approved content data items from the relevant datasets and creates new project specific person IDs.
- Standard data de-identification processes are undertaken (aggregation and removal of personal identifiable data) to minimise the risk of re-identification of the data.
- Quality assurance is undertaken ensuring technical and administrative processes align with the research request. A quality statement is then produced.
- The CVDL is currently moving from releasing de-identified extracts of data to researchers via a Secure Data Exchange to access via a secure cloud based Azure platform.

# Data Linkage Concept – Hospital data

Rec_ID	First Name	Surname	DoB	Gender	Diagnosis
3	Bob	Miller	16/8/1965	Male	C460
5	Jane	Smith	18/9/1971	Female	Z088
9	Terry	Soloff	19/1/1945	Male	K920

Rec_ID	First Name	Surname	DoB	Gender
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Rec_ID	Diagnosis
3	C460
5	Z088
9	K920

To Linkage Map To Content Integration

# Data Linkage Concept – Death Data

ID	First Name	Surname	DoB	Gender	Date of Death
X79	Robert	Miller	16/8/1965	Male	17/9/2016
X85	Jane	Smith	18/9/1971	Female	18/5/2001
X1112	Kirsten	Bell	02/02/1993	Female	3/2/2015

ID	First Name	Surname	DoB	Gender
X79	Robert	Miller	16/8/1965	Male
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To Linkage Map

To Content Integration

# Data Linkage Concept – Linkage Map

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Dataset 1

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Dataset 2

Linkage_ID	Rec_ID	ID
1	3	X79
2	5	X85
3	9	
4		X1112

Linkage Map

# Data Linkage Concept – Data Integration

Linkage_ID	Rec_ID	Diagnosis
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Linkage_ID	Rec_ID	Date of Death
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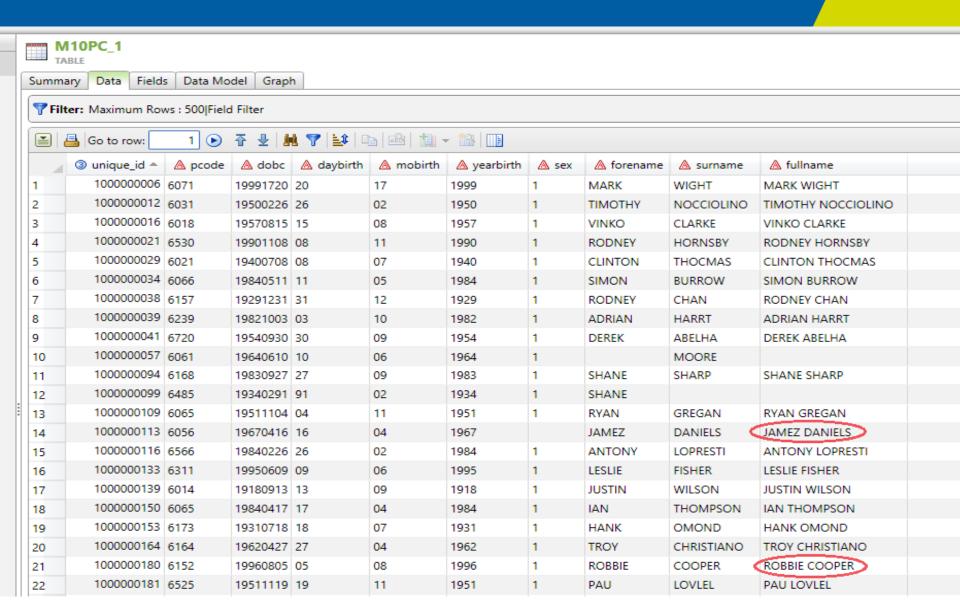
# Data Linkage Concept – Data Integration

