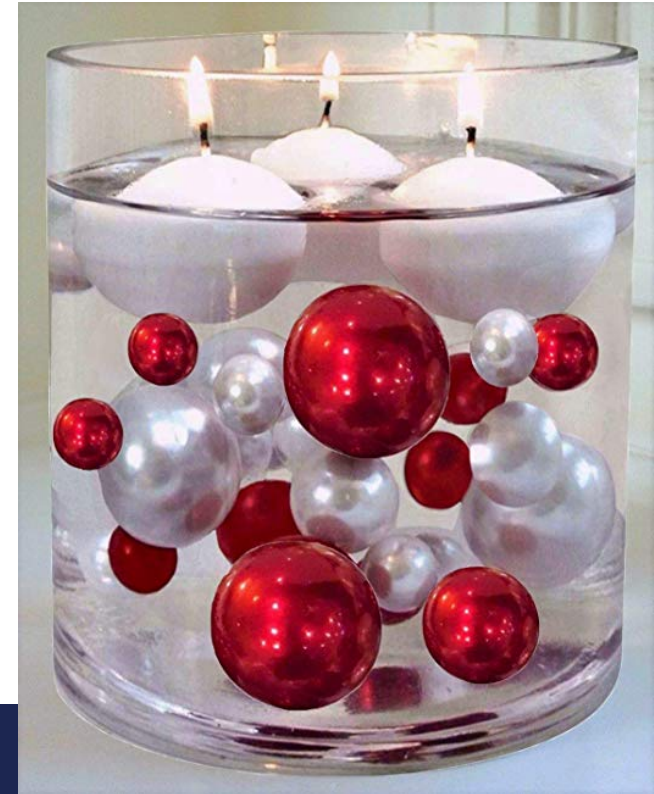# Creating the Digital Health Future

14 February 2020

Principles and strategy

- Base projects on defined industry outcomes and objectives

- Cluster partners on larger more impactful programs

- Focus on jurisdictional priorities and future direction

- Define commercial pathways early – meet ROI

- Established the company, ACNC status + governance committees

- Core team recruited

- Developed and released Research Education & Investment Framework + Funding Guidelines

- Appointed Flagship Research & Education Directors (FREDs)

- Education program released, MOOC under development, Flying Blind Volume 2

HIGHLIGHTS

1 July 2018 to 30 June 2019

80 bid participants

75 signed:
  44 additional participants
  31 core participants
    (23 members)

