

Digital health research methods and tools
Suggestions and selected resources for researchers

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ABSTRACT

This chapter provides an overview of digital health research, aimed at people who are new to conducting investigations in this field that seek to engage seriously with patients, clients and consumers.

Digital health is not a scientific discipline. This chapter argues that health and biomedical informatics offers a strong scholarly basis for research in this field, and it outlines the theoretical and conceptual frameworks, ethical considerations, research methods, and examples of tools applicable for studies of digital health interventions.

Researchers from clinical, IT, engineering and similar domains who plan to undertake studies involving digital health applications will be introduced to methodologies such as using guidelines and standards, performance indicators, validated input models and outcome measures, and evaluation resources. In the specific area of consumer health informatics research, an increasing array of tools and methods exist to investigate the interaction between consumers and their health data. In addition this chapter discusses research methods with health apps, patient-generated health data, social media and wearable self-tracking devices.

Practical advice is given on techniques such as critically appraising digital health research literature, primary data collection from devices and services, study reporting and publishing results.

KEYWORDS

biomedical informatics; consumer health informatics; digital health; health informatics; research methods

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Part 1: Introduction

1.1 Understanding what digital health means

This paper provides an overview of research methods and tools that are useful in human research settings in clinical care and public health, specifically those where the research design depends on patients, clients or consumers using internet-connected Information and Communication Technology (ICT) as part of a formal health service.

Internet-connected ICT has many names and nuances 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 [1]. For the purpose of this paper the term 'digital health' is used to describe this phenomenon, with a deliberate emphasis on the ways that these technologies enable patients, clients or consumers to participate actively in clinical care and health research.

This paper selects and synthesises reports on existing work in order to provide a sound foundation for anyone embarking on their own digital health research project of this kind. In these digital health research projects, technology is not simply used as a novel way for expert researchers to process participants' health data. Rather, the choice to use a particular technology is deliberately inclusive of participants and is intended to support them to take an interest in their own health data. This choice must be understood as a health intervention, with the ultimate objective of improving participants' health behaviours or health outcomes. The technology may also play combined or extended roles, for instance in projects that explore the potential for a learning health system [2].

The main aim of this paper is to serve as an introduction and resource for digital health researchers - who may be specialists in their field of health but at the same time novices in the foundation discipline of health and biomedical informatics. Digital health is a relatively new focus for research and is attracting wide interest from many people with diverse theory and practice backgrounds. These researchers may be unaware of the existence of relevant methods and tools and of the value these can have in strengthening their research.

To expand our understanding of digital health inevitably entails work to adapt existing research methods and tools and to develop new ones. It is important that such work builds on a solid foundation of knowledge about the existing contributions to research quality in this field. So this paper has a secondary aim, that is, where existing approaches to digital health research may be lacking, it aims to provide a base for informed innovation.

1.2 Defining your research as digital health research

The term digital health entered the research literature in the 1990s to broadly characterise the impact of Internet-connected ICTs on health care [3,4]. 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). Major digital health initiatives may bundle some of these technologies and can be categorised by the scope of the vision and the size of the investment in systems [5].

Progress to advance digital health has occurred in countries around the world [6]. For example, the Australian government established the Australian Digital Health Agency in 2016 to continue previous work by the National EHealth Transition Authority on consumer-controlled electronic health records, telehealth and related infrastructure [7]. The 2015-2016 federal budget allocated \$485 million to redevelop the My Health Record system and to strengthen national digital health governance through an Australian Commission for eHealth. 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, the effects are expected to be transformative or disruptive [8-10].

A major element of these transformations is the increasing autonomy of patients, clients and consumers of health services and citizens with an informal interest in health. Since the 1990s the Internet has democratised access to resources, including access to medical literature, connection with patient social networks and co-creation of open health data sets. Some of these resources are purpose-built, such as health information literacy aids, personal health records and patient portals, while others appropriated and repurposed, for instance when people use Facebook, YouTube or Twitter for health self-management. In health as in every other respect, the Internet is also a massive source of fake data, misinformation and pseudoscience.

Another major element of the transformations occurring as a result of digital health is the availability of big data sets and associated research into storage, integration, analytics, machine learning and related fields. These topics are inter-related closely with the use of consumer technologies in clinical care and public health. However often the research problems within these topics do not directly involve working with patients or citizens, once their data has been captured for study. So these topics are not treated in any detail in this paper.

