

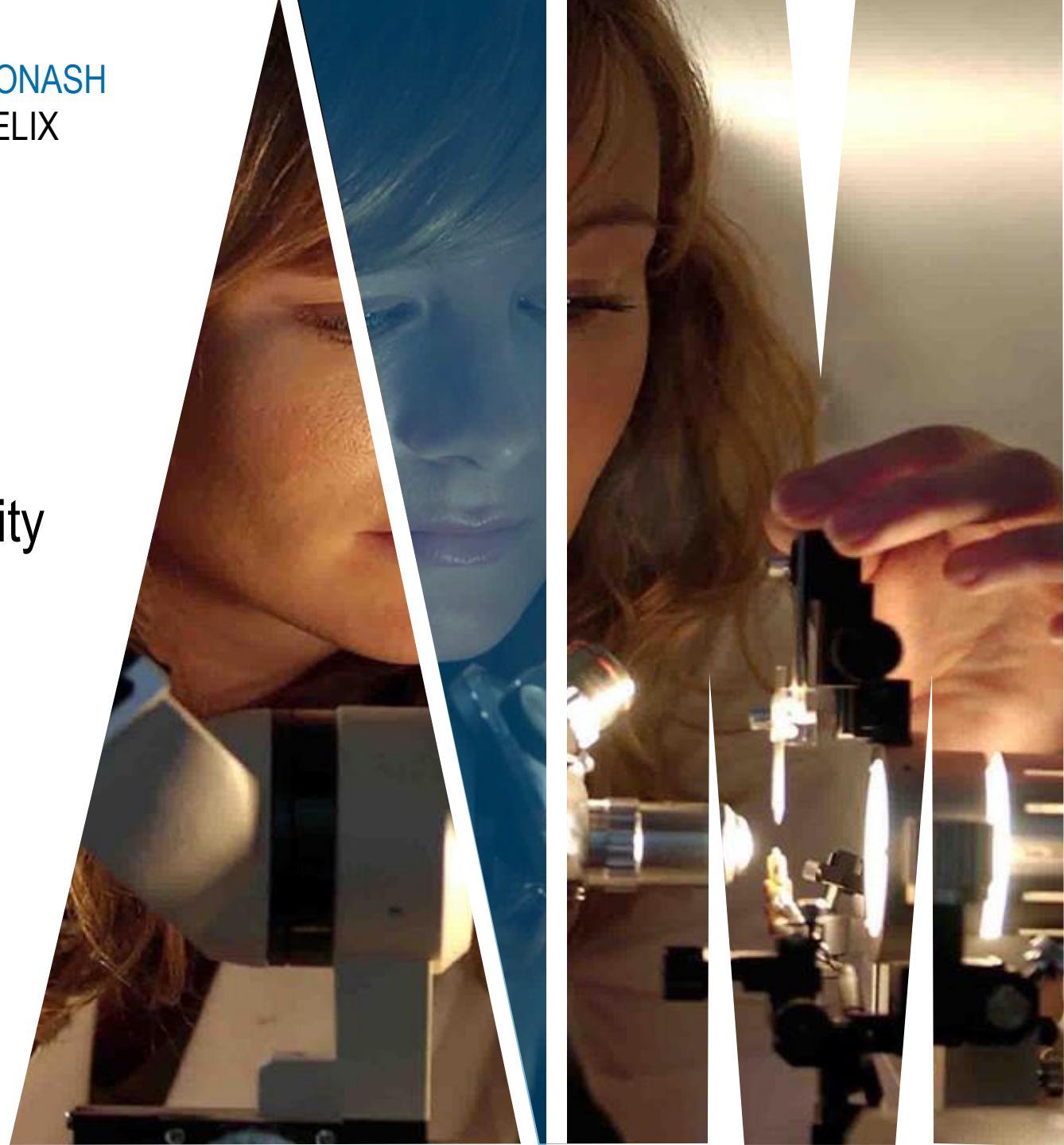
M-Link


Creating a Health Data Linkage Community of Practice at Monash University

Dianne Brown, A/Prof Nadine Andrew, Mark Lucas

18 October 2022

2022 eResearch Australasia Conference

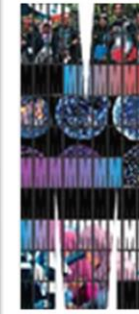




*We acknowledge the
traditional custodians
of the land and
waterways on which
we work.*