8 workshops held

240 attendees
**80** organisations represented

32 projects under development

Refreshed Board

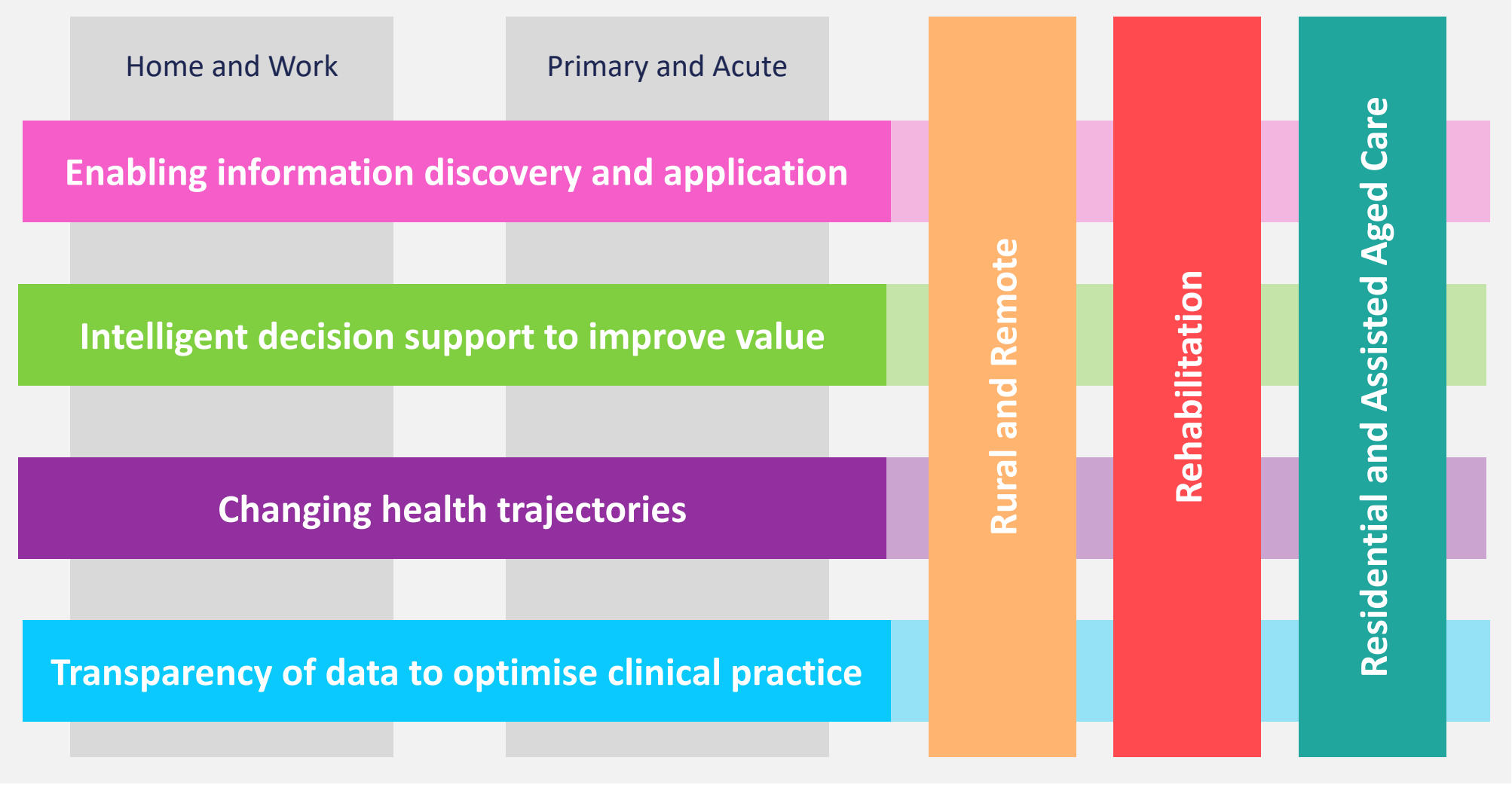| Director	Affiliation	Independent?	Term
Mr Michael Walsh (Chair)	Ex-Director General Queensland Health Chair, Australasian Institute of Digital Health	Yes	28 Nov 19 – 27 Nov 22
Professor Christine Bennett (AO)	DVC Research, Notre Dame University	No	11 May 18 – 10 May 20
Dr Neale Fong	Chair, WA Country Health Service Executive Chair, Bethesda Health Care	No	28 Nov 19 – 27 Nov 22
Dr Steve Hambleton	Ex-President, Australian Medical Association Co-Chair, Primary Health Reform Steering Group	Yes	27 June 18 – 26 June 20
Mr Bill Lucia	President and CEO, HMS	No	28 Nov 19 – 27 Nov 22
Mr Paul McBride	First Assistant Secretary, Department of Health (Cth)	No	28 Nov 19 – 27 Nov 22
Ms Kate Munnings	COO, Ramsay Healthcare Australia CEO, Virtus Health Limited	Yes	28 Nov 19 – 27 Nov 22
Dr Megan Robertson	Group Chief Research Officer, St Vincent's Health Australia	Yes	28 Nov 19 – 27 Nov 22
Dr Priscilla Rogers	COO, Wintermute Biomedical	Yes	28 Nov 19 – 27 Nov 22

Project Pipeline

- Developing pipeline of projects aligned to Flagships

  - 25 Opportunities
  - 2 PCP
  - 14 Plans   **57**
  - 1 Agreement
  - 15 Delivery