1.3 Drawing from health informatics for digital health research

In contrast to the definition of digital health, health and biomedical 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 so as to improve human health. Across the spectrum from molecular medicine to population health, health and biomedical 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 für 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 scholarly 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 research project that involves planning, development, implementation, operationalisation or evaluation of information and communication services, systems or technologies.

Some examples of health informatics methods and tools that can be leveraged for digital health research are: guidelines and standards for health apps and health data-sharing; systematic reviews in related areas, including search strategies and sources; health system performance indicators to contextualise health ICT research findings; validated instruments to measure technical performance and health outcomes of health innovations; consumer and community input models for public-facing ehealth systems; health social media practices to recruit participants, source data, share findings, crowd-source support; online survey methods and tools; research protocols for clinical studies of ICT interventions; data integration frames for self-tracking health data; specifications for health ICT tool development within a research project.

The technologies of digital health are increasing convergence between the informatics tools and methods that are designed for use by clinicians and public health workers, and those for patients, clients, consumers and citizens. New health and biomedical informatics methods are being used to facilitate 'systems medicine', that is, the evolution from reactive disease care to care that offers personalisation and precision, and services that emphasise participation, prediction and prevention [11,12].

Digital health research can benefit particularly from consumer health informatics research, which is concerned with information structures and processes used by people who are not clinically trained (so-called "consumers") to take an active interest in health. Consumer health informatics focuses on the types of tools or methods that make valid data, information and knowledge resources available to consumers, and aims to understand and improve the ways that these tools or methods work, for example: to enable health access materially and intellectually by consumers; to address the health needs, interests and contexts of consumers; to allow consumers to interact directly with resources without a healthcare professional's facilitation; to personalise and / or socialise consumers' interactions about their health needs and interests; to aid consumers' self-management and self-monitoring of health care plans; and to deepen consumers' engagement in clinical diagnosis, treatment and research [13,14].

1.4 Respecting participation in digital health research by patients, clients and citizens

Although digital health research occurs in the health sector context, where technological change has been slow, it also occurs in the context of a digital society and a digital economy, where the Internet has changed many aspects of how we live and a second generation of digitally native citizens is rising. The involvement of patients, clients and other citizens as full participants in digital health research responds to a social movement that is over a decade old. If it is new to you there are a variety of introductions to the concept [15,16] and a range of resources to help you do it well. Some examples follow.

Does your digital health research describe patients, clients or other citizens with a blanket term such as 'participants' or 'users'? If so, what terms do you employ to reflect their equal status with clinicians, public health workers and health service managers who may be considered 'participants' in the service

innovation or ‘users’ of the digital tool that is under investigation [17]? How fully does your research capture the interactions facilitated by the technology as a whole system or, if it does not, how fully is this acknowledged as a limitation of the study [18]?

At what point should you involve patients, clients or other citizens in your digital health research? The greatest benefit for you and for them may come from engaging them in defining and scoping the research at early stages. Strongly participant-driven digital health research approaches may be described as a form of ‘citizen science’ [19-22].

Are the methods well-founded that your digital health research employs to secure full participation by patients, clients or other citizens? Your strategy will be strengthened by building on the considerable experience of recruitment that has been reported in the literature [23,24].

Crucially, engagement with your target participants may be affected their levels of interrelated literacies – basic literacy, health literacy, information literacy and computer literacy. Bear in mind too that levels of information and computer literacies not only among lay people but also among health professionals or administrators may be sub-optimal for full participation; and in fact some lay people may be at more advanced levels than some health workers. There is a range of integrated approaches to these literacies from which to choose in screening your participants or collecting their baseline data [25,26].

Consumer participation in digital health design projects is not uncommon, but generic models and methods that enable this collaborative activity to be described as a research process are not well-documented overall; a selection of potentially relevant approaches is provided in [27-35].

Part 2: Methodological considerations

2.1 Framing your digital health research

Since digital health research is an immature field it is possible to make a substantial contribution to its body of knowledge if you think expansively. Determine how your research will address the opportunities and challenges that have been acknowledged in this field [36-39]. Consider the scope and the calibre of the contribution that your research will make to theory and to practice.

Whether you are a health researcher unfamiliar with the technology sector or an ICT researcher unfamiliar with the health sector, it is important to be explicit about the thinking that frames your digital health research project [40]. Start by exploring the rationale behind your research project. In what ways do you want to advance knowledge and practice in the health sciences and in the ICT disciplines? What particular assumptions and worldviews form the basis for these aspirations? [41-44].

