AHRA TRANSFORMATIONAL DATA COLLABORATION

TERMS OF REFERENCE

BACKGROUND

Australia has fragmented data holdings across all clinical domains with this fragmentation extending to terminologies, data models and the quality assurance mechanisms employed. The Transformational Data Collaboration aims to utilise the open, national collaborative nature of AHRA to uplift data use and re-use for research at a national level. Three foundational projects will sit within the collaboration at the outset: 1) Standard, open tools for dataset quality assessment; 2) Maximising the content, use and acceptance of the National Clinical Terminology Service (NCTS) for research; 3) Mapping datasets to common data models to support research data interoperability.

AIM

This collaboration directly addresses one of the key AHRA priorities ‘Integration of large data sets across the care continuum’. It will engage academia and government agencies to support a consistent strategy in advancing Health Data Science and shall accelerate both research and our ability to improve the health of Australians. The collaboration will work towards models for project sustainability and ongoing funding.

RESPONSIBILITIES

General:

(i) Establish a collaborative national network with the shared goal of uplifting data use and re-use for research at a national level
(ii) Include technical expertise from across Australia in the development and progression of activities within the collaboration
(iii) Support national data initiatives in an open, inclusive and non-competitive manner
(iv) Align collaboration activities with requirements of other Australian data assets where possible
(v) Encourage data hubs to uphold the FAIR principles (Findable, Accessible, Interoperable and Reusable)

Project specific:

(vi) Develop, evaluate and make available a Databank Data Quality Assessment tool to provide a standard way to assess data quality in datasets that may be used for research
(vii) Work towards convergence in terminology mappings in the primary care domain exploring how to maximise the use and acceptance of the ADHA Clinical Terminology Service as a key national resource for research
(viii) Provide resources to the national research community to help the community work towards the mapping of key research datasets into common data models. Resources supporting
mapping to the OHDSI OMOP Common Data Model shall be developed based on experience gained through the mapping of existing primary care and hospital datasets to OMOP CDM

GOVERNANCE

The collaboration is led by Melbourne Academic Centre for Health (MACH) (PI: A/Prof Dougie Boyle). A sub-committee consisting of a Chair (PI: A/Prof Dougie Boyle), MACH Project Officer and Lead/Co-Lead of each workstream will report to the AHRA Data-Driven Healthcare Improvement (DDHCI) Committee, as the Project Sponsor. An Advisory Committee consisting of a nominated representative from each contributing or endorsing organisation, and the AHRA DDHCI Committee will advise the sub-committee as required. Three project workstreams sit within the collaboration initially, each will have a Lead, or Co-Leads, who are technical experts within the field of that workstream. Workstream contributors will report activity status to the Workstream Leads on a regular basis, and ad hoc as required. MACH leads the coordination and administration of the sub-committee. Each stakeholder is responsible for the local management and administration of their own activities within the collaboration.

INITIAL MEMBERSHIP

The collaboration has two levels of membership:

(i) Contributing organisation – commitment of in-kind resources to support the aims of the collaboration
(ii) Endorsing organisation – publicly support the collaboration and provide advice and input on an ad hoc basis

MACH is the predominant funder of this collaboration at the outset. Additional stakeholders contributing in-kind support or endorsement of the collaboration are yet to be confirmed. Members are able to join or leave the collaboration at any time.

REPORTING REQUIREMENTS

To AHRA Council via council member (MACH Executive Director)
To AHRA DDHCI committee via sub-committee Chair
To sub-committee via Workstream Leads

MEETING FREQUENCY

The sub-committee will meet for 2 hours approximately every 12 weeks in advance of the AHRA DDHCI committee meetings. The workstream groups and Advisory Committee will convene as necessary to achieve collaboration goals.