- Approx 55 participants involved in projects
- 6 third parties participating on a project basis
- Total project pipeline cash value $25,442,998
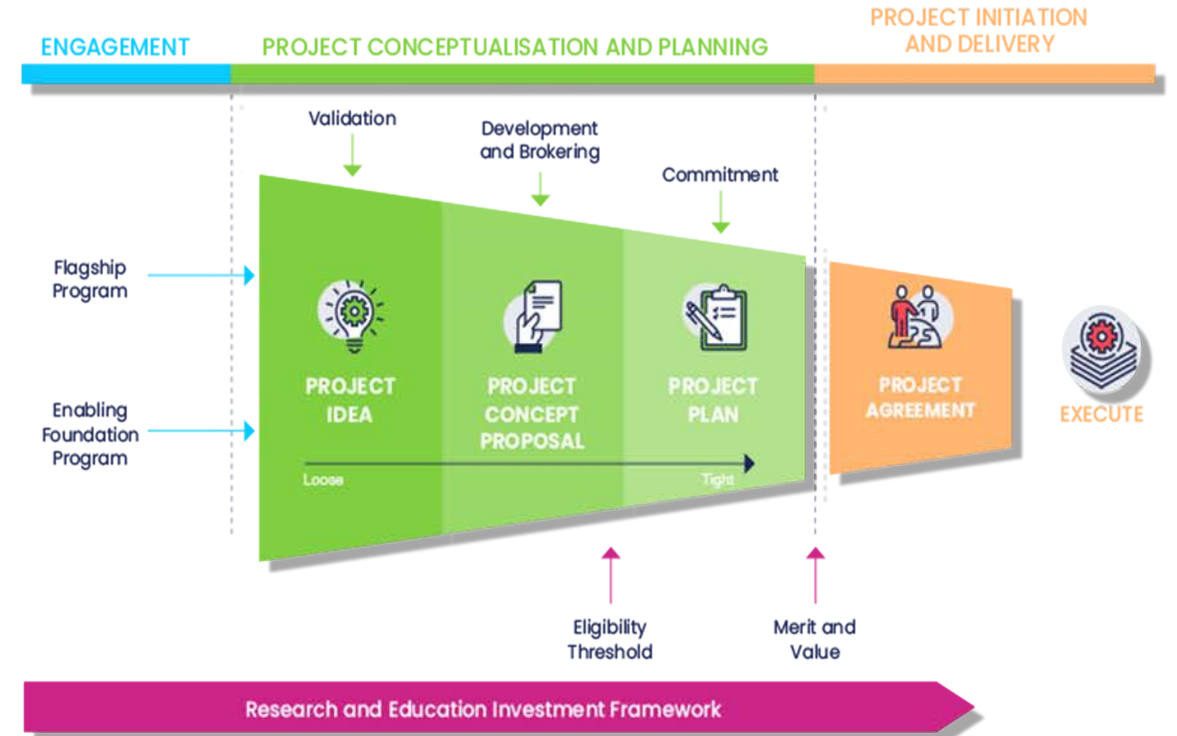
Our Research Matrix

Data eco-system

- The Exchange (DHCRC) 0091

- Governance, legal and ethical frameworks to support forward looking data use (DOH, PHRN) 0060, 0105

- Data extraction for multiple purposes 0096

- Synthetic data 0090

digital health
CRC

The Exchange

the right data – the right place – the right decision

Flagship: Enabling information discovery and application

Improve access and integration of health data

Developing opportunities for research and development:

- Increase ability to discover, collect, manage and manipulate large volumes of data within Digital Health systems

- Horizontal and Vertical data integration

- Technologies for unlocking information in structured and unstructured data (Analytics and AI)

- Increasing and exploiting the value of clinical, biological, population and environmental data for public benefit

- Facilitate and support high-quality data for (real-time) clinical decision-making, planning and research
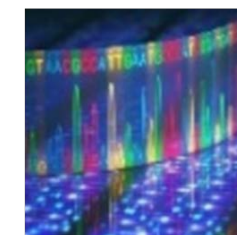
Enabling information discovery and application

Principles required to meet the needs of CRC research scenarios:

- Platforms that are flexible, scalable and *interoperable*

- Streamlined authorisation environment (*dynamic consent*)

- New and *innovative* ways of combining and investigating data

- Informatics platforms that enable *'safe' research*

- Secure movement of data in *real time*

- Improve *co-operation* and communication across CRC

The Exchange: functionality and features

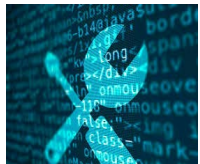**Connectivity**
- Internet
- Authorised users only

