

See discussions, stats, and author profiles for this publication at: <https://www.researchgate.net/publication/317216001>

# Digital health research methods and tools

## Suggestions and selected resources for researchers

Chapter · January 2017

CITATIONS

0

READS

59

2 authors, including:



**Kathleen Gray**

University of Melbourne

102 PUBLICATIONS 1,711 CITATIONS

SEE PROFILE

Some of the authors of this publication are also working on these related projects:



Mobile Augment Reality-Parkville [View project](#)



TaSoMe [View project](#)

All content following this page was uploaded by **Kathleen Gray** on 29 May 2017.

The user has requested enhancement of the downloaded file. All in-text references [underlined in blue](#) are added to the original document and are linked to publications on ResearchGate, letting you access and read them immediately.

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

Kathleen Gray and Cecily Gilbert

Associate Professor Kathleen Gray  
Health and Biomedical Informatics Centre  
The University of Melbourne  
Parkville VIC 3010 Australia  
[kgray@unimelb.edu.au](mailto:kgray@unimelb.edu.au) Phone 61 3 8344 8936 Mobile 61 418 318 920  
\* Corresponding author

Ms Cecily Gilbert  
Health and Biomedical Informatics Centre  
The University of Melbourne  
Parkville VIC 3010 Australia  
[cecilyg@unimelb.edu.au](mailto:cecilyg@unimelb.edu.au) Phone 61 3 9035 9573 Mobile 61 431 210 043

CHAPTER for

Holmes D, Jain L (date) Advances in biomedical informatics. Springer, (place) Series: Springer  
Intelligent Systems Reference Library.

## 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

## Contents

### Part 1: Introduction

- 1.1 Understanding what digital health means
- 1.2 Defining your research as digital health research
- 1.3 Drawing from health informatics for digital health research
- 1.4 Respecting participation in digital health research by patients, clients and citizens

### Part 2: Methodological considerations

- 2.1 Framing your digital health research
- 2.2 Contributing to the clinical evidence base through digital health research
- 2.3 Positioning your research as health services and systems research
- 2.4 Recognising computer science and information systems research in digital health research

### Part 3: Research techniques

- 3.1 Reviewing scientific and technical literature related to digital health research
- 3.2 Developing tools as part of digital health research
- 3.3 Working with data collected from digital devices and online services
- 3.4 Collecting data for research about digital health
- 3.5 Research data management and storage planning
- 3.6 Writing up and reporting digital health research

### Part 4: Technology-specific resources

- 4.1 Looking into specific settings of digital health research
- 4.2 Health apps
- 4.3 Health social media
- 4.4 Health self-tracking with consumer wearables

## List of Tables

- 1. Examples of meta-analyses of randomised controlled trials used in digital health research
- 2. High-level indicators of health system performance to guide digital health research: an Australian example
- 3. Example sources of digital health grey literature

## 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 (Taylor 2015). 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 (IOM 2011).

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.

IOM Institute of Medicine (US), Grossmann C, Powers B, McGinnis JM (2011) Digital infrastructure for the learning health system - the foundation for continuous improvement in health and health care: Workshop series summary. National Academy of Sciences, Washington, DC. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/22379651>

Taylor K (2015) Connected health: How digital technology is transforming health and social care. Deloitte Centre for Health Solutions, London. Retrieved from <https://www2.deloitte.com/uk/en/pages/life-sciences-and-healthcare/articles/connected-health.html#>

## 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 (Frank et al, 1999; Iyawa et al. 2016). 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 (Hagens et al. 2015).

Progress to advance digital health has occurred in countries around the world (WHO 2015). 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 (Australia 2016). 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 (Agarwal et al. 2010; Burrill 2012; Accenture 2016).

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.

