

## A GOVERNANCE FRAMEWORK SUPPORTING ACCESS TO HEALTH INFORMATION

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The National e-Health Transition Authority (NEHTA) defines health information as personal information that is associated with information about an individual's health or is collected to provide a health service<sup>1</sup>. Approaches to providing access to health information vary but generally fall into two general categories: centralised (e.g. data warehousing) and distributed (e.g. data virtualisation). While there are advantages and disadvantages to both approaches, a key disadvantage of data warehousing in a health environment is the loss of control for Data Custodians.

The e-Health Research Centre's Health Data Integration (HDI) product takes the distributed approach to accessing health information by virtualising data. To re-enforce Data Custodian Control of the data, HDI provides support in software for a strong governance framework which provides meta-level rules for:

- release of data by data custodians for use in Projects
- the management of the HDI installation
- support for the separation of identifying and clinical information
- building of virtual linked data set by Project Administrators for Users to access linked data

The governance framework describes a lifecycle model for Projects and is summarised at Table 1.

Stage	Description
Discovery	The discovery stage of the Project lifecycle is the period in which users pose questions and discover descriptions of data that could lead to answers to those questions.
Proposal	During the Proposal stage, the Project's potential stakeholders (including Data Custodians) decide whether or not to support the Project and the parties negotiate and agree the draft Project Charter.
Approval	The Approval stage sees the Projects users gaining formal approval from stakeholders and ethics bodies to conduct the Project under the conditions described in the Project Charter.
Setup	During the Setup stage, the administrative tasks required to support the execution of the Project are carried out.
Execution and monitoring	The Project is executed as per the Project Charter. Stakeholders may monitor the execution of the Project using monitoring tools such as audit and workflow systems.
Close	Access to stakeholder resources (e.g. custodial data) is removed and the Project is closed.

**Table 1 HDI Project Lifecycle**

The Discovery, Proposal and Approval stages of the lifecycle result in a Project Charter which becomes the key document for the Project. It contains detailed information on the rationale for the Project, identifies the Data Custodians who will provide the data for the

<sup>1</sup> NEHTA's Approach to Privacy, [http://www.nehta.gov.au/component/option.com\\_docman/task.doc\\_view/gid.49/Itemid.139/](http://www.nehta.gov.au/component/option.com_docman/task.doc_view/gid.49/Itemid.139/), last viewed 31 August 2006.

Project and how that data will be presented, the users who will be permitted access to data, their rights and responsibilities regarding access and use of the data and the products of the Project.

During the setup stage, Domain Administrators assist Project Administrators and Data Custodians to create the administrative constructs that govern access to the system. Domain Administrators create a new Project within the HDI installation and allocate the appropriate user(s) as its Project Administrator. Once this is done, Domain Administrators have no other involvement in the Project and the Project Administrator is responsible for allocating the required users to the Project.

Domain Administrators also assist Data Custodians to establish connectivity between the HDI installation and source data systems. Once connectivity has been established, Domain Administrators have no other involvement in the creation of Views and the Data Custodian is responsible for configuring and describing Views of their data, then for publishing those Views to the appropriate Project(s).

During the execution and monitoring stage of a Project, Project Users create and execute Queries and Links between the Views published to their Project. The results obtained by executing Queries and Links can be imported into 3<sup>rd</sup> party analytics and reporting tools (subject to the agreements documented in the Project Charter).

An important distinction between HDI's virtualisation approach and data warehousing approaches is that during the executing and monitoring stage of a Project, Data Custodians have the right to restrict access to their data on a Project-by-Project basis or to the HDI installation entirely.

The final stage in the lifecycle Project Closure. While an administrative task for Data Custodians and Project Administrators in the current implementation, automation of the lifecycle using workflow technologies is likely to be introduced in later releases that will see the product restrict access to Projects that have reached the time limit described in their Project Charter.

The presentation for this abstract will include a demonstration of the HDI product and discussion of the results of deploying the product to customer sites.

**Summary of Expertise:**

Simon McBride is a software architect working on the commercialisation of e-HRC's Health Data Integration product. Simon has over 10 years of software systems engineering experience across a number of domains in both commercial and research organisations. In recent years Simon has gained experience in bringing new technologies to the health domain, including being a member of the software engineering team responsible for the Brisbane South health *Connect* Trial (BSHCT) software – an implementation of an electronic health records system using openEHR technology.