Controlled Access
- Project controls
- Dynamic Consent Platform
- Facilitate consent process
- Communication between researchers and participants

Federation/Distribution
- Access
- Datasets
- Linkage/Integration
- Analysis

Environment
- Shared project collaboration space
- Data storage & management systems
- Secure analytics platform (HPC options)
- Advanced analytical tools (NLP, AI, ML etc)
- Control release of analytics outputs

Data Discovery and Integrity
- Dataset catalogue
- Dataset versioning
- Data quality statements
- Analytic tools

Hosting
- 'Cloud ready' or 'cloud friendly'
- Multiple secure tenancies

Data Linkage
- Integrated linkage functionality

Progress so far…

- ***Engagement:*** The Exchange concept was formed through the DHCRC participant workshops which identified a need for scalable, consistent and compatible research infrastructure linked with platforms to support care

- ***Repeatable:*** The idea of addressing common infrastructure challenges has been constant in DHCRC project development

- ***Developing a Roadmap:*** A series of workshops are being planned to ensure that the DHCRC vision for the Exchange is consistent (internally and externally) and to develop a high-level project plan

- ***Internationally:*** Health Data Research UK and Strategy for Patient-Oriented Research (SPOR) Canadian Data Platform have also identified the need for health data research hubs which provide interoperable research components

- ***Locally:*** Keen to explore opportunities with Victorian-based participants

Patient data access, trust and consent in general practice and related health care settings

Research participant
Monash University; Professor Kerry O'Brien

Industry participant
Commonwealth Department of Health, Shane Porter

Project objectives
- Improve patient access to their own data

- Improve patient knowledge of, and trust in, data collection/storage and sharing

- Improve patient consent mechanisms to not/share their own data

- Provide government guidance on a 'social license' to share/not share patient data for clinicians, researchers, and other health providers.

Expected Start Date: March 2020   **Expected End Date:** December 2023

Why do we need to review data access, trust and consent frameworks?

- Volume of digital data and its rate of growth too big for existing methods of management

- Demographic change and technological advances are key drivers of this change

- Opportunity to create frameworks for a developing technology landscape (future proof)

- Expectations and opportunities from technology (discoverability and real-time access)
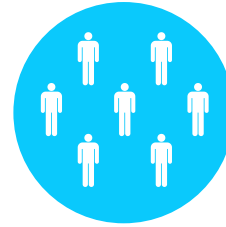
Demographic Shifts & Social Change

Technological Advances

Empowered Consumers

Globalisation of Care

Patient data access, trust and consent in general practice and related health care settings - project aims

Project aims to ***understand and improve*** data access and consent mechanisms in general practice and related health care settings:

- Establish what underpins people's willingness or unwillingness to provide consent for the use of their medical records

    - ***Trust*** - Data integrity (secure and accurate), data used appropriately, etc.

    - ***Knowledge*** - How data is used, benefits of data sharing, transparency in processes, etc.

    - ***Sense of ownership*** – Ability to provide feedback, need for social license, etc.

- Builds community understanding of the ***benefits of good data quality and data sharing*** and develop transparent mechanisms for patient data to be discoverable and used with community support to improve patient outcomes and system efficiency.

- Develop mechanisms that give patients ***access*** to their own GP data and the ability to ***control*** who can see their data

Principles

- Support development of systems of engagement

- Look to support mobile applications

- Test implementation of systems at scale

Integration of new decision support tools across jurisdictions

0085
0094
0100

How do we Integrate intelligent decision support tools into routine practice and at scale to improve value of care and systems efficiency. Understand contextual and human factors required for success

