

Mechanisms for the formation and maintenance of clinical dataset registries for research at Australian Health Research Translation Centres

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Abstract Title: Mechanisms for the formation and maintenance of clinical dataset registries for research at Australian Health Research Translation Centres.

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Background

In March 2018, The Australian Health Research Alliance (AHRA) held a workshop to investigate key priorities for Australian Health Research Translation Centres (AHRTCs) and Centres for Regional Health (CIRHs) in the area of data driven healthcare improvement [1]. Following a modified Delphi process and Nominal Group technique to rank priorities, the top two priorities identified were to:

1. Create virtual or actual health data research incubator hubs within the AHRTCs and CIRHs to stimulate partnerships across academic, clinician and industry stakeholders.
2. Integrate large scale data sets to undertake research and quality improvement across the primary care, and acute and sub-acute continuum

Similar priorities are shared by the Australian Research Data Commons (ARDC) [2]. The University of Melbourne in conjunction with the Melbourne Academic Centre for Health (MACH) are undertaking a project to determine 'What large clinical data sets exist across the member organisations of MACH, Melbourne'

Objectives

In-line with the aspirations of AHRTCs, CIRHs and ARDC, we shall report the mechanisms utilized to collate this data and to provide recommendations on how other centres may take such a model to provide on-going evolution and maintenance of such clinical data for research registries

Method

Tools for the collection of key data regarding clinical datasets for research shall be established through close consultation with MACH and MACH collaborating hospitals.

The tools shall be implemented across the ten hospitals in the MACH collaboration. Part of the project shall be to consider how MACH can support the ongoing maintenance and expansion of the clinical research registry over time.

Results

We shall report the methods and data collection templates utilised to gather the information above and the proposed mechanisms for their maintenance so that they may be more widely employed by AHRTCs and CIRHs nationally.