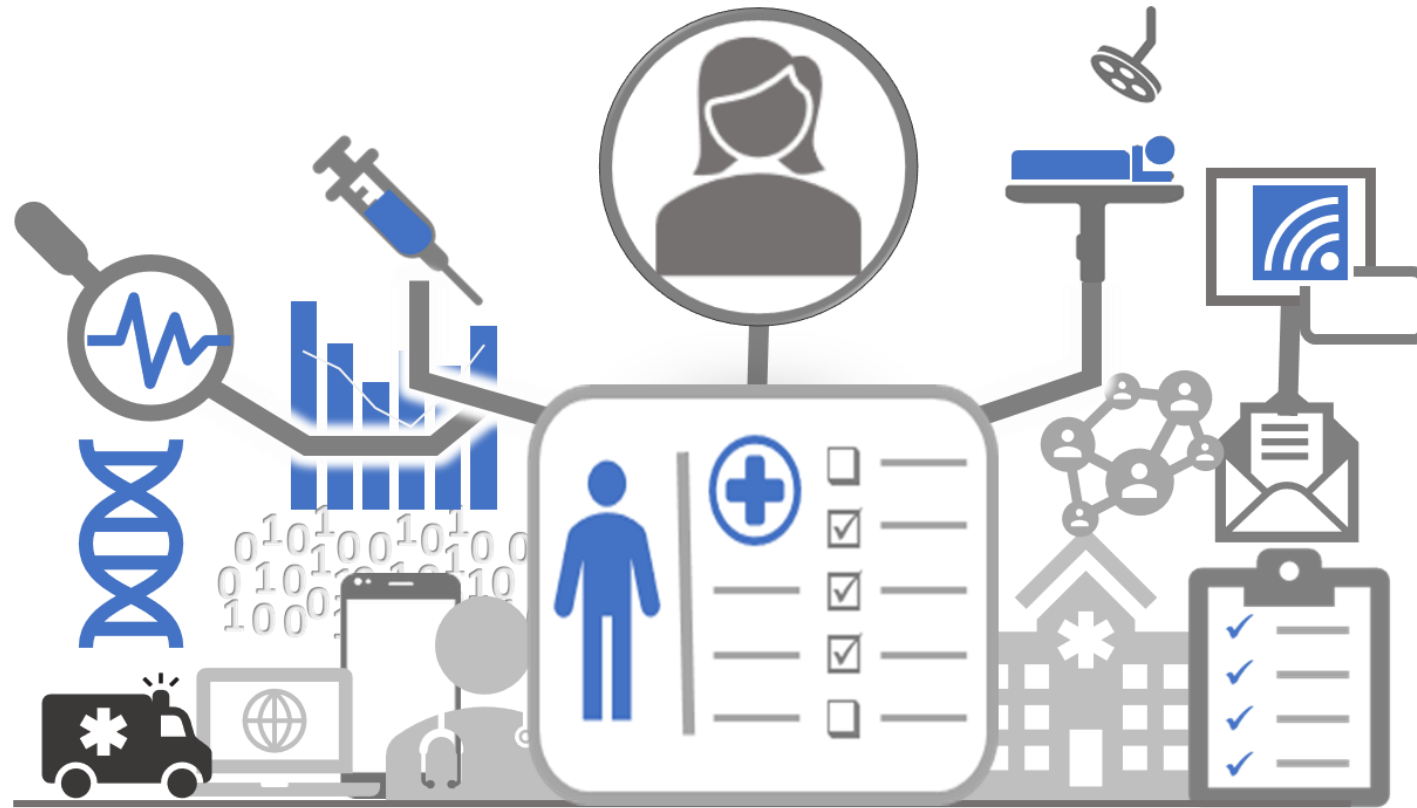
*We pay our respects to
these cultures, their
Elders past, present
and future, and
continue to uphold
their ongoing
relationship to the
land.*