Accenture (2016) Digital health tech vision, 2016. Retrieved from <https://www.accenture.com/au-en/insight-digital-health-tech-vision-2016>

Agarwal R, Gao G, DesRoches C, Jha AK (2010) Research commentary---the digital transformation of healthcare: Current status and the road ahead. *Inf Syst Res* 21:796-809. doi:10.1287/isre.1100.0327

Australia (2016) Public governance, performance and accountability (establishing the Australian Digital Health Agency) rule. Retrieved from <https://www.legislation.gov.au/Details/F2016L00070>

Burrill GS (2012) Digital health investment opportunities abound, but standouts deliver disruptive change. *J Commer Biotechnol* 18 (1):495. doi:10.5912/jcb495

Frank SR, Williams JR, Veiel EL (2000) Digital health care: Where health care, information technology, and the internet converge. *Manag Care Q* 8 (3):37-47

Hagens S, Zelmer J, Frazer C, Gheorghiu B, Leaver C (2015) Valuing national effects of digital health investments: An applied method. *Stud Health Technol Inform* 208:165-169

Iyawa GE, Herselman M, Botha A (2016) Digital health innovation ecosystems: From systematic literature review to conceptual framework. *Procedia Comput Sci* 100: 244-252.  
doi:10.1016/j.procs.2016.09.149

World Health Organisation (2016) Atlas of ehealth country profiles 2015: The use of ehealth in support of universal health coverage; based on the findings of the 2015 global survey on ehealth. WHO, Geneva. Retrieved from [http://www.who.int/goe/publications/atlas\\_2015/en/](http://www.who.int/goe/publications/atlas_2015/en/)

### 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 (Flores et al. 2013; Martin Sanchez et al. 2013).

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 (Demiris 2016; Flaherty et al. 2015).

Demiris G (2016) Consumer health informatics: Past, present, and future of a rapidly evolving domain. *Yearb Med Inform Suppl* 1:S42-47. doi:10.15265/IYS-2016-s005

Flaherty D, Hoffman-Goetz L, Arocha JF (2015) What is consumer health informatics? A systematic review of published definitions. *Inform Health Soc Care* 40 (2):91-112. doi:10.3109/17538157.2014.907804

Flores M, Glusman G, Brogaard K, Price ND, Hood L (2013) P4 medicine: How systems medicine will transform the healthcare sector and society. *Per Med* 10 (6):565-576. doi:10.2217/PME.13.57

Martin-Sanchez F, Lopez-Campos G, Gray K (2014) Biomedical informatics methods for personalized medicine and participatory health. In: Sarkar IN (ed) *Methods in biomedical informatics*. Academic Press, Oxford, pp 347-394. doi:10.1016/B978-0-12-401678-1.00011-7

#### **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 (Greaves et al. 2014; Okun and Caligtan 2017) 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 (Kushniruk and Turner 2011)? 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 (Stephanie and Sharma 2016)?

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' (Awori and Lee 2017; Filonik et al. 2015; Swan 2012; Vayena and Tasioulas 2013).

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 (Lane et al. 2015; O'Connor et al. 2016).



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 (Karnoe and Kayser 2015; Mackert et al. 2014).

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 here: (Agarwal et al. 2011; Elwyn et al. 2011; Eyles et al. 2016; Johnson and Turley 2007; Kayser 2015; Marquand and Zayas-Caban 2012; Mummah et al. 2016; Valdez et al. 2014; Van Gemert et al. 2011).

Agarwal R, Anderson C, Crowley K, Kannan PT, Westat (2011) Improving consumer health IT application development: Lessons from other industries, background report. AHRQ Publication No. 11-0065-EF. Agency for Healthcare Research and Quality, Rockville, MD

Awori J, Lee JM (2017) A maker movement for health: A new paradigm for health innovation. *JAMA Pediatr* 171 (2):107-108. doi:10.1001/jamapediatrics.2016.3747

Center for eHealth Research and Disease Management, University of Twente (2012) CeHRes roadmap. Retrieved from [http://www.ehealthresearchcenter.org/wiki/index.php/Main\\_Page](http://www.ehealthresearchcenter.org/wiki/index.php/Main_Page)

Elwyn G, Kreuwel I, Durand MA, Sivell S, Joseph-Williams N, Evans R, Edwards A (2011) How to develop web-based decision support interventions for patients: A process map. *Patient Educ Couns* 82 (2):260-265. doi:10.1016/j.pec.2010.04.034

Eyles H, Jull A, Dobson R, Firestone R, Whittaker R, Te Morenga L, Goodwin D, Mhurchu CN (2016) Co-design of mhealth delivered interventions: A systematic review to assess key methods and processes. *Curr Nutr Rep* 5 (3):160-167. doi:10.1007/s13668-016-0165-7

