National Digital Health Strategy Consultation

Submission from Curtin University

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What are your organisation's priorities in respect to digital health or eHealth?

At a time when the volume of structured and unstructured digital data has exploded, there has been an enormous growth in the creation of data about individuals that can be used for understanding and treating disease. Digital health and eHealth has a range of factors driving growth, development and research applications. This increase in digital information provides the building blocks for critical analysis used to shape policy, evaluate performance and improving public services.

Curtin University is the largest and most comprehensive provider of health sciences research in Western Australia, bringing together scientists and researchers to uncover better methods of preventing, diagnosing and treating a range of chronic conditions and lifestyle diseases. Experienced researchers within the Faculty work in innovative facilities to advance health and wellbeing nationally and internationally. Research is focussed on ageing, chronic disease, Indigenous health, mental health, population health, health services research, health policy analysis

Health research programmes at Curtin are supported by access to, and integration of, rich sources of data. Data from government (administrative data collections), other health agencies (pathology, radiology, etc.) and non-health organisations (criminal justice agencies, education, etc.) need to be seamlessly integrated with other datasets and made available for research and analysis. Curtin University's technical innovation priorities have focussed around efficiently and effectively leveraging value from these digital data 'assets' to benefit the whole community.

Data Linkage & Data Integration at Curtin

Data linkage involves bringing together and matching data from different sources, including disease registers and clinical datasets, to provide a richer information source for research and analysis. The benefits of linked data include reduced data collection costs and more detailed and extensive analysis.

Curtin University has had a significant role in the development of data linkage in WA and nationally during the last decade. At state level, Curtin has been a core partner in Data Linkage Australia (WA Centre of Excellence, 2006-2012), led the development of the spatial information health program through the CRC-SI (2009-2014) and is lead partner in the Lotterywest WA Data Linkage Infrastructure Project ($5.11 million, 2013-2017). At national level, Curtin established the Centre for Data Linkage (CDL) in 2009 as part of the Population Health Research Network (PHRN) within the NCRIS 2009-17 strategic initiatives. The CDL is located within the Faculty of Health Sciences. It has established large and secure linkage

capabilities to perform national data linkage between states and territories, and to other national datasets.

Data Analytics & Computation at Curtin

Curtin has established a broad footprint in data analytics which includes capabilities in computation (e.g. Curtin Institute for Computation), technology and innovation (e.g. Cisco Internet of Everything Innovation Centre) and health data analytics. Curtin's Institute for Computation (CIC) has the capacity to support the analysis of large-scale administrative data. Resources available to the Curtin research community include the Pawsey Supercomputing Centre which operates the most powerful public research supercomputer in the southern hemisphere. It is also the WA node of the NeCTAR Research Cloud, providing scalable computing for increasingly large and complex analytical projects.

The CIC was founded to meet increasing demand for computational modelling, data analytics and visualisation. CIC was formed by combining and expanding on the foundation laid by two former centres: the Centre for Process Systems Computation and Curtin Industrial Modelling and Optimisation. The Institute initiates and fosters collaborative, interdisciplinary research and education programs that apply computational methods across computing, engineering and health to provide innovative solutions to complex problems. It builds on the significant investments made by Curtin and its partners in the Square Kilometre Array (SKA) project and the Pawsey Supercomputing Centre, and complements activities within major research centres and institutes at the University.

Industry plays an important role in research at Curtin, with a key focus on creating practical applications for computational technology. The Cisco Internet of Everything Innovation Centre (CIIC) is an additional facility at Curtin which facilitates this work, providing a hub where CIC researchers, industry and entrepreneurs can work together to accelerate innovation in next-generation technologies.

Health Data Analytics

Curtin University also supports a health data analytics platform to complement established research areas in health services, population health research, clinical trials and the NHMRC Centre for Clinical Research Excellence in Cardiovascular Outcomes Improvement. The Health Data Analytics initiative aims to develop Australia's ability to utilise large scale health datasets from a variety of administrative and clinical settings to better understand care practices associated with positive health outcomes.

In summary, digital health research capabilities at Curtin comprise:

- Centre for Data Linkage (CDL)
- Curtin Institute for Computation (CIC)
- Cisco Internet of Everything Innovation Centre (CIIC)
- Curtin - Monash Accident Research Centre (C-MARC)
- WA Primary Health Appliance (WAPHA)
- Public Health
- Medical School
- PAWSEY (Super Computing)

Research partnerships with government, industry partners and other research groups (such as the WAHTN, C-MARC, WADLIP, SJOG and WAPHA collaborations) and the establishment of the Curtin Medical and Law Schools further capitalise on Curtin's productive use of digital health data from all possible sources.

How could data and technology be better used to improve health and wellbeing?