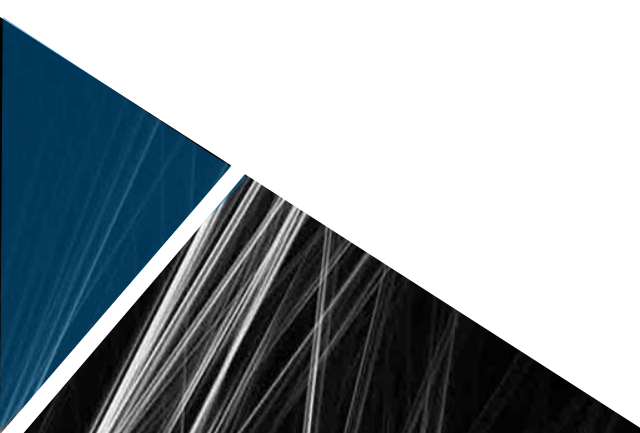
High impact health research is a key pillar of Monash University...



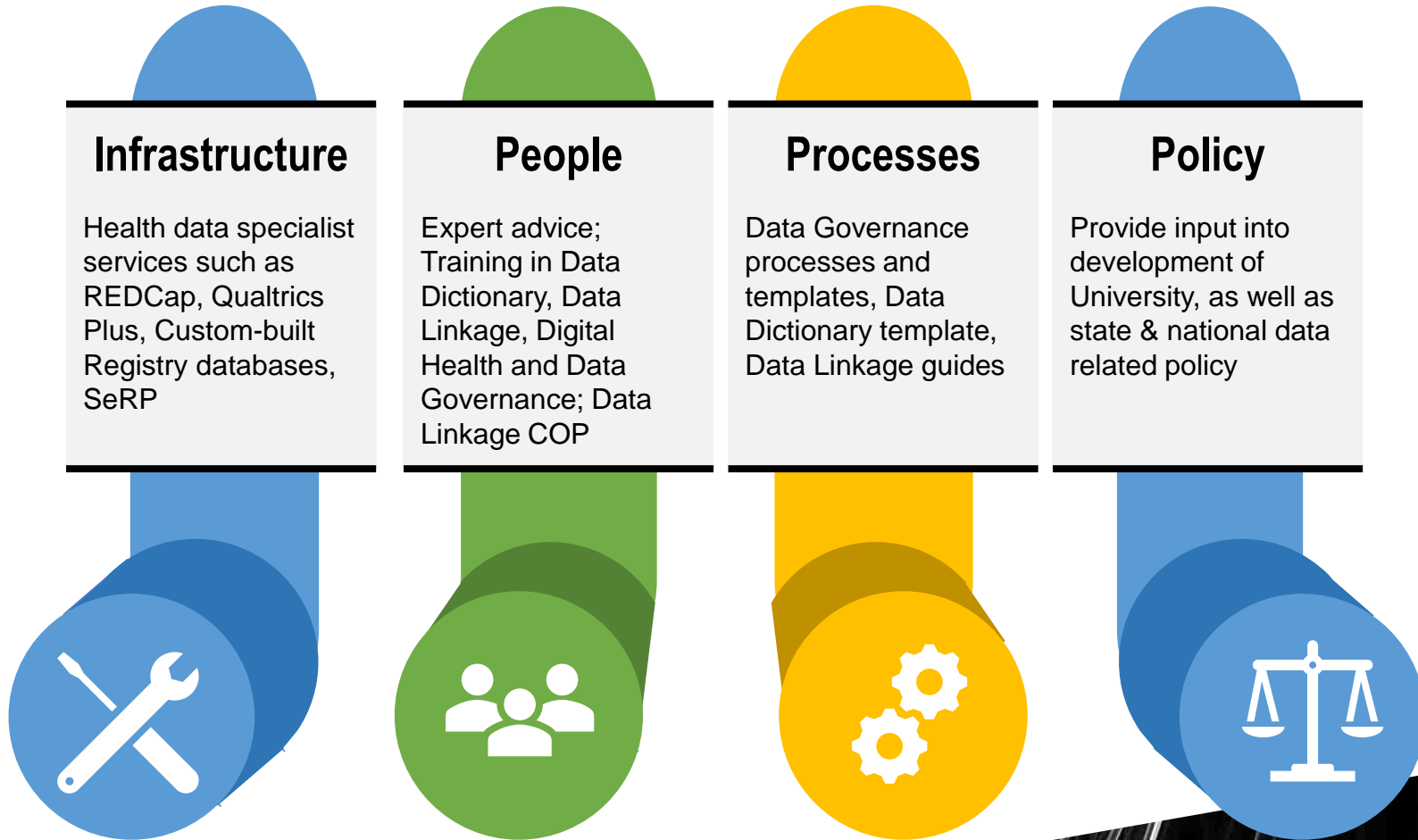
Thriving communities

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

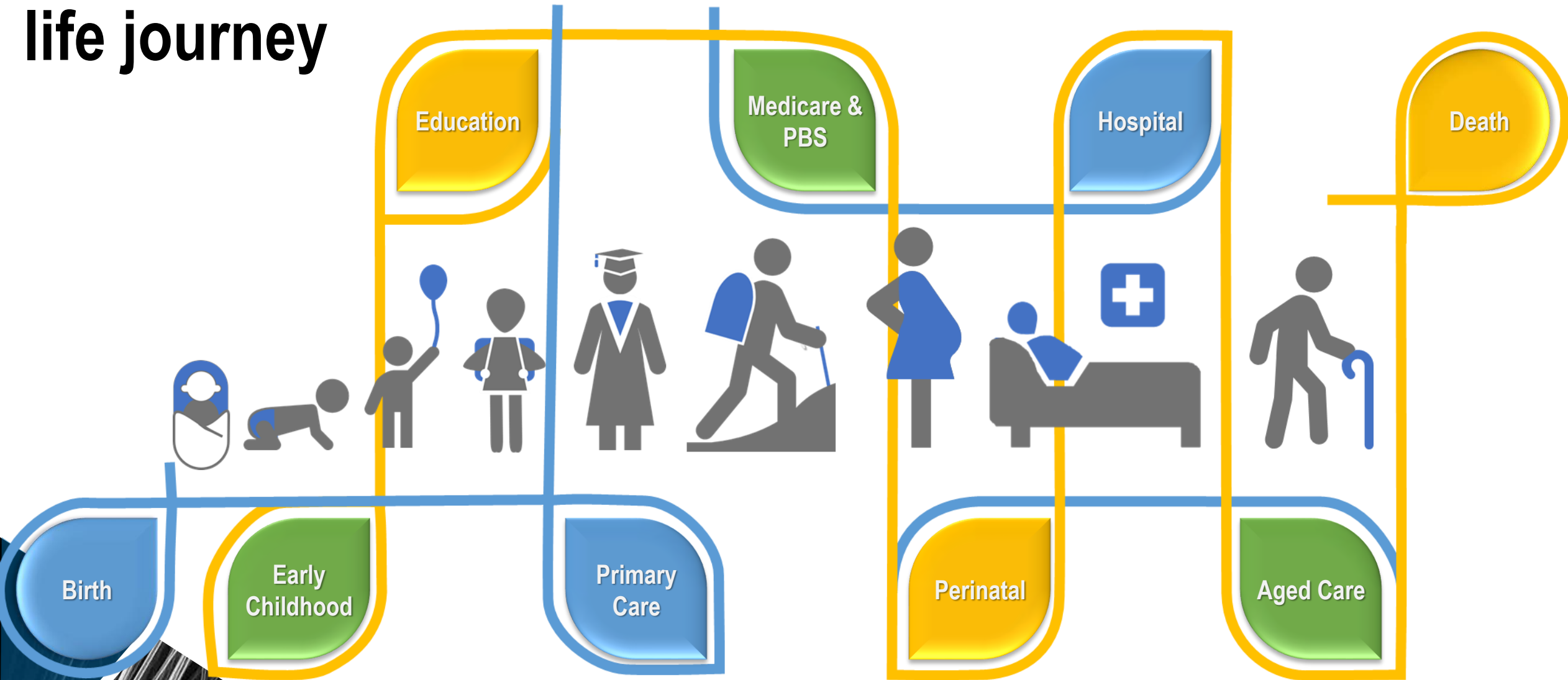