2.2 Contributing to the clinical evidence base through digital health research

It is a fundamental expectation in health science that good professional practice is based on best available research evidence, for preference evidence that arises from synthesis of findings from randomised controlled trials.

In the main, digital health does not yet have an extensive evidence base or well-established research protocols [45-47]. Reviews (such as [48-50]) 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 researchers should adopt these strong methods for generating data and making sense of it in their studies. Selected recent examples of in meta-analyses of randomised controlled trials show that this level of rigor is being applied in many fields of research, such as cancer, diabetes and other chronic diseases, exercise and nutrition, mental health and sexual health as shown in Table 1.

Table 1. Examples of meta-analyses of randomised controlled trials used in digital health research

Agboola SO, Ju W, Elfiky A, Kvedar JC, Jethwani K (2015) The effect of technology-based interventions on pain, depression, and quality of life in patients with cancer: A systematic review of randomized controlled trials. <i>J Med Internet Res</i> 17 (3):e65. doi:10.2196/jmir.4009
Direito A, Carraca E, Rawstorn J, Whittaker R, Maddison R (2016) mHealth technologies to influence physical activity and sedentary behaviors: Behavior change techniques, systematic review and meta-analysis of randomized controlled trials. <i>Ann Behav Med</i> doi:10.1007/s12160-016-9846-0
Mita G, Ni Mhurchu C, Jull A (2016) Effectiveness of social media in reducing risk factors for noncommunicable diseases: A systematic review and meta-analysis of randomized controlled trials. <i>Nutr Rev</i> 74 (4):237-247. doi:10.1093/nutrit/nuv106
Or CK, Tao D (2014) Does the use of consumer health information technology improve outcomes in the patient self-management of diabetes? A meta-analysis and narrative review of randomized controlled trials. <i>Int J Med Inform</i> 83 (5):320-329. doi:10.1016/j.ijmedinf.2014.01.009
Rasekaba TM, Furler J, Blackberry I, Tacey M, Gray K, Lim K (2015) Telemedicine interventions for gestational diabetes mellitus: A systematic review and meta-analysis. <i>Diabetes Res Clin Pract</i> 110 (1):1-9. doi:10.1016/j.diabres.2015.07.007
Spijkerman MP, Pots WT, Bohlmeijer ET (2016) Effectiveness of online mindfulness-based interventions in improving mental health: A review and meta-analysis of randomised controlled trials. <i>Clin Psychol Rev</i> 45:102-114. doi:10.1016/j.cpr.2016.03.009
Wayal S, Bailey JV, Murray E, Rait G, Morris RW, Peacock R, Nazareth I (2014) Interactive digital interventions for sexual health promotion: A systematic review and meta-analysis of randomised controlled trials. <i>The Lancet</i> 384 (Spec Issue):S85. doi:10.1016/S0140-6736(14)62211-X
Williams G, Hamm MP, Shulhan J, Vandermeer B, Hartling L (2014) Social media interventions for diet and exercise behaviours: A systematic review and meta-analysis of randomised controlled trials. <i>BMJ open</i> 4 (2):e003926-002013-003926. doi:10.1136/bmjopen-2013-003926
Zachariae R, Lyby MS, Ritterband LM, O'Toole MS (2016) Efficacy of internet-delivered cognitive-behavioral therapy for insomnia - a systematic review and meta-analysis of randomized controlled trials. <i>Sleep Med Rev</i> 30:1-10. doi: 10.1016/j.smrv.2015.10.004

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 appropriate methods [51-54].

Two key steps to avoid oversimplifying the organisational and cultural factors inherent in the introduction of digital health interventions into a health care environment are firstly, to incorporate socio-technical theory in the research design [55,56] and secondly, to conduct a suitably detailed feasibility study [57,58].

2.3 Positioning digital health research as health services and systems research

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 [59-61].

Digital health researchers may wish 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 [62]. The variety of these indicators ranges from accessibility and appropriateness to safety and trust. The next paragraph shows a worked example, namely the indicators that could be used to contextualise the aim of a digital health research project in Australian policy. By making reference to the equivalent high level indicators, a similar approach can be taken in other jurisdictions. 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.

