

MONASH HELIX

M-Link

Creating a Health Data Linkage Community of Practice at Monash University

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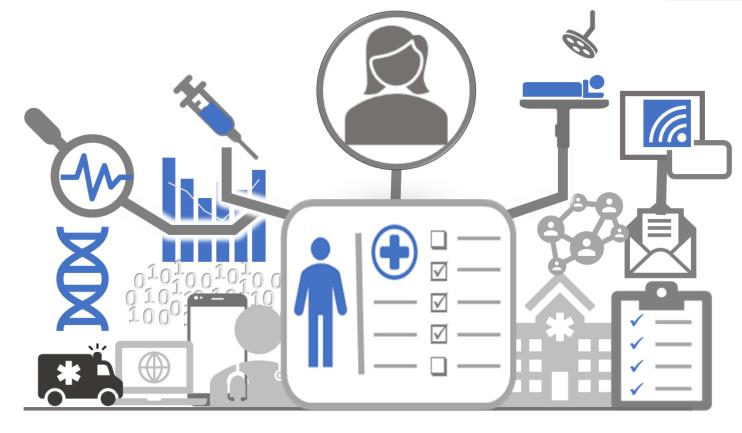


High impact health research is a key pillar of Monash University...



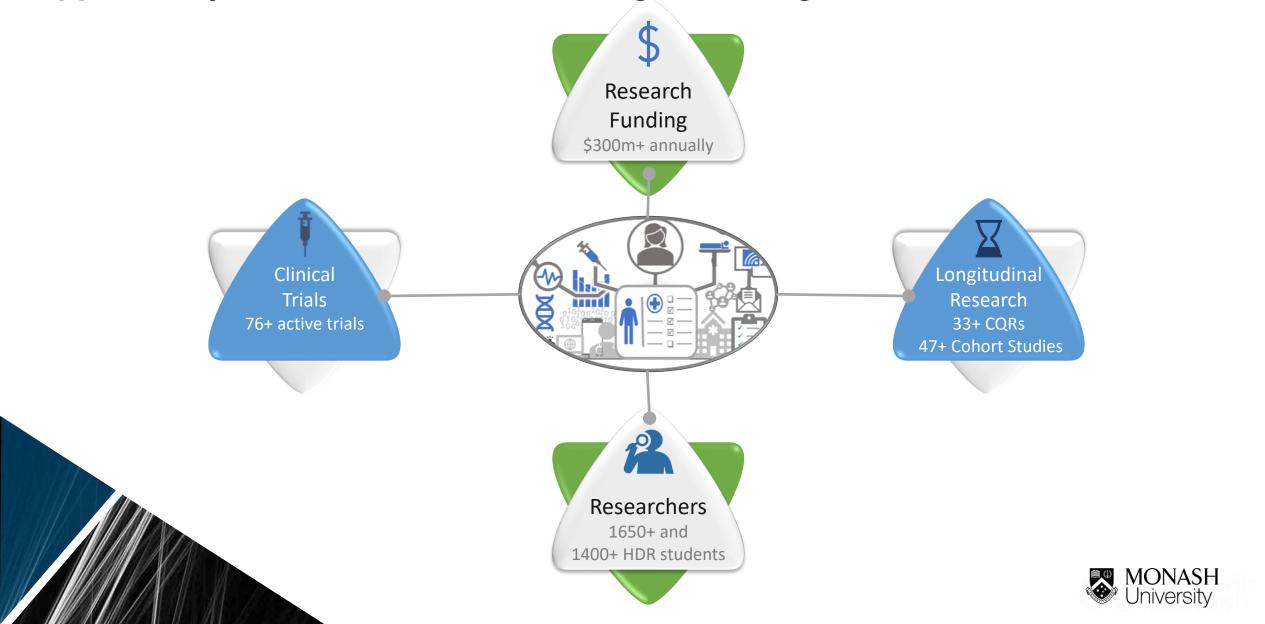
Thriving communities

Living well and together requires understanding and solution of medical, health and technological issues, and systemic social issues.