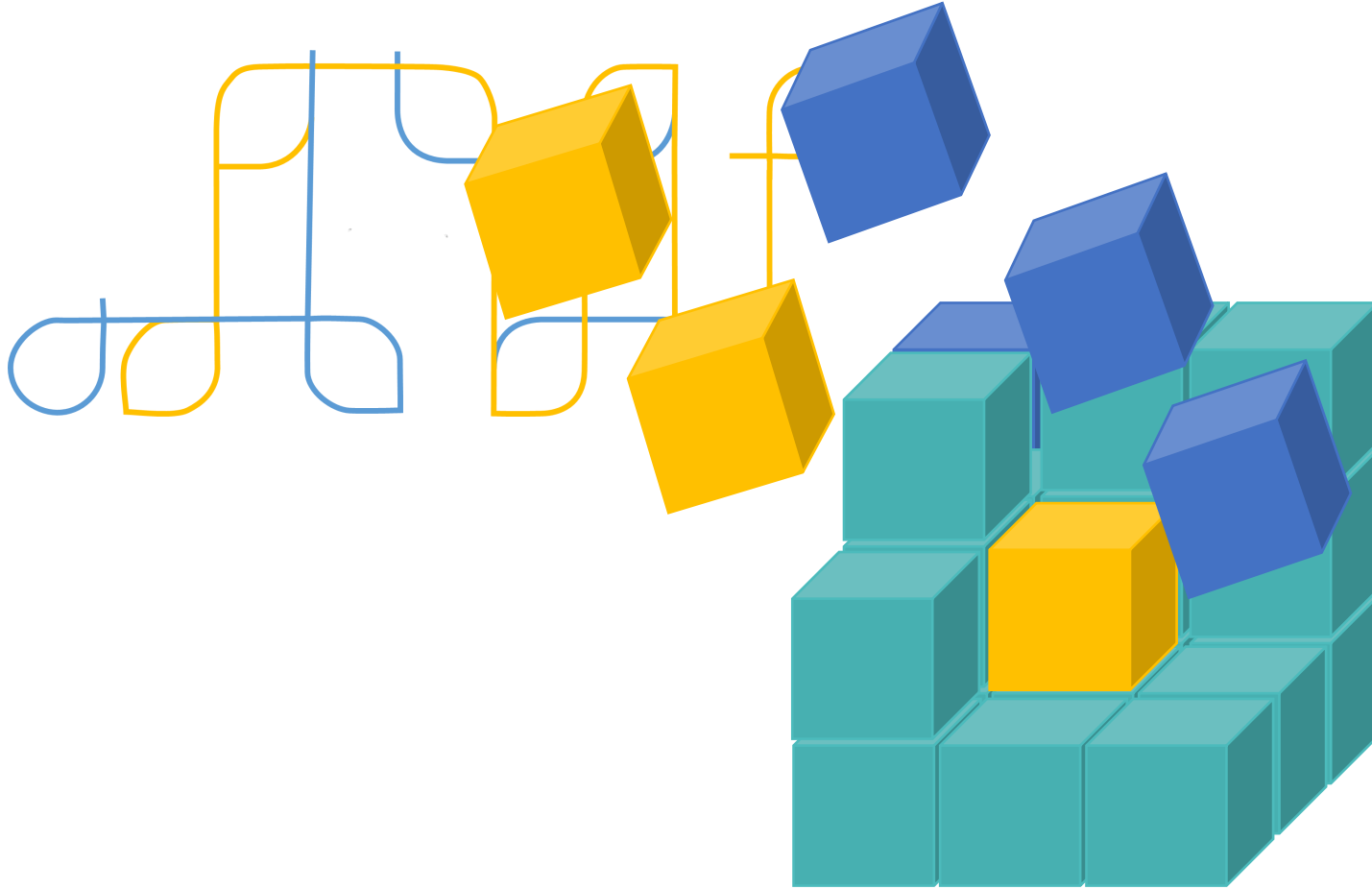
Helix was established to build health research capabilities