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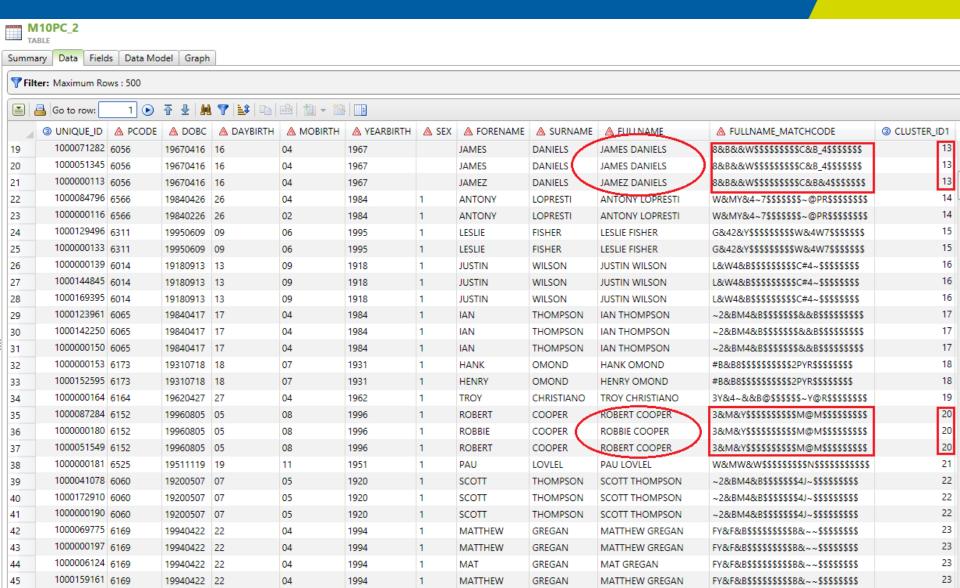
Linkage_ID	Diagnosis	Date of Death
456789	C460	9/2016
369789	Z088	5/2001
369124	K920	
101245		2/2015

Researcher

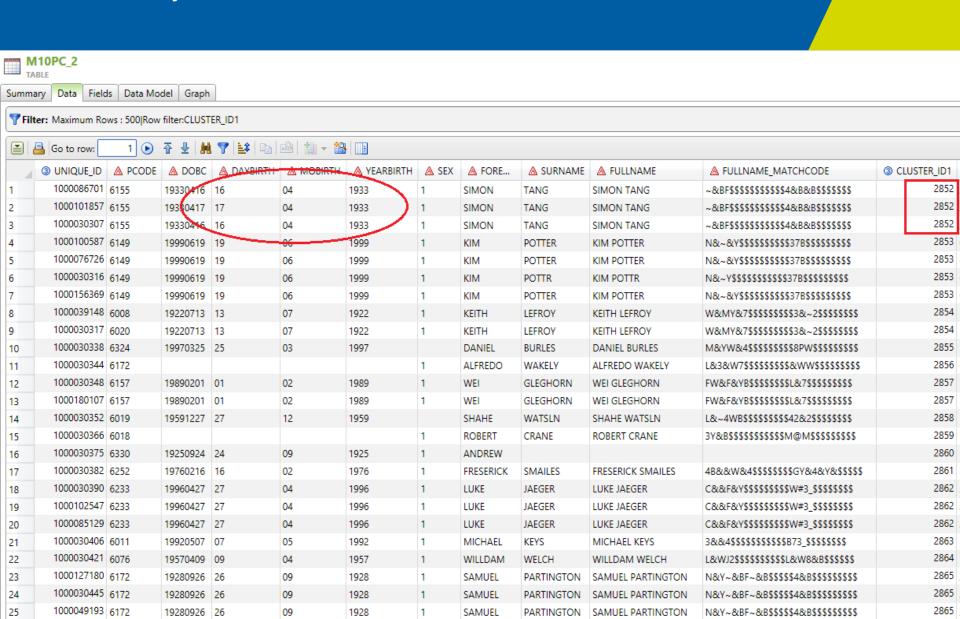
# CVDL Systems



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# Future directions: Linkage quality

- The quality of linkage is influenced by several factors, including the quality of the underlying data and the matching methodology.
- Independent review of the CVDL's linkage quality by Curtin University indicated the number of false positive errors in records linked by the CVDL was low
- However, there is evidence that there are a relatively high number of true links missed by the CVDL. This outcome is clearly related to the deterministic methods currently used by the CVDL.
- The CVDL is considering future options for linkage software, which
  may result in future adoption of probabilistic methods rather than the
  current deterministic methods.