Filonik D, Bednarz T, Rittenbruch M, Foth M (2015) Collaborative data exploration interfaces - from participatory sensing to participatory sensemaking. Paper presented at the 1<sup>st</sup> IEEE Symposium on Big Data Visual Analytics (BDVA), Hobart, Tas, 22-25 Sept 2015. doi:10.1109/BDVA.2015.7314289

Greaves F, Millett C, Nuki P (2014) England's experience incorporating "anecdotal" reports from consumers into their national reporting system: Lessons for the United States of what to do or not to do? *Med Care Res Rev* 71 (5 Suppl):65S-80S. doi:10.1177/1077558714535470

Johnson CM, Turley JP (2007) A new approach to building web-based interfaces for healthcare consumers. *e-Journal Health Inform* 2 (2):8. Retrieved from <http://www.ejhi.net/ojs/index.php/ejhi/article/view/30>

Karnoe A, Kayser L (2015) How is ehealth literacy measured and what do the measurements tell us? A systematic review. *Knowledge Management & E-Learning* 7 (4):576-600

Kayser L, Kushniruk A, Osborne RH, Norgaard O, Turner P (2015) Enhancing the effectiveness of consumer-focused health information technology systems through ehealth literacy: A framework for understanding users' needs. *JMIR Hum Factors* 2 (1):e9. doi:10.2196/humanfactors.3696

Kushniruk AW, Turner P (2011) Who's users? Participation and empowerment in socio-technical approaches to health it developments. *Stud Health Technol Inform* 164:280-285

Lane TS, Armin J, Gordon JS (2015) Online recruitment methods for web-based and mobile health studies: A review of the literature. *J Med Internet Res* 17 (7):e183. doi:10.2196/jmir.4359

Mackert M, Champlin SE, Holton A, Muñoz II, Damásio MJ (2014) Ehealth and health literacy: A research methodology review. *J Comput Mediat Commun* 19 (3):516-528. doi:10.1111/jcc4.12044

Marquard JL, Zayas-Caban T (2012) Commercial off-the-shelf consumer health informatics interventions: Recommendations for their design, evaluation and redesign. *J Am Med Inform Assoc* 19 (1):137-142. doi:10.1136/amiajnl-2011-000338

Mummah SA, Robinson TN, King AC, Gardner CD, Sutton S (2016) Ideas (integrate, design, assess, and share): A framework and toolkit of strategies for the development of more effective digital interventions to change health behavior. *J Med Internet Res* 18 (12):e317. doi: 10.2196/jmir.5927

O'Connor S, Hanlon P, O'Donnell CA, Garcia S, Glanville J, Mair FS (2016) Understanding factors affecting patient and public engagement and recruitment to digital health interventions: A systematic review of qualitative studies. *BMC Med Inform Decis Mak* 16 (1):120-016-0359-0353. doi:10.1186/s12911-016-0359-3

Okun S, Caligtan CA (2018) The engaged epatient. In: Nelson R, Staggers N (eds) *Health informatics: An interprofessional approach*. 2nd edn. Elsevier, St Louis, MO, p 204-219

Stephanie FL, Sharma RS (2016) Health on a cloud: Modeling digital flows in an e-health ecosystem. *Journal of Advances in Management Sciences & Information Systems* 2:1-20. Retrieved from [www.lifescienceglobal.com/pms/index.php/jamsis/article/viewFile/3606/2124](http://www.lifescienceglobal.com/pms/index.php/jamsis/article/viewFile/3606/2124)

Swan M (2012) Health 2050: The realization of personalized medicine through crowdsourcing, the quantified self, and the participatory biocitizen. *J Pers Med* 2 (3):93-118. doi:10.3390/jpm2030093

Valdez RS, Holden RJ, Novak LL, Veinot TC (2015) Transforming consumer health informatics through a patient work framework: Connecting patients to context. *J Am Med Inform Assoc* 22 (1):2-10. doi:10.1136/amiajnl-2014-002826

van Gemert-Pijnen JE, Nijland N, van Limburg M, Ossebaard HC, Kelders SM, Eysenbach G, Seydel ER (2011) A holistic framework to improve the uptake and impact of ehealth technologies. *J Med Internet Res* 13 (4):e111. doi:10.2196/jmir.1672

Vayena E, Tasioulas J (2013) Adapting standards: Ethical oversight of participant-led health research. *PLoS Med* 10 (3):e1001402. doi:10.1371/journal.pmed.1001402

## **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 (Andersen 2015; Baker 2014;

Holden 2016; Patrick 2016). 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 (Gray and Sockolow 2016). 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? (Cano et al. 2014; Hu 2015; Lupton 2016; Sjöström et al. 2014).