Changing Health Trajectories

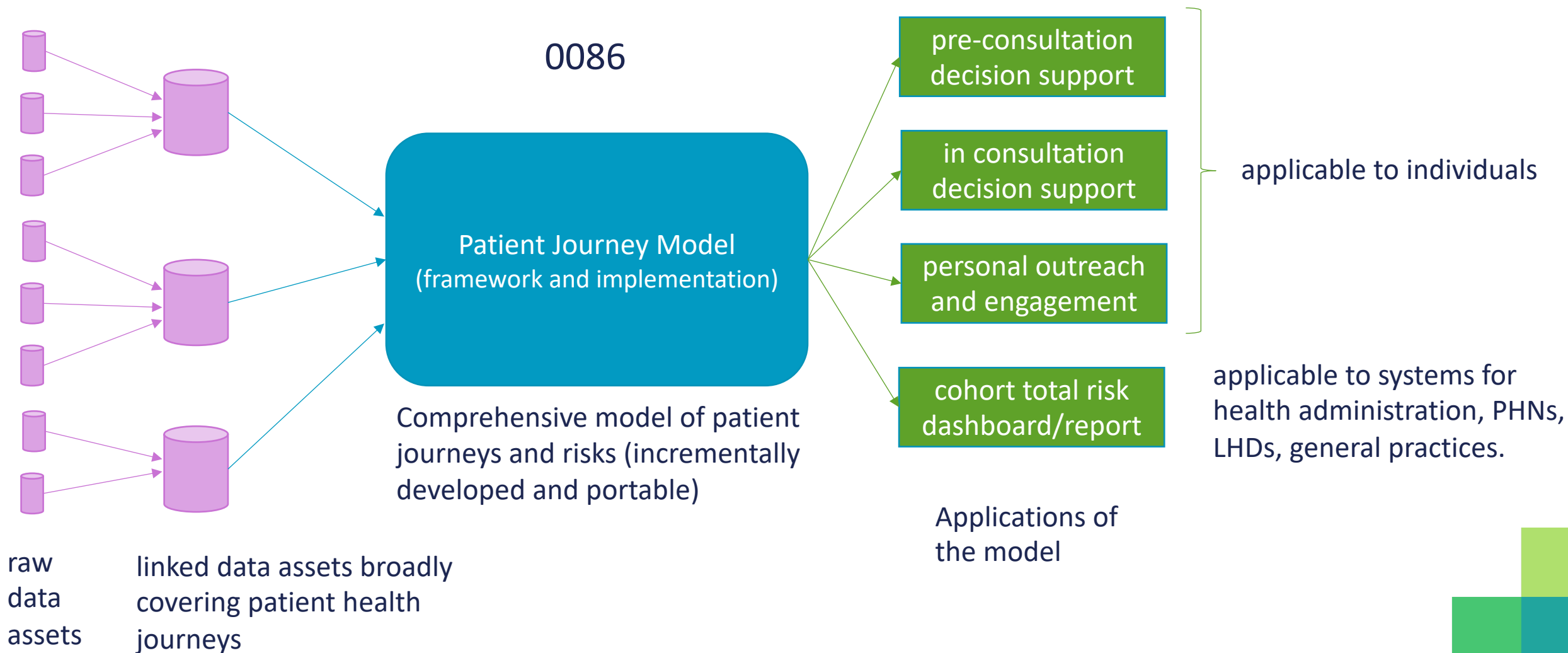Support at scale patient outreach and engagement – transform discharge and outpatient services
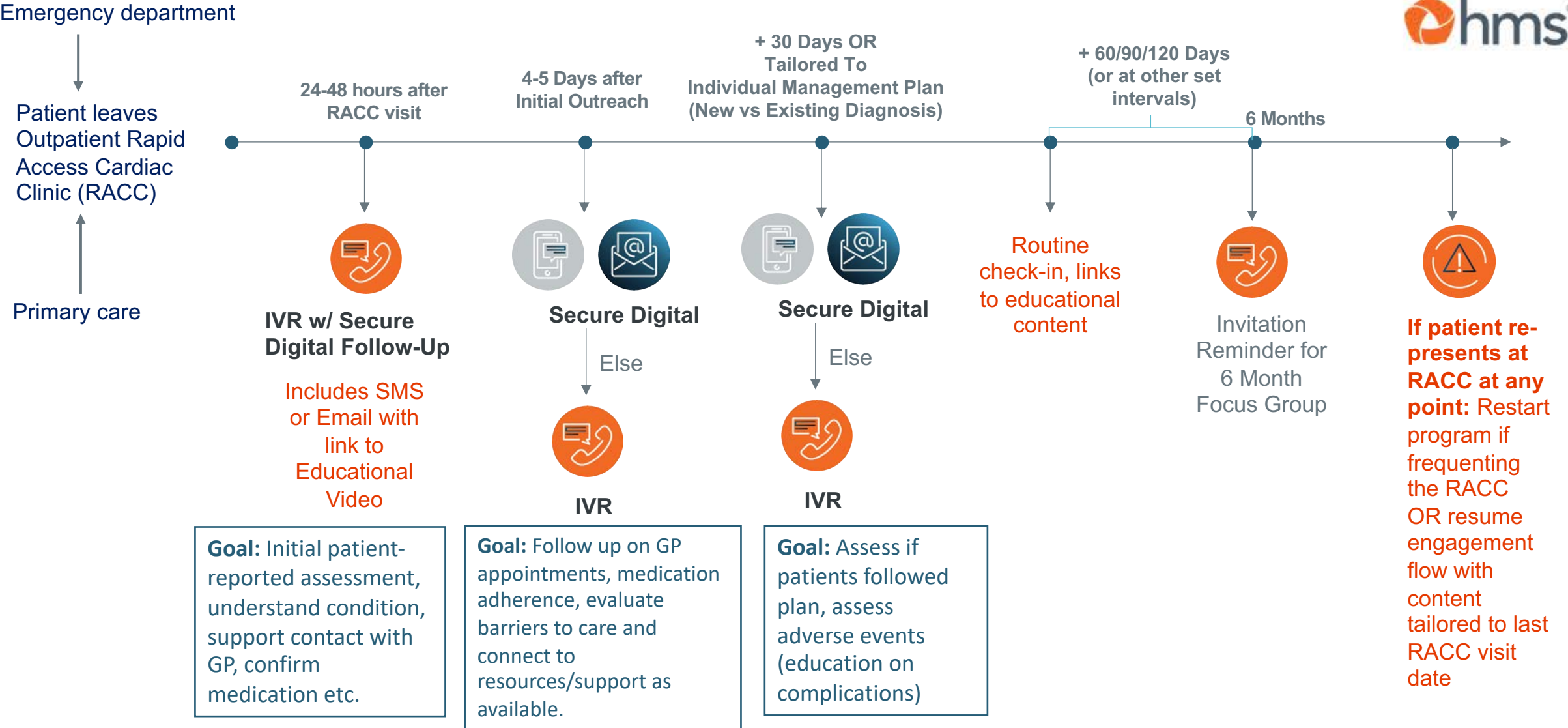
Principles

