Submission to the Australian Digital Health Agency How do you see the future of digital health? Your health. Your say.

The submission has been made by Professor Tim Shaw and Professor Jonathan Morris on behalf of the Informatics & eHealth Strategic Network and the Health Data Science Coalition at The University of Sydney.

The impact of Digital or eHealth on Health and Wellness

Digital health, or eHealth, is revolutionising the way health and wellness is managed. This includes transforming how traditional care is delivered through to empowering us all as citizens to maintain our health and wellbeing.

The University of Sydney is leading the development of an Informatics and eHealth Network to facilitate collaboration in the practical application of data science and eHealth to support care delivery and research. By collaborating with various faculties with relevant expertise, including but not limited to Health Sciences, Engineering, Architecture and Design, and Business, the University will provide a broad perspectives and innovative strategies around eHealth. The Network works alongside the significant investment that the University has made in the Centre for Translational Data Science and Data Science Hub. The University is particularly focused on working with service providers, clinicians, and government agencies in the co-design, implementation and evaluation of effective digital innovations. It is a member of Sydney Health Partners and thus has a conduit through which it can effect measurable health change.

The following are a selection of priority areas that will be included in the focus of the Network as it matures over the next 12-24 months.

Data usage and integration

A clear priority has to be around how data is integrated and managed between primary, secondary, tertiary, private, and community sectors, as well as the identification of areas where this integrated dataset will have the biggest impact on patient outcome and service delivery. Health data often does not follow patients as they move between services and on a larger scale, population data is collected but not always meaningfully used to provide informed, personalised medicine. The fragmentation of data at the population level also contributes to duplication of efforts and inefficiency in research and care delivery. In order to address system inefficiencies, drive down costs, and improve outcomes for individuals and caregivers, there should be greater integration of data and collaboration between care providers and data centres. Once data is available through initiatives such as My Health Record, emphasis needs to be placed on developing tools and processes to turn the data into knowledge that can be used to support clinical decision making and to target professional development. Greater focus must also be placed on demonstrating the return to clinicians in investing the time required to enter and manage health data within their practice. As systems are rolled out, new partnerships need to be formed between multiple research organisations, health consumers, caregivers, health services and government bodies to complete comprehensive and evidence-based evaluations.

To support effective use of data at a state or national level, a coordinated approach is needed surrounding federated enterprise data warehouses together with a standard analytics platform that can be used for the dual purpose of supporting clinical decision making as well as research. The lack of integration of clinical data with research programs is

significantly impeding progress and innovation. Key to successful integration of practice and research data will be the development of new approaches to data governance and custodianship. The University looks forward to engaging with the ADHA in helping shape how the data within My Health Record is governed and integrated into practice and research. Central to this are activities that promote public confidence in the sharing of data.

In regard to data analysis and informatics, projects should be driven by issues identified by clinicians, patients, and carers which need to be solved. Additionally, there needs to be a shift away from collection of administrative data sets towards use of real time clinical data extracted from EHRs. This requires improved data sharing between facilities and researchers, as well as communication between health service providers, engineers, researchers, clinicians, carers and patients. In addition, greater interpretation of data via improved visualization and analytics aids is key to helping clinicians provide improved care (e.g. what tools can be developed to ensure that rare malignancies are actually detected). The University is investing substantial resources in the development of a Health Data Science Coalition, based in the Westmead Precinct, to develop innovative approaches to data analytics and visualisations to support evidence-based predicative healthcare and personalised medicine. With the University's multidisciplinary access to ethicists, lawmakers, as well as current collaborating cross-faculty groups including Medicine, Engineering, Health Sciences, and the Business School on current projects, a broad perspective can be provided in analysing and applying data in research as well as the development of health models. It is hoped that the data within My Health Record will add considerably to the pool of data that can be harnessed to improve clinical decision making across individual and populations.

Health in the Hands of Consumers

Perhaps one of the most obvious and substantial impacts of technology on health has been the explosion in the availability of increasingly sophisticated devices and apps to cover almost all aspects of health from managing serious medical conditions through to maintaining personal fitness and wellbeing. The University has developed a number of apps that have had measurable positive impacts on health, from SMS reminder systems to chat lines and e-forums. The shifting accessibility of apps and digital technologies is reshaping the health sector to be increasingly focused on consumer empowerment and self-management. This is particularly important in an era burdened by chronic disease and an aging population, where self-management of care is pivotal to ensuring individuals can be actively engaged throughout their healthcare journey.