# Future directions: Privacy preserving linkage methods

- Where possible, SLK-based linkage should be replaced with linkage using full identifiers, as this will improve linkage quality within the VLM.
- However, this is not always possible due to methods of data collection in service delivery organisations
- There are other sensitive datasets where availability of identifiers may be limited due to the sensitivity of the data (for example primary health data collected from GPs).
- CVDL is exploring high-quality, probabilistic privacy-preserving approaches (PPRL) that are now available, for example, Bloom filters
- Some limited exposure to Data61's Protari product

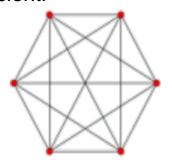
# Future directions: Victorian population spine

A linkage spine includes a small number of high quality data sets and provides the base that all other datasets are linked from .

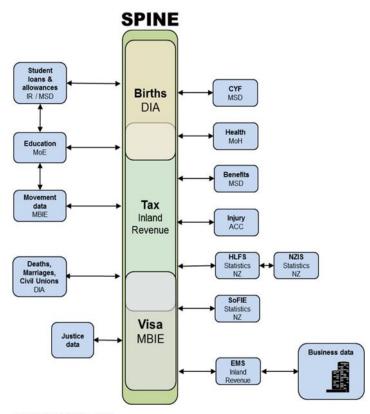
The linkage spine forms a bridge to link satellite data sets

The current CVDL linkage process is intensive as it makes links from any dataset to any other dataset

Linkage using a spine requires far fewer links to be made and is therefore more efficient.



# New Zealand IDI Spine



Source: Statistics New Zealand

# Future directions: Victorian population spine

- The spine will include a small number of high quality person-based datasets with comprehensive population coverage
- Requires datasets which include a broad range of high quality identifiers - names, birth dates AND addresses
- A distinct ID number such as a driver's licence number or medicare number assists the linkage

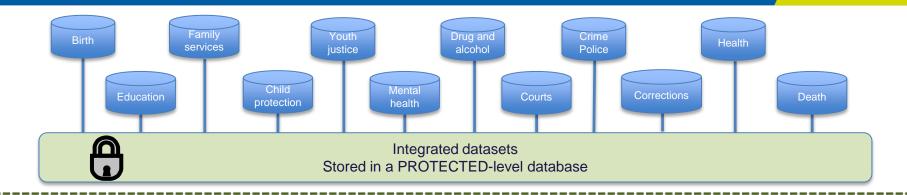
#### **Proposed Victorian Data Sets**

- Births Registry of Births
   Deaths and Marriages already
   held
- Drivers licences Vic Roads
- Electoral records Victorian Electoral Commission

# Future Commonwealth Data sets

- Medicare Enrolment Data
- Immigration
- CVDL's accreditation as an integrating authority has now been confirmed

# Future directions: Cloud-based repository and analytic tools



Row level de-identified: new secure environment for each approved request



- Separate data environments for each project to ensure security for data custodians
- Privacy & security legislative compliance assured
- Data remains in secure DHHS cloud environment
- Data science tools available e.g. R, SAS
- Research outputs facilitated by DHHS administrator
- Cost recovery model