Data is collected for various purposes throughout our life journey



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

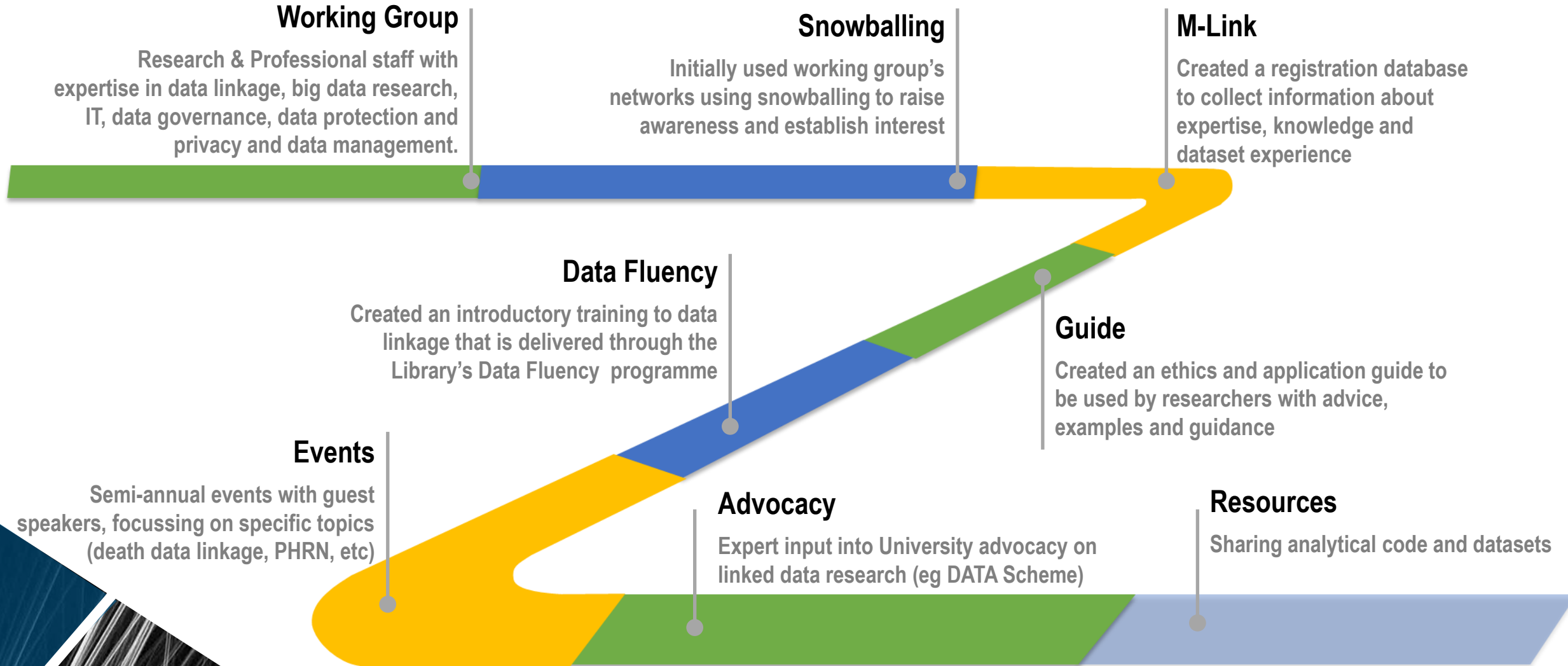


Technical Support

HELIX Platforms
(SeRP)
Code sharing
(GitHub)



The road so far



What has worked....