Andersen T, Kensing F, Kjellberg L, Moll J (2015) From research prototypes to a marketable ehealth system. *Stud Health Technol Inform* 218:40589

Baker TB, Gustafson DH, Shah D (2014) How can research keep up with ehealth? Ten strategies for increasing the timeliness and usefulness of ehealth research. *J Med Internet Res* 16 (2):e36. doi:10.2196/jmir.2925

Cano I, Lluch-Ariet M, Gomez-Cabrero D, Maier D, Kalko S, Cascante M, Tegner J, Miralles F, Herrera D, Roca J, Synergy-COPD Consortium (2014) Biomedical research in a digital health framework. *J Transl Med* 12 Suppl 2. doi:10.1186/1479-5876-12-S2-S10

Gray K, Sockolow P (2016) Conceptual models in health informatics research: A literature review and suggestions for development. *JMIR medical informatics* 4 (1):e7. doi:10.2196/medinform.5021

Holden RJ, Bodke K, Tambe R, Comer RS, Clark DO, Boustani M (2016) Rapid translational field research approach for eHealth R&D. *Proc Int Symp Hum Factors Ergon Healthc* 5 (1):25-27. doi:10.1177/2327857916051003

Hu Y (2015) Health communication research in the digital age: A systematic review. *J Commun Healthc* 8 (4):260-288. doi:10.1080/17538068.2015.1107308

Lupton D (2016) Towards critical digital health studies: Reflections on two decades of research in health and the way forward. *Health (London)* 20 (1):49-61. doi:10.1177/1363459315611940

Patrick K, Hekler EB, Estrin D, Mohr DC, Riper H, Crane D, Godino J, Riley WT (2016) The pace of technologic change: Implications for digital health behavior intervention research. *Am J Prev Med* 51 (5):816-824. doi: 10.1016/j.amepre.2016.05.001

Sjöström J, von Essen L, Grönqvist H (2014) The origin and impact of ideals in eHealth research: Experiences from the U-CARE research environment. *JMIR research protocols* 3 (2):e28. doi:10.2196/resprot.3202

## **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 (Ammenwerth 2015; Mookherji et al. 2015; Rigby et al. 2012). Reviews (such as Black et al.

2011; Parthasarathy and Steinbach 2015; Ravka 2014) 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 (Barratt et al. 2016; Hubner 2015; Liao et al. 2015; Washington et al. 2015).

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 (Georgiou and Whetton 2010; Scott and Briggs 2010) and secondly, to conduct a suitably detailed feasibility study (Levati et al. 2016; Orsmond and Cohn, 2015).

Ammenwerth E (2015) Evidence-based health informatics: How do we know what we know? *Methods Inf Med* 54 (4):298-307. doi:10.3414/ME14-01-0119

Barratt H, Campbell M, Moore L, Zwarenstein M, Bower P (2016) Randomised controlled trials of complex interventions and large-scale transformation of services. *Health Services and Delivery Research* 4 (16):19-36. doi:10.3310/hsdr04160-19

Black AD, Car J, Pagliari C, Anandan C, Cresswell K, Bokun T, McKinstry B, Procter R, Majeed A, Sheikh A (2011) The impact of ehealth on the quality and safety of health care: A systematic overview. *PLoS Med* 8 (1):e1000387. doi:10.1371/journal.pmed.1000387

Georgiou A, Whetton S (2010) Broadening the socio-technical horizons of health informatics. *Open Med Inform J* 4:179-180. doi:10.2174/1874431101004010179

Hubner U (2015) What are complex eHealth innovations and how do you measure them? Position paper. *Methods Inf Med* 54 (4):319-327. doi:10.3414/ME14-05-0001

Levati S, Campbell P, Frost R, Dougall N, Wells M, Donaldson C, Hagen S (2016) Optimisation of complex health interventions prior to a randomised controlled trial: A scoping review of strategies used. *Pilot Feasibility Stud* 2:17. doi:10.1186/s40814-016-0058-y