#### **Azure Virtual Machines**

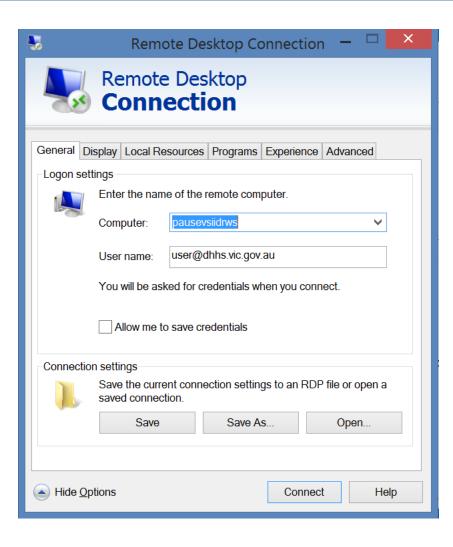
- Security
  - Microsoft Azure IRAP Certification to protected
  - Multi-factor authentication
  - Data remains in the VM
- Familiar look and feel
- Scalable computer power
- R, Python and SQL BYO licence STATA, SAS, etc.
- Machine Learning







### AZURE Remote Desktop Access





# **AZURE VM Workspace**























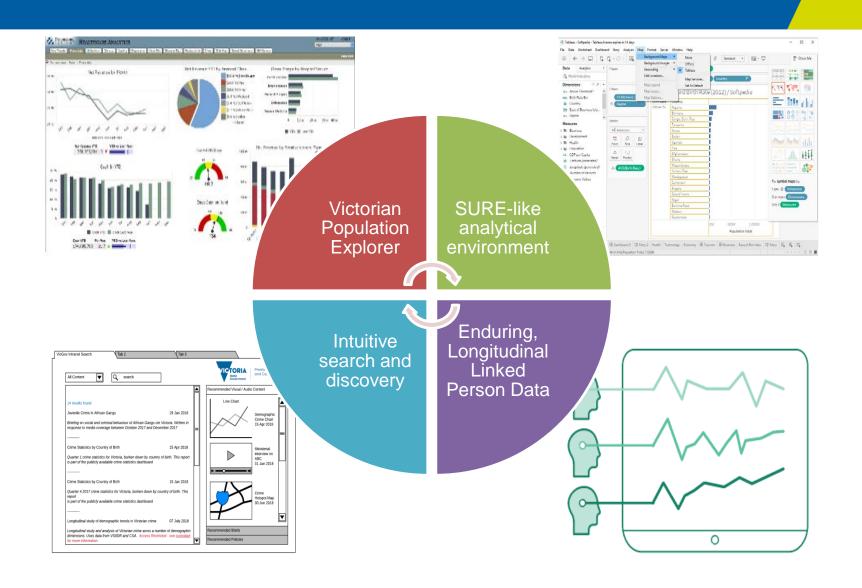








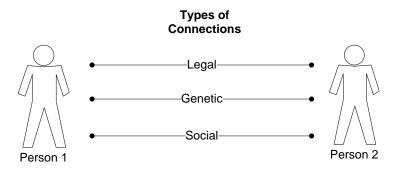
# CVDL Future Product Roadmap



# Future directions: increase usability of the data

- The Integrated Data Resource is extremely large and complex, which generally limits access to skilled analysts with high level statistical programming skills.
- Work undertaken by the CVDL to increase usability includes:
  - common reference tables and derived content tables
  - dataset summaries and data dictionaries
  - summary reports including demographic details (for example, sex, age breakdowns, aboriginality), appearance in other datasets ("common clients") and residential locations.
- Development of summary business intelligence reports and associated data cubes will make this summary information accessible to a broad range of users for answering some simple policy questions and assist scoping broader and more complex research and policy questions.

# Future directions: Familial linkage



- The VLM and IDR capture information regarding individuals, but many policy questions require an understanding of family and intergenerational relationships
- The CVDL holds births data dating back to 1993 and can identify the biological mother and father (if recorded) of persons registered from 1993.
- Some relationships are captured in a small number of datasets, in particular child protection and family services data.

# Familial linkage continued

- CVDL undertook a project with Department of Premier and Cabinet and Curtin University to identify a methodology for familial linkage
- The project identified different classes and types of relationships, and potential datasets to build up a store of interpersonal relationships, including births, deaths, marriages, perinatal, crime and public housing datasets
- Methods for identifying derived relationships were also included, for example, using shared address as a proxy for household relationships.
- The CVDL is continuing to explore this methodology but progress has been limited due to resource constraints.