In the case of Australia, a National Health Performance Framework sets out performance indicators for hospitals and health networks. These indicators are underpinned by the Review of Government Service Provision Framework, which distinguishes between outputs (the actual service delivered), and outcomes (the impact of a service on the status of an individual or a group and on the success of the service achieving its objectives). This framework emphasises three top priorities - equity, effectiveness and efficiency - and unpacks them into six aspects of performance: accessibility; continuity of care; effectiveness; efficiency and sustainability; responsiveness; safety [63,64]. We can investigate digital health by locating specific research projects in relation to these six aspects of performance. We can go further, by augmenting them with predefined indicators of performance (for example, in Table 2), to understand the impact of digital health in four dimensions: its contribution to consumer centred care; to clinical safety and quality of care; to service sustainability and to infrastructure utility.

Table 2. High-level indicators of health system performance to guide digital health research: an Australian example.

Dimension and Source	Indicators
1 Consumer centred care	Accessible and affordable care. Appropriate care that meets the needs and preferences of individuals, that is evidence based, high quality and safe.
Consumers Health Forum of Australia [65]	Whole of person care that takes into account people's lives and personal and cultural values; that is inclusive of carers and family.

	<p>Coordinated and comprehensive care that provides multidisciplinary care and facilitates continuity across the different levels of the healthcare system. Trust and respect at all times, including timely and efficient complaint resolution processes.</p> <p>Support to enable informed decision-making including access to clear and understandable information about treatment options, risks and costs.</p> <p>Meaningful involvement of people at all levels of planning, system design, service development and in key governance structures to ensure sustainability.</p>
<p>2 Clinical safety and quality of care</p> <p>Australian Commission on Safety and Quality in Health Care [66]</p>	<p>Appropriateness: health summary; timely initial needs identification; client assessment; complete care plan and timely review; recalls and reminders; adherence to clinical guidelines; medication review</p> <p>Effectiveness: client improvement / stabilization; attainment of goals of care</p> <p>Coordination: referral process and content; allocation of care coordinator; timely communication with care team</p> <p>Safety: adverse drug reactions and medication allergies; documented near misses or adverse events investigated and followed up; infection control.</p>
<p>3 Service sustainability</p> <p>[Dimensions covered by 1 or 2 above are bracketed]</p> <p>Australian Council on Healthcare Standards [67]</p>	<p>[Service delivery] [Provision of care]</p> <p>Information management: health records management systems support the collection of information and meet the consumer / patient and organisation's needs; corporate records management systems support the collection of information and meet the organisation's needs; data and information are collected, stored and used for strategic, operational and service improvement purposes; the organisation has an integrated approach to the planning, use and management of information and communication technology (ICT).</p> <p>Workforce planning and management: workforce planning supports the organisation's current and future ability to address needs; the recruitment, selection and appointment system ensures that the skill mix and competence of staff, and mix of volunteers, meets the needs of the organisation; the continuing employment and development system ensures the competence of staff and volunteers; employee support systems and workplace relations assist the organisation to achieve its goals.</p> <p>Corporate systems and safety: the organisation provides quality, safe health care and services through strategic and operational planning and development; governance is assisted by formal structures and delegation practices within the organisation; external service providers are managed to maximise quality, safe health care and service delivery; the organisation's research program develops the body of knowledge, protects staff and consumers / patients and has processes to appropriately manage the organisational risk; safety management systems ensure the safety and wellbeing of consumers / patients, staff, visitors and contractors; buildings, signage, plant, medical devices, equipment, supplies, utilities and consumables are managed safely and used efficiently and effectively; emergency and disaster management /security management /waste and environmental management supports safe practice and a safe environment</p>
<p>4 Infrastructure utility and warranty</p> <p>Australia College of Rural & Remote Medicine [68]*</p>	<p>Adequate performance of IT equipment and infrastructure: The equipment works reliably and well over the locally available network and bandwidth. / The equipment is compatible with the equipment used at the other telehealth sites and in the home. /All the participating healthcare organisations meet the standards required for security of storage and transmission of health information. /Peripheral devices are used in a fit for purpose manner jointly</p>

	<p>determined by the patient and clinician. / The equipment is installed according to producer's guidelines, where possible in collaboration with other organisations/clinicians using the system. / The equipment and connectivity are tested jointly by the participating healthcare organisation to ensure that they do what the producer claims they will.</p> <p>IT risk management: Risk analysis is performed to determine the likelihood and magnitude of foreseeable problems. / There are procedures for detecting, diagnosing, and fixing equipment problems. / Technical support services are available during the time that equipment is operating. / There is back-up to cope with equipment or connectivity failure, proportionate to the consequences of failure.</p>
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*Telehealth is used as an example here. Equally it is possible to substitute technology management and governance frameworks applicable to other kinds of healthcare infrastructure, for example, digital hospitals (<https://infostore.saiglobal.com/en-us/Standards/SA-HB-163-2017-1919534/>) or smart medical devices (<https://www.fda.gov/downloads/AboutFDA/CentersOffices/OfficeofMedicalProductsandTobacco/CDRH/CDRHReports/UCM459368.pdf>) .