- Support linkage of primary and acute data sets and their application

- Embedding in jurisdictional programs (collaborative commissioning (NSW), digital first outpatient (WA), linked primary and acute (VIC)

- Lots of opportunity for SMEs – need to be strategic and opportunistic

- Chance to bring in new partners

Patient journey modelling – collaborative commissioning

0086

Patient Journey Model
(framework and implementation)

Comprehensive model of patient
journeys and risks (incrementally
developed and portable)

pre-consultation
decision support

in consultation
decision support

personal outreach
and engagement

cohort total risk
dashboard/report

applicable to individuals

applicable to systems for
health administration, PHNs,
LHDs, general practices.

Applications of
the model

raw
data
assets

linked data assets broadly
covering patient health
journeys

Outpatient support for Atrial Fibrillation – collaborative commissioning

Emergency department

Patient leaves Outpatient Rapid Access Cardiac Clinic (RACC)

Primary care

24-48 hours after RACC visit

4-5 Days after Initial Outreach

+ 30 Days OR Tailored To Individual Management Plan (New vs Existing Diagnosis)

+ 60/90/120 Days (or at other set intervals)

6 Months

IVR w/ Secure Digital Follow-Up

Includes SMS or Email with link to Educational Video

Secure Digital

Else

IVR

Secure Digital

Else

IVR

Routine check-in, links to educational content

Invitation Reminder for 6 Month Focus Group

If patient re-presents at RACC at any point: Restart program if frequenting the RACC OR resume engagement flow with content tailored to last RACC visit date

Goal: Initial patient-reported assessment, understand condition, support contact with GP, confirm medication etc.

Goal: Follow up on GP appointments, medication adherence, evaluate barriers to care and connect to resources/support as available.

