Health Informatics Research and Education as Essential Infrastructure for Digital Health

Submitted by: The University of Melbourne, Health and Biomedical Informatics Centre (HaBIC)

Contact information: Associate Professor Kathleen Gray, Director.

Web www.healthinformatics.unimelb.edu.au Email: kgray@unimelb.edu.au Phone 8344 8936

Thank you for the opportunity to provide a submission to the consultation on the Australian National Digital Health Strategy.

HaBIC

The Health and Biomedical Informatics Centre (HaBIC) at The University of Melbourne was formed In 2010, as a University Centre as a collaboration between the Faculty of Medicine, Dentistry and Health Sciences, the Faculty of Engineering and the Institute for a Broadband Enabled Society (IBES). It was formally launched with an international symposium in 2014. HaBIC has subsequently formed a wide variety of partnerships with industry, the health sector and government and developed a range of teaching and research training programs.

Digital health

Digital health is the latest of many terms used to encapsulate many Internet-connected ICT phenomena in health: health IT, health innovation, health social media, health or bio- or med- tech, health 2.0 or 3.0, connected health, ehealth, mhealth or mobile health, online health, P4 medicine, smart health, telehealth or telemedicine, wearable health, and so on. The term 'digital health' entered the research literature in the 1990s to broadly characterise the impact of Internet-connected ICTs on health care. It has many synonyms, as noted; it includes an array of technologies, particularly when they are implemented at scale and integrated to work within or across health service provider organisations (for example, electronic health records, mobile telehealth, electronic referral and prescribing systems, automated clinical decision support, registry databases, direct-to-consumer online health services, smart biomedical devices; and also health-information-related aspects of apps and social technologies, analytics, ontologies, machine learning, sensors and robotics). Digital health is not compatible with 'business as usual'; at levels from whole of clinic to whole of health system and whole of health profession, it is anticipated that the effects will be transformative or disruptive.

Digital health depends on health informatics knowledge and skills

In contrast, health informatics is an established field that advances the effective use of data, information and knowledge in scientific inquiry, problem solving, behaviour change, decision making and service design dedicated to the advancement of human health. Across the spectrum from molecular medicine to population health, health informatics provides the scientific and scholarly foundations for managing raw health data, organising it into meaningful health information and systematising it as health knowledge. The field traces its origins from the development of the Index Medicus in 1879, the establishment of the American Association of Medical Records Librarians in

1928 and the Deutsche Gesellschaft fur Medizinische Dokumentation, Informatik und Statistik in 1949, and the formation of the UNESCO International Federation for Information Processing, Technical Committee 4 on Health Care and Biomedical Research in 1967. Health informatics research work with the Internet began in the early 1970s. In other words, this is a longstanding interdisciplinary field of research and professional practice internationally, with its own peer-reviewed journals, scientific conferences and learned societies. Its principles, methods and tools can add rigor and relevance to any health project that involves planning, development, implementation, operationalisation or evaluation of information and communication services, systems or technologies.

Digital health depends on informatics generalists and specialists in the health workforce

Without a health workforce whose skills are grounded in health informatics, Australia is unlikely ever to achieve optimal safety, quality, efficiency or innovation from its investments in technology and systems for health data, information and knowledge management. Governments and industry bodies around the world have undertaken workforce reviews and planning of the specialised workforce to plan and manage digital health initiatives, the way this workforce is developed, and the contribution it makes. However the nature and scope of this specialised workforce is still poorly understood in Australia, particularly in comparison to other health professions. Furthermore, most Australian clinical health professions make little provision for informatics knowledge and skills in their education and professional development. There are longstanding unresolved concerns with recognition and regulation of health information work. Based on official classification and codng schemes Health Informatics is not recognised as an occupation, industry labour force or source of income tax revenue in Australia. In 2015 and again in 2016, peak health information professional groups held summit meetings to highlight major challenges of skilled workforce shortages, uneven career structures and future configurations.

Digital health depends on access to education and training for all stakeholders

Education is not usually connected with large-scale digital health implementations in a transparent or accountable way. While the decision to offer or to pursue various approaches to digital health education may be influenced by the status of digital health strategy in the local healthcare context, there is no assurance that such education will:
have curriculum appropriately aligned to the strategy (for example, will it equip participants to work with the particular tools and standards that are used in the national system or is it more generic?), or
be accessible to the people who are most directly affected by implementation of new systems (for example, will it reach widely dispersed community and primary care providers as well as the hospital-based workforce?), or
be taken up by a critical mass of stakeholders (for example, will it reach patients and carers in sufficient numbers to make a real impact in aged care and chronic disease management?).