2.4 Recognising computer science and information systems research in digital health research

To someone who is unfamiliar with ICT research, it may appear that a digital health study can proceed simply on the basis of a simple licensing agreement with a software vendor or a short-term contract with a software developer, plus some 'common sense' survey questions to deal with attitudinal and behavioural aspects of the project. This may not suffice.

Such an approach in your research design may imbue your work with potentially serious oversights or shortcomings. To address these may entail revising your expectations about what your project can achieve within your timeline and resources. You may need to do further background research, invite an expert co-investigator to join your project team, and / or add detailed specifications to your agreement with a vendor or contractor.

Even though the aim of digital health research is to improve or advance health, this research draws heavily on research methods and tools that have been refined in ICT disciplines such as computer science and information systems. A range of well-founded ICT research methods exists already that is suited to explore many aspects of digital health. It is preferable to use these where possible rather than inventing idiosyncratic methods. It is possible to gain some insights into the methods in this field by scanning selected summary papers (such as [69-71]).

Your digital health research will benefit even more if you have a basic understanding not just of computer science and information systems concepts, but also of the special modifications to these in health settings. Even skimming the contents of introductory health informatics textbooks can be useful to help you reflect on aspects of the ICT body of knowledge where your project may need more attention to detail (for example [72-75]).

Three examples serve to illustrate the range of methodological issues, in areas essential for digital health researchers to consider, that are being addressed in current ICT research: information retrieval [76,77]; privacy and security [78,79]; and human-computer interaction [80,81].

Part 3: Research techniques

3.1 Reviewing scientific and technical literature related to digital health research

Conducting reviews both of existing research literature and of the state of current technology is advisable as a preliminary to designing a digital health research project. Because of the complexity that is characteristic of digital health interventions, neither type of review is straightforward. Sources of information are more widely scattered and more difficult to synthesise, and methods of reviewing are more variable, than you would expect in a narrower field of research [82,83].

Peer-reviewed publications appear both in the biomedical and healthcare literature, mainly in journals, and also in the engineering and ICT literature, often in conference proceedings [84,85]. To do a thorough search of the literature thus requires you to consult the major databases in both fields [86], and to use a multiplicity of search terms. The field of health technology assessment offers some parallels [87].

Your digital health research design may not factor in major advances if you rely on peer-reviewed sources entirely. You may benefit from information in sources such as project reports, blogs, policy documents, industry white papers, and so on. This non-peer-reviewed literature – also known as ‘grey’ literature – is important because the rate of technological change is much faster than the rate of scholarly research reporting. There are a number of ways to ensure that you have done a thorough job of scanning this grey literature. Examples are shown in Table 3.

Table 3. Example sources of digital health grey literature

Databases		
Canadian Agency for Drugs and Technologies in Health	Search health technology assessment reports	https://www.cadth.ca/reports
National Technical Reports Library USA	Use keywords to search a comprehensive collection of government-sponsored research	https://ntrl.ntis.gov/NTRL/
Primary Health Care Research & Information Service Australia	Outlines a method for manual searching	http://www.phcris.org.au/guides/grey_literature.php
Consulting companies		
Accenture Consulting Health	Blogs and reports	https://www.accenture.com/au-en/health-industry-index
Ernst and Young	“Health reimagined: A new participatory health paradigm” report, 2016	http://www.ey.com/au/en/industries/health/
Gartner Group	“Hype Cycles” for Telemedicine, Healthcare Provider Applications, Analytics and Systems, AND Healthcare Provider Technologies and Standards	http://www.gartner.com/technology/consulting/healthcare-providers.jsp
Government and non-government agencies		