Leveraging complex health data, there are over 3,000 researchers and students supported by \$300m in research funding delivering this vital research



Helix was established to build health research capabilities

Infrastructure

Health data specialist services such as REDCap, Qualtrics Plus, Custom-built Registry databases, SeRP

People

Expert advice; Training in Data Dictionary, Data Linkage, Digital Health and Data Governance; Data Linkage COP

Processes

Data Governance processes and templates, Data Dictionary template, Data Linkage guides

Policy

Provide input into development of University, as well as state & national data related policy





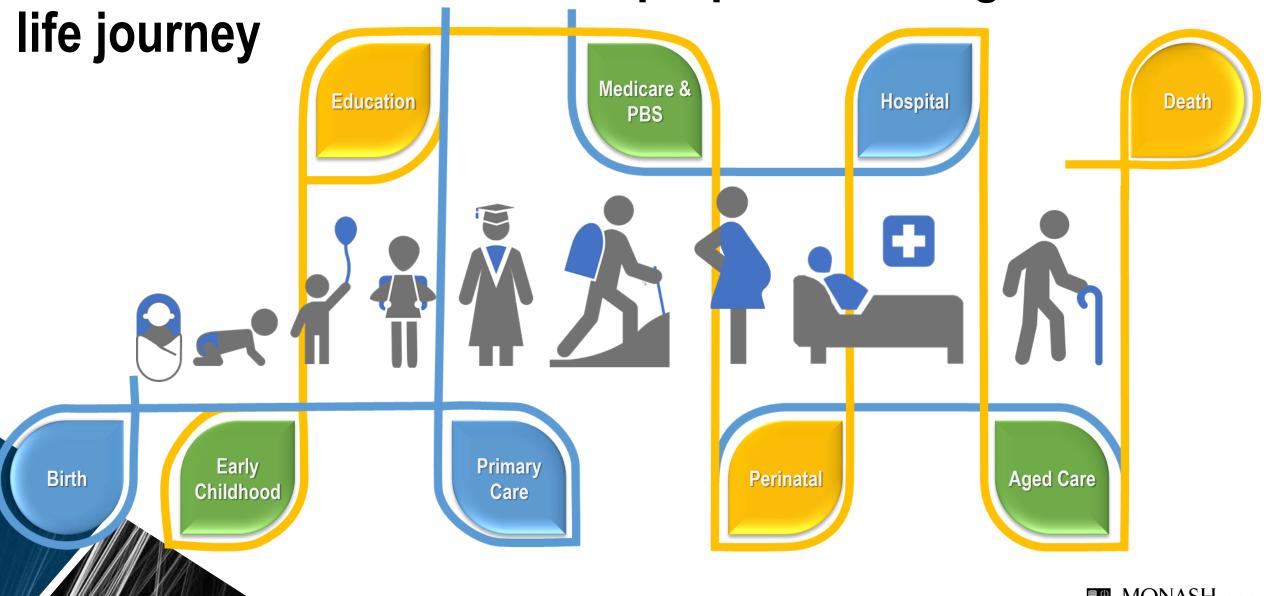




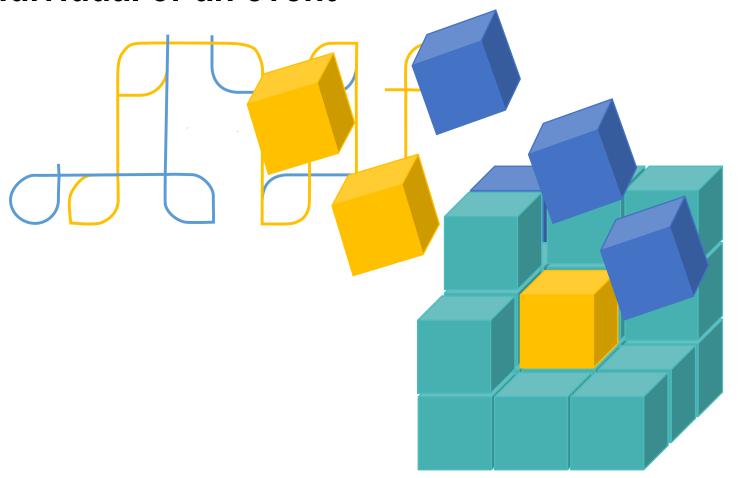




Data is collected for various purposes throughout our



Data Linkage draws this data together to increase the depth and breadth of information about an individual or an event