Liao P, Klasnja P, Tewari A, Murphy SA (2016) Sample size calculations for micro-randomized trials in mhealth. *Stat Med* 35 (12):1944-1971. doi:10.1002/sim.6847

Mookherji S, Mehl G, Kaonga N, Mechael P (2015) Unmet need: Improving mhealth evaluation rigor to build the evidence base. *J Health Commun* 20 (10):1224-1229. doi:10.1080/10810730.2015.1018624

Orsmond GI, Cohn ES (2015) The distinctive features of a feasibility study: Objectives and guiding questions. *OTJR (Thorofare N J)* 35 (3):169-177

Parthasarathy R, Steinbach T (2015) Health informatics for healthcare quality improvement: A literature review of issues, challenges and findings. Paper presented at AMCIS 2015: Twenty-first Americas Conference on Information Systems, Fajardo, Puerto Rico, 2015. Retrieved from [www.aisel.aisnet.org/cgi/viewcontent.cgi?article=1203&context=amcis2015](http://www.aisel.aisnet.org/cgi/viewcontent.cgi?article=1203&context=amcis2015)

Ravka N (2014) Informatics and health services: The potential benefits and challenges of electronic health records and personal electronic health records in patient care, cost control, and health research – an overview. In: El Morr C (ed) *Research perspectives on the role of informatics in health*

policy and management. IGI Global, Hershey, PA, USA, p 89-114. doi:10.4018/978-1-4666-4321-5.ch007

Rigby M, Ammenwerth E, Beuscart-Zephir MC, Brender J, Hypponen H, Melia S, Nykanen P, Talmon J, de Keizer N (2013) Evidence based health informatics: 10 years of efforts to promote the principle. Joint contribution of IMIA WG EVAL and EFMI WG EVAL. Yearb Med Inform 8:34-46.

Scott PJ, Briggs JS (2010) STAT-HI: A socio-technical assessment tool for health informatics implementations. Open Med Inform J 4:214-220. doi:10.2174/1874431101004010214

Washington P, Kumar M, Tibrewal A, Sabharwal A (2015) Scaledmed: A methodology for iterative mhealth clinical trials. Paper presented at 17th International Conference on E-Health Networking, Application & Services, HealthCom 2015, Boston, MA, USA, October 14-17, 2015, 2015. doi:10.1109/HealthCom.2015.7454487

### **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 (for example Bowling 2014; Gräbel et al. 2015; Scutchfield et al. 2012).

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 (Smith et al. 2012). 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 (AIHW, 2009; AIHW, n.d.) 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
<p>1</p> <p>Consumer centred care</p> <p>Consumers Health Forum of Australia</p> <p>(CHF 2016)</p>	<p>Accessible and affordable care.</p> <p>Appropriate care that meets the needs and preferences of individuals, that is evidence based, high quality and safe.</p> <p>Whole of person care that takes into account people's lives and personal and cultural values; that is inclusive of carers and family.</p> <p>Coordinated and comprehensive care that provides multidisciplinary care and facilitates continuity across the different levels of the healthcare system.</p> <p>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</p> <p>Clinical safety and quality of care</p> <p>Australian Commission on Safety and Quality in Health Care</p> <p>(ACSQHC 2012)</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</p> <p>Service sustainability</p>	<p>[Service delivery]</p> <p>[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</p>

<p>[Dimensions covered by 1 or 2 above are bracketed]</p> <p>Australian Council on Healthcare Standards</p> <p>(ACHS n.d.)</p>	<p>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</p> <p>Infrastructure utility and warranty</p> <p>Australia College of Rural &amp; Remote Medicine</p> <p>(ACRRM 2012)*</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 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</p>



	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.
--	---

\*Telehealth is used as an example here. Equally it is possible to substitute management and governance frameworks more applicable to other kinds of care infrastructure.

