A situational analysis of clinical data sets for research across Melbourne Academic Centre for Health: Results and Lessons learnt for the ARDC and 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) and in April 2019, the ARDC invited submissions for projects in the area of Data and Services Discovery [2]. The University of Melbourne in conjunction with the Melbourne Academic Centre for Health (MACH) proposed a project to advance the aims of AHRTCs, CIRHs and ARDC by undertaking a project to determine:

'What large clinical data sets exist across the member organisations of MACH, Melbourne and how can we collate and curate them to maximise research outcomes?'

This project has been supported by the ARDC and will be undertaken from June 2019 – October 2019 [3]. This is a first step towards collating clinical health data from hospitals and clinical practices that fall under the collaborative umbrella of the Melbourne Academic Centre for Health (MACH) into a curated data commons for research. This curated data will be in-line with the aspirations of AHRA and support ARDC national data and services discovery in the area of transformative data programs.

METHODS

This project aims to meet the above project requirements through answering the questions below utilizing a broad consultative process and through the development of a standard template for knowledge discovery:

1. What isolated clinical data sets exist in the major hospitals and clinical practices across the MACH that could be collated and harnessed for research that will have a positive impact on society?
2. What are the political, social, and technical problems that must be overcome to get this data into a FAIR format that can be used by researchers?
3. What are the political, social and technical issues around the data that would have to be addressed for the data set to become widely available?
4. What governance and participation structures might be required for this data collection to ensure ethical use, privacy, security and sustainable community ownership of the collection?
5. Is there an obvious data format or platform that should be used to standardise the collation of the data sets that would fit with potential ARDC infrastructure strategy?

DISCUSSION

We shall report the methods and data collection templates utilised to gather the information above so that they may be more widely employed by AHRTCs and CIRHs nationally. We shall also report the key findings of this knowledge discovery project.

REFERENCES

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2. ARDC Open Call for Data and Services Discovery project proposals. Available from: https://ardc.edu.au/project/data-and-services/, accessed June 2019

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