Goal: Assess if patients followed plan, assess adverse events (education on complications)

eliza

Program supported by access to linked primary and acute care data sets to personalise messaging

Principles

- Support access and usage of health data by clinicians and teams to reduce variation in care

- Support new digitally enhanced approaches to accredication

- Support consumer access to outcome data as well as use of PROMs and PREMS

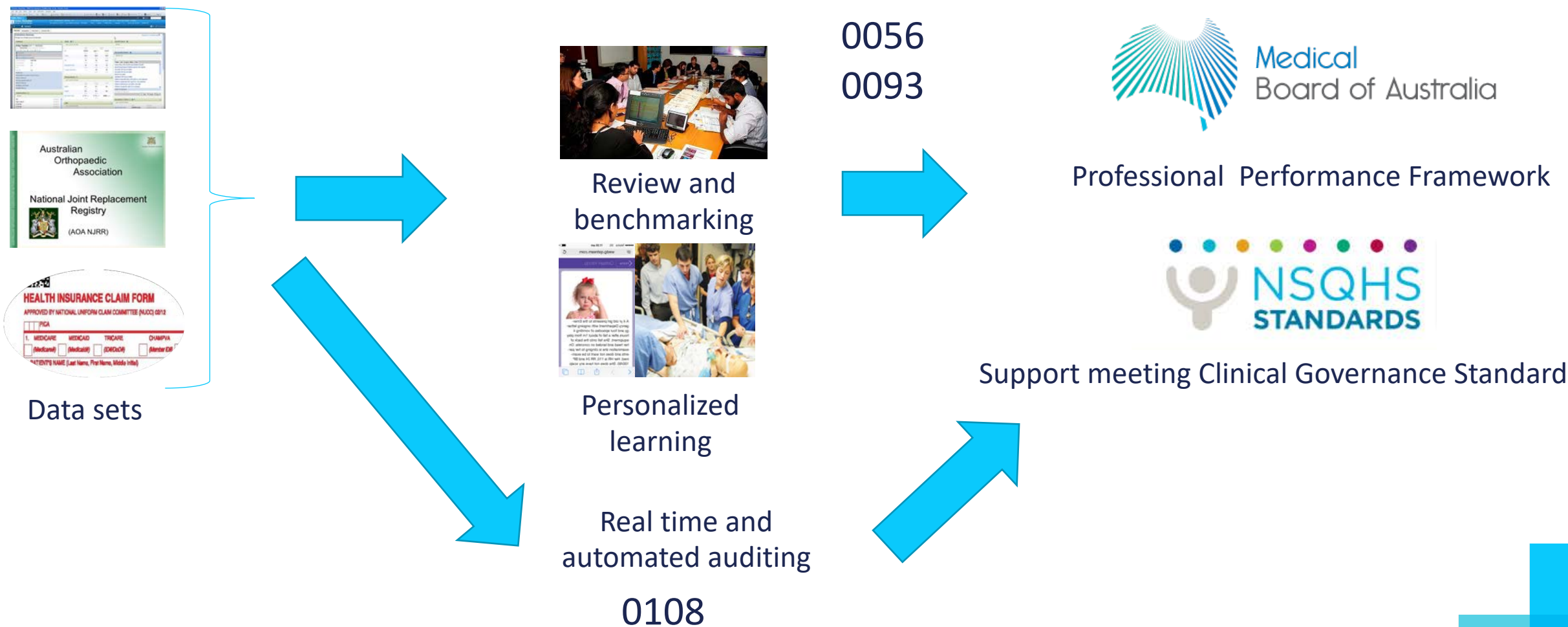# Practice analytics - participants

Likely to join

Practice analytics

Data sets

Review and benchmarking

Personalized learning

Real time and automated auditing

0108

0056
0093

Professional Performance Framework

Support meeting Clinical Governance Standard

Snapshot

Confirmed:

- Postdoctoral Researcher Fellow [University of Sydney]

- PhD Scholarship [University of Sydney] - Attitudes toward performance data

- PhD Scholarship [University of Sydney] - Visualising Performance Data

- PhD Scholarship [Monash University] - Sense Making with data

- PhD Scholarship [Monash University] - Defining clinical practice

Pending

- Post doc in data science

- PhD Scholarshop (tbc): Use of PROMS and PREMS

- PhD Scholarshop (tbc): Impact of costing data

- PhD Scholarshop (tbc): Ethics and governance framework

Rural and Remote

- Telehealth workshop February 20th

- West Alliance meeting Ballarat tomorrow

- Using big data and economic modelling to support pop health management and decision support 0076