In terms of formal quality assured educational processes, health informatics related activities have a tenuous foothold in the recognition of post-secondary vocational education and training. However this field of study is altogether absent from the broader classification system applied in education nationally. This has adverse implications for the visibility, credibility and marketability of tertiary study programs offered by Australian providers.

Digital health needs research

Overall, digital health does not yet have an extensive evidence base or well-established research protocols. Reviews reveal not only that more research is needed but also that the research methods used – whether quantitative or qualitative – need more rigor. Some digital health research proceeds along conventional lines, following established protocols for the conduct of clinical trials, controlled case studies and cohort studies. Wherever possible, digital health research studies need to adopt these strong methods for generating data and making sense of it. An issue with randomised controlled trials for digital health research is that in many cases they are not controlled for all of the ICT factors that may influence the results. This is especially likely if researchers who are specialists in a clinical area but naïve about health and biomedical informatics make 'common sense' assumptions about the technology to be used in the trial. Digital health interventions are complex interventions and such trials need to use appropriately sophisticated methods.

When one looks closely at the health improvement or advancement aim that is expressed in a digital health research project, often one finds a question or problem that is not strictly clinical, in other words, a project where treatment interventions and outcomes are not the only focus or even the main focus of research. Such projects are strengthened if they are broadly informed by constructs from health services and systems research. In such cases, digital health researchers should be encouraged to connect their aims with performance indicators and criteria selected from those commonly applied in public policy to monitor the operation of health care systems. Using such a method to specify, categorise and evaluate research findings in terms of impact on the overall performance of a health system is a stronger research approach than selecting random criteria or applying unconventional measures to make sense of digital health research findings.

Patients, clients or other citizens should be invited in as respected participants in consumer-centred digital health research. The greatest benefit may come from engaging them in defining and scoping the research at early stages. Strongly participant-driven digital health research approaches have the potential to become a new form of 'citizen science'.

Digital health needs research infrastructure

If, as part of a funded research project, researchers develop a new tool or portal or platform to collect and manage patient data, they are often unaware that international and national standards cover some but not all aspects of this work. If research funds are being used to develop a tool that does not meet the practice standards that apply in the jurisdiction where its use is intended, it may work well for immediate research purposes. However it may not be suitable for scaled up use, and therefore represents a lost opportunity for digital innovation and enterprise. Compliance and governance aspects of digital health often are not the radar of technology developers, even those with experience in the health sector.

Research that relies on digital health data raises many familiar issues of safeguarding personal health data, plus a few new ones. There are many ethical and legal aspects of this research that are unclear. Laws governing the use of health data differ from country to country even though, especially in commercial services, the data may flow across national borders and be held and owned in a jurisdiction different from where the data are generated.

Data analytics methods for working with digital health data, including patient generated health data, are a topic of great current interest, for example to improve clinical decision support and health promotion, based on aggregation and analysis of patterns of illness/treatment/response in the

broad population. However researchers' ability to conduct studies efficiently is hampered by the lack of interoperability provisions, making it time-consuming and error-prone to share and integrate data across the range of platforms and tools used to collect them, for example hospital in-patient, hospital out-patient, general practice, residential aged care and home-based community care data.

Australian research in this field is not easily identifiable in influential research classification systems. It may be formally classified as:
a sub-group of Information and Computing Sciences research: DIVISION 08 INFORMATION AND COMPUTING SCIENCES > GROUP 0807 LIBRARY AND INFORMATION STUDIES > 080702 Health Informatics
a sub-group of Medical and Health Sciences research: DIVISION 11 MEDICAL AND HEALTH SCIENCES > GROUP 1117 PUBLIC HEALTH AND HEALTH SERVICES > 111711 HEALTH INFORMATION SYSTEMS (INCL. SURVEILLANCE)
and sometimes within a group of Engineering research: DIVISION 09 ENGINEERING > GROUP 0903 BIOMEDICAL ENGINEERING.
or (mistakenly) classified within the Sciences as DIVISION 06 BIOLOGICAL SCIENCES > BIOCHEMISTRY AND CELL BIOLOGY> 060102 BIOINFORMATICS.

Recommendations

As part of Australia's National Digital Health strategy and Implementation planning, encourage and support:

1. Health informatics as the foundation discipline for approaches to development. implementation and evaluation of digital health projects and programs.
2. Professionalising the digital health information workforce and also improving digital health capabilities in all clinical health professions.
3. National standards of digital health curriculum development and integration within the formal post-secondary education and training system.
4. Digital health research that is rigorous, scalable, inclusive and efficient.
5. Digital health research infrastructure development as an intrinsic aspect of digital health design.