ACHS Australian Council on Healthcare Standards (n.d.) EQUIP National Table. Retrieved from [http://www.achs.org.au/media/38984/table\\_equipnational\\_standards.pdf](http://www.achs.org.au/media/38984/table_equipnational_standards.pdf)

ACRRM Australian College of Rural & Remote Medicine (2012) ACRRM Telehealth Advisory Committee standards framework. Retrieved from [http://www.ehealth.acrrm.org.au/system/files/private/ATHAC%20Telehealth%20Standards%20Framework\\_0.pdf](http://www.ehealth.acrrm.org.au/system/files/private/ATHAC%20Telehealth%20Standards%20Framework_0.pdf)

ACSQHC Australian Commission on Safety and Quality in Health Care (2012) Practice-level indicators of safety and quality for primary health care specification (Version 1.0). ACSQHC, Sydney. Retrieved from <https://www.safetyandquality.gov.au/our-work/information-strategy/indicators/practice-level-indicators-of-safety-and-quality-for-primary-health-care/>

AIHW Australian Institute of Health and Welfare (n.d.) National health reform: Performance and accountability framework. AIHW, Canberra. Retrieved from <http://www.aihw.gov.au/health-performance/performance-and-accountability-framework/>

AIHW Australian Institute of Health and Welfare, & National Health Information Standards and Statistics Committee. (2009). Revised National Health Performance Framework, 2nd edn. AIHW, Canberra. Retrieved from <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442472799>

Bowling A (2014) Research methods in health: Investigating health and health services. 4<sup>th</sup> edn. Open University Press, Maidenhead

CHF Consumers Health Forum of Australia, George Institute for Global Health (2016) Putting the consumer first: Creating a consumer centred health system for a 21st century Australia - a health policy report. CHF, Sydney. Retrieved from <https://chf.org.au/sites/default/files/putting-the-consumer-first-apr16.pdf>

Gräbel E, Donath C, Holleder A, Drexler H, Kornhuber J, Zobel A, Kolominsky-Rabas P (2015) Evidence-based health services research--a short review and implications. *Gesundheitswesen* 77 (3):193-199. doi:10.1055/s-0034-1382042

Scutchfield FD, Perez DJ, Monroe JA, Howard AF (2012) New public health services and systems research agenda: Directions for the next decade. *Am J Prev Med* 42 (5 Suppl 1):S1-S5. doi:10.1016/j.amepre.2012.01.027

Smith PC, Anell A, Busse R, Crivelli L, Healy J, Lindahl AK, Westert G, Kene T (2012) Leadership and governance in seven developed health systems. *Health Policy* 106 (1):37-49. doi:10.1016/j.healthpol.2011.12.009

## 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 Mora et al. 2012; Riedl and Rueckel 2011; Venkatesh et al. 2013).

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 Coiera 2015; Shortliffe and Cimino 2014; Venot et al. 2014; Weaver et al. 2015).

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 ( Li et al. 2015; Zuccon et al. 2016); privacy and security (Arora et al. 2014; Kotz et al. 2016); and human-computer interaction (Lennon et al. 2015; Wilson and Djamshibi 2015).

Arora S, Yttri J, Nilse W (2014) Privacy and security in mobile health (mhealth) research. *Alcohol research : current reviews* 36 (1):143-151. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4432854/>

Coiera E (2015) *Guide to health informatics*, 3rd edn. CRC Press, Boca Raton, FL

Kotz D, Gunter CA, Kumar S, Weiner JP (2016) Privacy and security in mobile health: A research agenda. *Computer* 49 (6):22-30. doi:10.1109/MC.2016.185

Lennon M, Baillie L, Hoonhout J, Robertson J, Fitzpatrick G (2015) Crossing HCI and health: Advancing health and wellness technology research in home and community settings. Paper presented at CHI EA '15 Proceedings of the 33rd Annual ACM Conference Extended Abstracts on Human Factors in Computing Systems, Seoul. doi:10.1145/2702613.2702652

Li F, Li M, Guan P, Ma S, Cui L (2015) Mapping publication trends and identifying hot spots of research on internet health information seeking behavior: A quantitative and co-word biclustering analysis. *J Med Internet Res* 17 (3):e81. doi:10.2196/jmir.3326

Mora M, Steenkamp AL, Gelman O, Raisinghani MS (2012) On IT and SwE research methodologies and paradigms: A systemic landscape review. In: Manuel M, Ovsei G, Annette LS, Mahesh R (eds) *Research methodologies, innovations and philosophies in software systems engineering and information systems*. IGI Global, Hershey, PA, p 149-164. doi:10.4018/978-1-4666-0179-6.ch008