Austrade	Digital Health. Health IT Industry Capability Report, 2016	http://www.austrade.gov.au/ArticleDocuments/2814/DigitalHealth_IndustryCapabilityReport.pdf.aspx
Capital Markets Cooperative Research Centre	"Flying blind" Australian consumers and digital health report, 2016	https://flyingblind.cmcrc.com/
National Broadband Network	Health blog	http://www.nbnco.com.au/blog/health
News aggregators		
Computer World	Healthcare IT news section	http://www.computerworld.com/category/healthcare-it/
European EHealth News		http://www.ehealthnews.eu/
Healthcare IT News		http://www.healthcareitnews.com/
Information Week	Healthcare IT news section	http://www.informationweek.com/healthcare.asp
Pulse+IT Magazine		http://www.pulseitmagazine.com.au
Industry interest groups		
Australasian TeleHealth Society		http://www.aths.org.au
Health Informatics Society of Australia		www.hisa.org.au
Health Information and Management Systems Society		http://www.himss.org

3.2 Developing tools as part of digital health research

If, as part of your research project you need to develop a new tool or portal or platform to support participation by patients and consumers, be aware that international and national standards cover some but not all aspects of this work. If you develop a tool that does not meet the standards that apply in the jurisdiction where you intend it to be used, it may work well for your immediate research purposes. However it may not be suitable for scaled-up use.

Compliance and governance are specialised and rapidly evolving aspects of digital health and often are not the radar of technology developers, even those with experience in the health sector. Ultimately it is your role as the responsible researcher to specify your requirements so that the tools developed through your research funding can support rigorous and transparent research. If you are developing digital health resources for the Australian health sector, at the minimum you should be aware of the following kinds of information:

Australian Digital Health Agency (formerly National EHealth Transition Authority) Resources for implementers and developers <https://www.digitalhealth.gov.au/implementation-resources>

and

Standards Australia. EHealth Standards <http://www.ehealthstandards.org.au/Home/Publications.aspx>

Anyone can 'have a go' at developing digital health tools, by taking advantage of open source resources for developers (for example, OpenmHealth <http://www.openmhealth.org>). Technology developers can be found among people in the maker movement or start-up companies. In a university, development may be in the skillset of your research colleagues or their students; or there may be specialised research

support services (such as the E-Research Group <http://eresearch.unimelb.edu.au/> and the Research Information Technology Unit <http://www.grhanite.com> at the University of Melbourne). Established businesses which are members of industry organisations (for example the Medical Software Industry Association <https://www.msia.com.au>) are able to offer a grounded perspective on the viability of what you plan to develop as part of your digital health research.

If you anticipate that the tool you develop will be implementable in routine professional practice, be aware of advisory services from professional and provider organisation, such as:

Pharmacy Guild of Australia Pharmacy innovations in digital health (eHealth).

<https://www.guild.org.au/docs/default-source/public-documents/issues-and-resources/Fact-Sheets/factsheet-pharmacy-innovations-in-ehealth.pdf?sfvrsn=4>

Royal Australian College of General Practitioners Digital Business Kit. One. Using technology to deliver healthcare. <http://www.racgp.org.au/digital-business-kit/one/>

Royal College of Physicians. Using Apps in Clinical Practice: Important things that you need to know about apps and CE marking. <https://www.rcplondon.ac.uk/file/175/download?token=5nTJceC1>

Victoria. Health Department Health Technology Program. <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/speciality-diagnostics-therapeutics/health-technology-program>

If you are interested in the broad commercialisation prospects for the tool you develop, you should seek professional advice through an incubator or accelerator program. Some programs are offered through research institutions (for example the University of Melbourne Accelerator Program <http://themap.co> and Murdoch Childrens Research Institute Bytes4Health <https://www.mcri.edu.au/bytes4health>). The Australian Government provides links to other reputable resources that it sponsors (at <http://www.innovation.gov.au/page/incubator-support-programme>); one example is the MTPConnect MedTech and Pharma Growth Centre (<http://www.mtpconnect.org.au>).

3.3 Working with data collected from digital devices and online services

Digital health devices and online services used by patients or citizens who are research participants may automatically generate biometric data or may prompt the user to enter this data manually into a system. A common acronym for this is PGHD, that is, patient- or person-generated health data [88]. In general, research methodologies are still immature in this area, and thought-provoking accounts are worth weighing up before you wade in (for example [89-93]). Further guidance on working with data from specific technologies appears in Part 4 of this paper.

Data analytics methods for working with patient generated health data are a topic of great current interest. By definition the data are likely to be 'patient-centred' but such research may not engage with patients at all (for example [94,95]). A few analytics research approaches envisage fuller engagement with the patients whose data are under study (for example [96]). There are particular challenges in enabling active patient participation in analytics research (touched on by [97-99] and the subject of a popular work by Taylor [100]).