- Reviewing and managing Chronic Kidney Disease to improve outcomes 0073

- Addressing paediatric aboriginal ear disease in rural and remote Australia 0098

Aged care flagship program research objectives

1. Delivery of real time actionable data for providers
2. Identify the technologies that support independence for older people
3. Identify clinical and technical data standards that support sharing of information across the continuum of care
4. Digitise quality and safety audits in residential aged care
5. Support the development of a technology literate and enabled aged care workforce
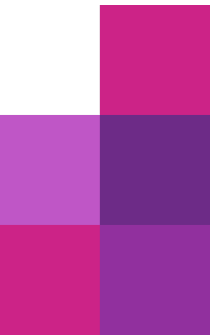
Collaboration with aged care peak bodies to advance digital health engagement

DHCRC is collaborating with aged care peak bodies to advance effective use of digital health in the aged care industry

- Establish a National Living Lab initiative for Aged Care

- Provide technology developers the opportunity to trial and showcase technologies in real world settings

- To lead the development of national aged care frameworks around digital technology adoption

- Benefit Australians receiving aged care services and their families, providers and government

Parties include the Aged Care Guild, ACSA, Aged Care Industry IT Council (ACIITC), DHCRC

National Aged Care Living Lab(s)

- National Aged Care Living Lab(s) will be established to pioneer and trial digital technologies for the aged care sector in Australia

  - Piloting new and innovative approaches at a small scale in real-life settings and then through industry buy-in, providing opportunities for massive scale up

- The Living Lab will be the 'front door' for major technology players to demonstrate technologies and approaches at a national level

  - Potential to be the national platform for investment from government and the aged care industry to ensure a coordinated and national approach

DHCRC Funded Projects underway

- Predicting clinical deterioration & acute care needs of residents (DHCRC 0078)

    - Industry Partner: Telstra Health

    - University Partner: RMIT

- Enabling interoperability & reuse of aged care assessment data for benchmarking & CQI (DHCRC 0013)

    - Industry Partners: Bupa Health Foundation, DoH (tbc)

    - University Partner: University of Queensland

What other DHCRC projects will help transform aged care?

The Royal Commission recommends comprehensive reform and major transformation of the aged care system in Australia.

- Care needs to be compassionate, empathetic and customised to high standards of quality and safety.

Peak provider organisations have committed to driving strategic, scaled transformation in the way we support older people in Australia

Some questions for the Forum:

- How might we create a step change in medication quality and safety in aged care?

- Can best practice operating standards for residential aged care service delivery be defined that reduce variation in operational performance?

- How might we enable personal safety monitoring for vulnerable communities?

Aged Care Data Compare – at Project Plan stage

Aim of project: To tackle the lack of consistency of data representation in residential aged care information management systems; and to deliver a prototype data hub to support benchmarking of clinical outcomes amongst residential aged care providers

This flagship project will be delivered over 3-4 phases:

- Phase 1: Deliver a technical specification for representing functional assessment data using international data & interoperability standards

- Phase 2/3: Build a prototype data hub to support benchmarking of quality outcomes using new standards; and 18-month trial to deliver & evaluate benefits of benchmarking services

- Phase 4: Define a roadmap for scaling & refining prototype data and benchmarking hub

Bupa Health Foundation, University of Queensland, DHCRC

March 2020 – Dec 2023

Indicative outline for *Aged Care Data Compare*

Phases	Why	What	When
Phase 1: Deliver a technical specification (Implementation Guide)	Enable interoperability and reuse of aged care data	Deliver data exchange specification (using FHIR standard)	Year 1
Phase 2: Build a prototype data hub using specification	Normalises heterogenous data into a common format	Prototype data hub Benchmarking /Analytics	Year 1-2
Phase 3: Demonstration	Prove existing vendors can adopt new specifications & data hub can deliver value to consumers, providers and regulators	Run 18-month trial 30 RACF facilities >3 different vendors Deliver benchmarking services	Year 2-3
Phase 4: Define operating model for scaling	Inform reform roadmap & assist adoption in Australia and elsewhere	Define standards adoption, IP, licensing implications for scaling	Year 3