Health and care systems are complex with many interactions and linkages. Using a whole system approach acknowledges that various interrelated factors can impact different parts of the health system and that service design and solutions to problems have to be developed taking all the variables and interactions into consideration.

No single part of the health system provides the complete picture. It is the whole system and the way that the different parts work together that unlocks the research power of administrative datasets. The information to support whole system research requires the development of new approaches to join datasets and identify individuals across different data collections.

Improve access to and integration of health datasets

Access to and integration of health datasets is crucial in supporting policy and improving public services. Many administrative datasets are held by government departments and other organisations to measure and monitor operations during the delivery of a service. The high-value characteristics of administrative data include coverage of the whole population, which allows analysis of small group and vulnerable, collection quality standards (with metadata) and long-term analysis to a level of detail not permitted by sample surveys. The use of administrative data provides a cost effective and efficient method for population based research and avoids imposing a further burden on respondents.

The benefits of data sharing have been shown to improve research skills and analytical tools significantly for complex integrated data, enabling new research that enhances the delivery of public services. Access to high quality information is essential for efficient and effective government systems and services.

Inclusion of new/emerging and 'hard to get' digital datasets in health research

Non-traditional sources of digital health data are emerging (i.e. from sources other than administrative health) and there are opportunities to include these in innovative health research. Emerging health datasets include the use of mobile phone records and Google search histories for disease surveillance, patient collected data from wearable devices and manual journaling through mobile phone applications. Data from the private health sector and from government administrative datasets that lie outside the health sector are also of interest, as is spatial information which has direct application for understanding exposures and inequalities. The key to unlocking this data is in relating details at an individual patient level to provide an understanding of risk factors and appropriate interventions.

The advent of new technology such as privacy-preserving record linkage (PPRL) potentially heralds a new era of population-focused health research using linked digital data, bridging gaps and opening up opportunities for new and different forms of linkage-based research. PPRL methods provide a mechanism for accessing and integrating data from 'hard to get' datasets and from new and emerging sources. As well as data from new technologies (e.g.

wearable devices, smartphone apps, etc), these new sources include the private health sector which has, to date, had limited exposure to, and engagement with, data linkage frameworks.

Provisioning of secure and scalable analytic capabilities

Health datasets are sensitive and there are community expectations around the protection of privacy and confidentiality of data. Increasingly, researchers require analytical environments that provide large-scale and secure computing facilities, with robust data management/curation services and access to tools/resources for computational modelling, data analytics and visualisation.

What are the barriers or challenges to innovation in health and care?

Governments and Universities understand that digital health data can provide an unparalleled resource for the monitoring and evaluation of services. However, for a number of reasons, administrative data have not been readily accessible to researchers. Challenges/barriers to be resolved in realising the potential of digital data through data integration include:

- *Authorising environments* - it is time-consuming to undertake research projects in terms of approvals and governance arrangements. Establishing transparent and consistent procedures that manage/streamline all these processes would ensure effective and efficient access to digital data. Transparent and consistent processes would reduce uncertainty around ethics, privacy and data custodian constraints;

- *Legislation* – many of the significant datasets are subject to specific legislation that define the conditions of data release and/or use. The extent of this type of legislation and its complexity creates difficulties of interpretation with regard to the release of data. New technologies such as privacy-preserving record linkage (PPRL) may assist;

- *Operational efficiencies* – The "quantity of data" emerging from electronic data collections also poses challenges (i.e. Big Data). Increasing demand on data services also puts significant pressure on infrastructure to deliver in a timely fashion;

- *Capacity* – at present, the operations required to service health research can pose a substantial burden on organisational resources. Infrastructure enabling research needs to be scalable, fast and efficient to ensure timely responses to important policy and research questions;

- *Expertise* – big data analytics requires expertise in three broad areas – knowledge of the datasets available along with their characteristics and limitations, skills in integration methods and skills in using/analysing bid data.

The methods and techniques around data integration in Australia are well established. However, new developments (exploiting advances in technology) have the potential to improve timeliness and efficiency.

How would you describe the working relationship between the research and science community and the technology sector in respect to healthcare innovation?

The healthcare sector is highly complex and is under increasing pressure to improve patient outcomes while delivering cost effective services. The research community and technology experts must work together to break through the complexity and enable new techniques that maximise data resources and facilitate innovative research.

Collection, storage and management of data have come a long way in the last two decades with significant developments in technology in terms of power and capacity. The volume of digital data is increasing exponentially, providing more available data for research.

Initiatives like the Cisco Internet of Everything Innovation Centre (CIIC) - a newly established industry and research collaboration centre at Curtin University - bring together industry experts, developers and researchers in an open environment to create ground-breaking and innovative solutions that foster growth, provide jobs and help build sustainable economies.