3.4 Collecting data for research about digital health

Apart from biometric data captured by devices or input prompts, there are other sorts of data that you may wish to collect by other means to find out about the use of digital health technologies as a form of human behaviour. People's attitudes to and experiences with digital health technology are often of

particular interest to researchers. It is inadvisable to create data collection metrics and scales from scratch for this purpose, unless you are certain that there is not a validated method or tool already in existence that will meet your needs.

Evaluation is often the aim of digital health research, and evaluation resources abound (examples are [101-107]). Less abundant but equally important are methods for doing implementation research (for example [108,109]).

There is great scope for original work in digital health research that deploys instruments recognised in health science along with others from information science, and correlates the findings from both. From the health sciences perspective, an important source of patient-reported health outcome measures is PROMIS www.nihpromis.com. The many other ways of eliciting patient health effects include narratives [110] and activation measures [111]. The health science literature also offers several systematic reviews of research on digital health patient engagement and impact, from which accepted methods can be derived (examples are [112,113]).

From the information science perspective, studying the user experience is a highly sophisticated type of research. A neat summary of user-centred design study methods has been produced by the US government (<https://www.usability.gov/what-and-why/user-research.html>) and there are many other resources from science and industry (such as [114-116]).

3.5 Research data management and storage planning

As early as possible in your research, it is advisable to construct a formal data management plan. This specifies why, where and how you will organise, secure, store and potentially share the data collected in your research. This information is required as part of many ethics and funding application pro formas, and it will also be useful for the core task of organising your research data.

General guidance is offered by research institutes (for example, University of Melbourne Research Data Management <http://research.unimelb.edu.au/infrastructure/doing-data-better/how>) and funding bodies such as the Australian Research Council (<http://www.arc.gov.au/research-data-management>) and the National Health & Medical Research Council (through its *Code for the Responsible Conduct of Research* <https://www.nhmrc.gov.au/guidelines-publications/r39> ; note this Code is currently under review and a new version is in preparation).

Digital health projects have the potential to generate terabytes of raw patient health data. This scenario will require that you arrange large-volume storage. You may be able to apply to your research infrastructure support unit for this; or you may need to discuss it with your institution's IT services unit; or you may need to identify and pay for an appropriately secure private storage provider. Be ready with a detailed outline of the data quantity, format, retention period, and details of collaborators who will require access over the lifetime of the study.

Research that relies on patient-generated 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.

The Privacy Rule in the USA's Health Insurance Portability and Accountability Act (HIPAA) is often mentioned in the published literature (for example [117]). Be aware that it is not the most applicable law for Australian researchers. The Australian Privacy Act gives special protection to health data (<https://www.oaic.gov.au/privacy-law/privacy-act/health-and-medical-research>) and the Australian Information Commissioner reports annually on particular digital health data activities (<https://www.oaic.gov.au/about-us/corporate-information/annual-reports/ehealth-and-hi-act-annual-reports/>).

You should also consider policies and recommendations on data sharing; indeed this may be mandated by some research funders. These are designed to extend the value of the data collected in the study, by encouraging re-use of de-identified or anonymised datasets (e.g. NH&MRC <https://www.nhmrc.gov.au/grants-funding/policy/nhmrc-statement-data-sharing>). If you are aware of this option at the outset, you'll have the opportunity to incorporate re-use provisions in the phrasing of recruitment material, project information sheets, and participant consent forms. The Australian National Data Service offers guides and examples for sharing sensitive data at <http://www.ands.org.au/working-with-data/sensitive-data/sharing-sensitive-data>.

3.6 Writing up and reporting digital health research

The range of journal, conference and monograph resources cited in this chapter offers many pointers to the presentation and publication forums that accept reports of digital health research. In writing up your research for publication, you may seek to communicate its contribution to theory or its contribution to practice, or both.

Your research can be assured of being readable and replicable if you report it in a structured manner. Specific reporting protocols exist that are applicable to many types of digital health research. There are key papers that you should know about, that can help you to describe formally all of the important elements of your digital research project [118-124].

Part 4: Technology-specific resources

4.1 Looking into specific settings of digital health research

So far, this paper has provided broad-brush suggestions and high-level resources for digital health researchers. There are three more specific aspects to consider in pursuing rigorous digital health research in your actual setting.