Knowledge Sharing

Resources
Mentoring
Experience



Monash Health Data Linkage Knowledge Base

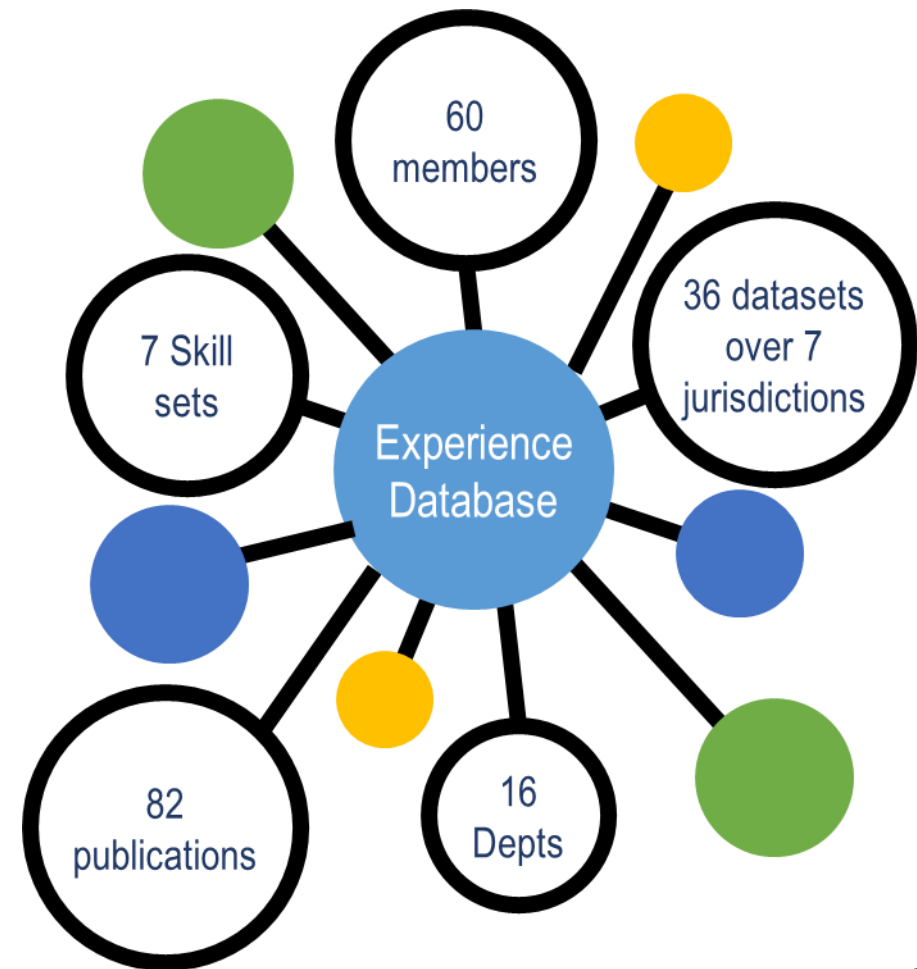
As part of Monash's Data Governance Framework to provide support to users of health data, a Data Linkage Working Group has been established to develop a community of practice to advance data linkage capabilities across the university. The Data Linkage Working Group would like to facilitate increased 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.

Returning?

AAA
⊕ ⊞



MONASH
University

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 decision-making table
-

Acknowledgements

Other Members of Helix Data Linkage Working Group

A/Prof Richard Beare

A/Prof Monique Kilkenny

Mr Anthony Del Monaco

Prof Belinda Gabbe

Ms Megan Fincher

Dr Jenni Ilomaki

Mr Mark Lucas

A/Prof Suzanne Nielsen