We are only at the beginning in many respects of understanding how the rise of consumer driven technologies is going to impact on the traditional patient-clinician relationship, and the evidence base for many new technologies is still very weak. There are also issues surrounding data governance, specifically around the ownership of data that is collected by commercial apps that need to be addressed. Furthermore, the creation of tools like mobile apps should be informed by an identified need (e.g. through data analysis to confirm a suspected health issue, such as high rates of diabetes mismanagement). Such resources should be critically analysed for relevance, applicability, and accessibility, with consideration of cultural and socioeconomic factors (e.g. reachability to those without smartphones or variations in technological and health literacy). Data analysis and research can guide this, both in benchmarking the influence of digital tools like apps, as well as identifying whether such tools are impactful and thus worthy of use. We are wanting to design an innovative eHealth ecosystem of complementary programs, quality certified apps and e-tools aligned to a common set of standards, integrations, interfaces and technologies. Central to this platform is the use of the My Health Record to integrate communication between patients and clinicians, and to provide a central data repository for all stakeholders. We have developed a model for eHealth that is currently being submitted from publication that has been derived from consultation with multiple stakeholders (appendix 1). The model

describes three overlapping domains of eHealth (Health in the Hands of Consumers, ICT supported Communication and Management of Health Data). We are focused on the sweet spot where these domains overlap and are encouraging any interventions we generate to consider all three aspects of eHealth in their development.

Need for eHealth Readiness

A key issue facing the future of digital health is how to empower health professionals to truly integrate digital or eHealth into everyday practice. To do this, we need a deeper understanding of the competencies in digital or eHealth that the health workforce needs in order to harness technology for delivering high quality care, as well as the implications of these changes on professional roles and career pathways. These changes need to start by harnessing educational initiatives to prepare the future workforce within tertiary institutions, through to the continued professional development and career advancement of our current workforce and systems leaders. For this to be realised, we believe that there is an urgent need to move beyond a focus on traditional competencies in technical skills and informatics skills through integrating eHealth into practice and transforming the way care is delivered. With the growing role of eHealth in wellness and maintenance of health, emphasis is needed regarding how health professionals can empower their patients to use eHealth to improve their wellbeing and also expands the role of health professional to include fitness coaches and other allied professionals.

Greater consideration must be given to broader professional standards and competencies that lend to professional attributes of an adaptable and innovative workforce that can operate in evolving workplaces with emerging technologies.

Equity and Accessibility in eHealth

Equity of access to digital health and associated technologies is another key challenge to address. Digital tools are rapidly being created and used by clinicians, though such technologies are not always accessible across culturally, economically or geographically diverse populations. Great care needs to be taken that we don’t create a digital divide between those that do and do not access digital health innovation and thus exacerbating current health inequities.

Summary

While the future is bright for the ongoing impact of technology on health and wellness there are significant challenges to overcome.

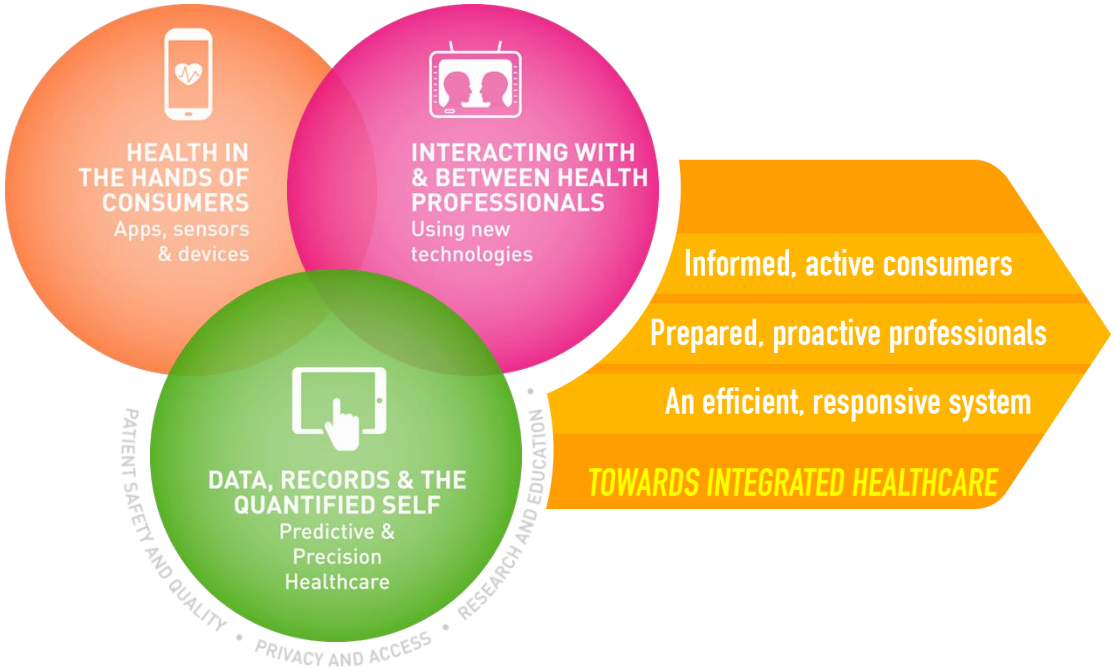
Continued emphasis needs to be on defining the problems to be addressed by technology and ensuring that clinicians and consumers are engaged fully in the development and implementation process. For universities, we need to actively engage with services, health consumers, clinicians and government agencies to ensure we undertake research that adds value.

We look forward to collaborating with the Australian Digital Health Agency in progressing research and practice in Digital Health.

Appendix 1

NB, Please contact Professor Tim Shaw prior to distribution of this model as it is currently being submitted for peer review.

A Model to Support Practice, Research and Education in eHealth



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