Effective data linkage requires a set of skills



Study Design

Ensuring that linked data is right for the study design



Ethics & Governance

Creating the formal agreement between two or more parties to share their data



Linkage Techniques

Techniques used to link data sets together with a high degree of accuracy



Data Storage & Security

Providing secure
data storage with
fully governed
access, in line with
data custodian
agreements



Data Cleaning and Analysis

Skills and tools required to ensure appropriate and reliable outputs



So Helix created a working group, with range of expertise, to focus on four areas

Knowledge Sharing

Resources Mentoring Experience



Data Access

Connect researcher/
custodian
Assistance with
processes
Secured shared
Environments

Training and Analytics

Internal courses
Workshops
Promotion of
external courses



Technical Support

(SeRP)

Code sharing (GitHub)





The road so far

Working Group

Research & Professional staff with expertise in data linkage, big data research, IT, data governance, data protection and privacy and data management.

Snowballing

Initially used working group's networks using snowballing to raise awareness and establish interest

M-Link

Created a registration database to collect information about expertise, knowledge and dataset experience

Data Fluency

Created an introductory training to data linkage that is delivered through the Library's Data Fluency programme

Guide

Created an ethics and application guide to be used by researchers with advice, examples and guidance

Events

Semi-annual events with guest speakers, focussing on specific topics (death data linkage, PHRN, etc)

Advocacy

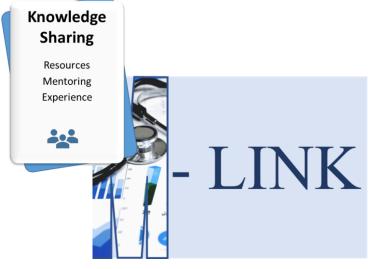
Expert input into University advocacy on linked data research (eg DATA Scheme)

Resources

Sharing analytical code and datasets



What has worked....



eResearch Co

C Returning?

AAA

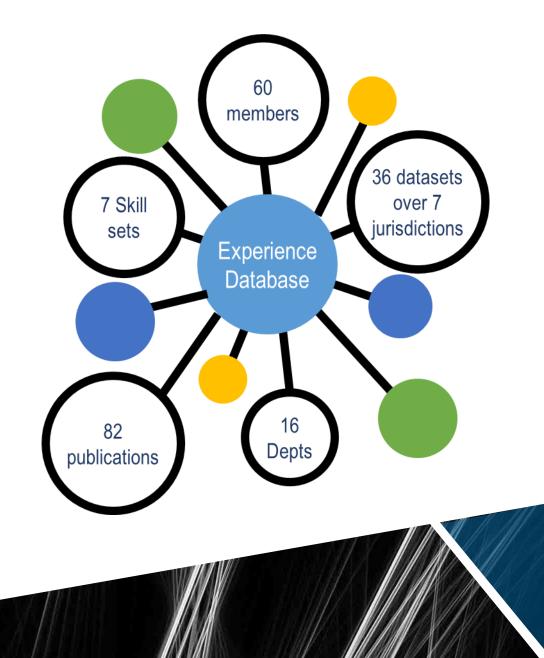
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Monash Health Data Linkage Knowledge Base

As part of Monash's Data Governance Framework to provide support to users of health data, a Data Linkage Working Group has been established to develop a community of practice to advance data linkage capabilities across the university. The Data Linkage Working Group would like to facilitate increased knowledge sharing across faculties about data linkage, including governance, ethics, analysis and other technical and practical issues.

As a first step, the Data Linkage Working Group would like to understand the current state of data linkage activities across Monash University and where existing data linkage expertise lies. The Working Group is aware that, in the course of your work at Monash, you may have dealt with various health datasets.

The attached survey seeks to collect information from you about your experiences in dealing with health datasets in the course of your work. This information will be used by the Data Linkage Working Group to plan our activities and to create a knowledge sharing online tool - a "who's who" of data linkage within Monash called M-Link to connect researchers working in this space and facilitate peer support within this complex area of research. This will allow Monash Researchers to connect with those that have experience and support the growth of our data linkage research community.





What remains...

Data Access

Connect researcher/
custodian
Assistance with
processes
Secured shared
Environments

Requirements

- Resources/ Time
- Higher profile across the University
- Broad representation of research "voice" at decisionmaking table
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