First, familiarise yourself with the barriers and facilitators in the healthcare setting where your research is conducted. For example: Your hospital may have a bring-your-own-device policy; how does this govern what you plan to do with patient-generated data? Your clinic may have a substantial investment in proprietary record management or knowledge management software; does this offer any of the functionality that you need for your intervention? A patient advocacy organisation in your field of healthcare already may be using online health platforms expertly; how might your project complement these activities?

Second, do a scoping review of the scientific literature and industry resources that are specific to your field of health, to augment the more generic ones mentioned in Parts 1 to 3. In some fields, for example

diabetes and mental health, there is already a substantial body of published digital health research and an array of clinically tested digital health products and services. Be clear about what pressing needs you are going to fill and what new knowledge you are going to discover.

Third, investigate the existence of guidelines that pertain to the specific form of technology that interests you. To support the way you plan and carry out your digital health research project, the final sections of this paper list a cross-section of recent resources related to health apps, health social media, and healthcare wearables.

4.2 Health apps

Health apps vary widely in quality and functionality, and many fail rapidly. Guidelines after the fact for health app users would be needed less if these apps were developed more consistently and more rigorously in the first place. An enormous number of scientific papers have been published about health app research, from design and development to implementation and evaluation, and there is voluminous report literature from commercial and government sources. However, closer inspection of the literature reveals surprisingly few sources of evidence-based advice that apply generically across the stages of an app's lifecycle. Guidelines and advisory documents may emanate from many different countries, that is, from many different healthcare system jurisdictions. Given the variation in legislation and in technology policies related to health data, for example, this makes it difficult for researchers and developers to easily determine which of these sources of advice are applicable to comply with local health data privacy laws, and to address local clinical guidelines. There is much scope for further systematic research to bring refinement to this area of digital health [125-140].

4.3 Health social media

Web 2.0, the social web and social media are terms used interchangeably since 2005 to describe how the World Wide Web has become a medium for content, interactions and transactions, using channels such as audio and video podcasting, blogging and microblogging, social networking, virtual worlds and more. This change in the Internet has generated huge innovation in health. Examples include direct-to-consumer diagnostic services online, platforms for personal health data sharing, patient experience video channels, and new approaches to public health promotion and surveillance. Digital health research may consider social media to be a tool for research, a setting for research, or a focus for research. Often researchers fail to clarify their research orientation to health social media, resulting in research designs and methods that hinder best use of participants' data and reflections on data. Examples of strong methodological contributions are captured in the selection of papers provided here [141-163].

4.4 Health self-tracking with consumer wearables

Consumers have direct off-the-shelf access to a range of wearable devices that offer tools for self-quantification of diet, exercise, sleep, medication, mood, blood pressure, body temperature, environmental exposure, and other indicators of health and wellness. Wearables are worn on or sometimes in the body (as distinct from carrying a mobile phone); examples include watches, glasses, contact lenses, e-textiles and smart fabrics, headbands, beanies and caps, jewellery such as pendants, rings, bracelets, earrings etc. They use sensors to completely or partially automate data collection, and they have built-in functionality to ship the collected data to a cloud-based server for analysis and sharing. There are many angles that this area of digital health research may explore: wearables are

developing capabilities that rival those inside an intensive care unit; they are not categorised as regulated medical devices nor are the data from them readily able to integrate with clinical information systems; their use is assuming fad proportions and generating volumes of data that may or may not lead to sound decisions about healthcare. The selection of papers provided here illustrates some of the scholarly and scientific approaches that are emerging to advance research in this field [164-178].

Part 5. Conclusion

Digital health is a popular and convenient way to convey the changes that new technologies are bringing to healthcare in the twenty-first century. However, digital health can mean many things to many people, and digital health is not a scientific discipline.

Further, many researchers from clinical, IT, engineering and similar domains, are new to conducting investigations in this field, and may be unfamiliar with the sorts of engagement with patients, clients and consumers that new technologies enable.

Therefore, this chapter has provided an overview of digital health research and offered health and biomedical informatics foundations of research in this field. It has outlined theoretical and conceptual frameworks, ethical considerations, research methods, and examples of tools that may be included in studies of digital health interventions. Although many of the examples are from the Australian context, there may be equivalents in other jurisdictions; if not, the Australian examples are edifying.

Digital health research is important, and conducting this research by building upon what is already known is also important, so that investments in digital health in our healthcare systems may be informed by the strongest possible evidence base.

[END]

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