Riedl R, Rueckel D (2011) Historical development of research methods in the information systems discipline. In: *AMCIS 2011 Proceedings - All Submissions*, Detroit, MI. Paper 28. Retrieved from [http://aisel.aisnet.org/amcis2011\\_submissions/28](http://aisel.aisnet.org/amcis2011_submissions/28)

Shortliffe EH, Cimino JJ (2014) *Biomedical informatics: Computer applications in health care and biomedicine*, 4th edn. Springer Verlag, London. doi:10.1007/978-1-4471-4474-8

Venkatesh V, Brown SA, Bala H (2013) Bridging the qualitative-quantitative divide: Guidelines for conducting mixed methods research in information systems. *MIS Quarterly* 37 (1):21-54. Retrieved from <http://aisel.aisnet.org/misq/vol37/iss1/3/>

Venot A, Burgun A, Quantin C (eds) (2014) *Medical informatics, e-health: Fundamentals and applications*. Springer Verlag, Paris. doi:10.1007/978-2-8178-0478-1

Weaver CA, Ball MJ, Kim GR, Kiel JM (eds) (2016) *Healthcare information management systems: Cases, strategies and solutions*, 4th edn. Springer International Publishing, Geneva. doi:10.1007/978-3-319-20765-0

Wilson V, Djasasbi S (2015) Human-computer interaction in health and wellness: Research and publication opportunities. *AIS Transactions on Human-Computer Interaction* 7 (3):97-108. Retrieved from <http://aisel.aisnet.org/thci/vol7/iss3/1/>

Zuccon G, Palotti J, Goeriot L, Kelly L, Lupu M, Pecina P, Mueller H, Budaher J, Deacon A (2016) The IR task at the CLEF eHealth evaluation lab 2016: User-centred health information retrieval. Paper presented at the CLEF 2016-Conference and Labs of the Evaluation Forum, Evora, Portugal. Retrieved from <http://ceur-ws.org/Vol-1609/16090015.pdf>

## **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 (Gallivan and Tao 2014; Guise et al. 2014).

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 (DeShazo et al. 2009; Weigel et al. 2013). To do a thorough search of the literature thus requires you to consult

the major databases in both fields (Urquhart and Currell, 2016), and to use a multiplicity of search terms. The field of health technology assessment offers some parallels (Pfadenhauer et al. 2016).

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	<a href="https://www.cadth.ca/reports">https://www.cadth.ca/reports</a>
National Technical Reports Library USA	Use keywords to search a comprehensive collection of government-sponsored research	<a href="https://ntrl.ntis.gov/NTRL/">https://ntrl.ntis.gov/NTRL/</a>
Primary Health Care Research & Information Service Australia	Outlines a method for manual searching	<a href="http://www.phcris.org.au/guides/grey_literature.php">http://www.phcris.org.au/guides/grey_literature.php</a>
Consulting companies		
Accenture Consulting Health	Blogs and reports	<a href="https://www.accenture.com/au-en/health-industry-index">https://www.accenture.com/au-en/health-industry-index</a>
Ernst and Young	“Health reimaged: A new participatory health paradigm” report, 2016	<a href="http://www.ey.com/au/en/industries/health/">http://www.ey.com/au/en/industries/health/</a>
Gartner Group	“Hype Cycles” for Telemedicine, Healthcare Provider Applications, Analytics and Systems, AND Healthcare Provider Technologies and Standards	<a href="http://www.gartner.com/technology/consulting/healthcare-providers.jsp">http://www.gartner.com/technology/consulting/healthcare-providers.jsp</a>
Government and non-government agencies		
Austrade	Digital Health. Health IT Industry Capability Report, 2016	<a href="http://www.austrade.gov.au/ArticleDocuments/2814/Digital%20Health.%20Industry%20Capability%20Report.pdf.aspx">http://www.austrade.gov.au/ArticleDocuments/2814/Digital Health. Industry Capability Report.pdf.aspx</a>
Capital Markets Cooperative Research Centre	“Flying blind” Australian consumers and digital health report, 2016	<a href="https://flyingblind.cmrc.com/">https://flyingblind.cmrc.com/</a>

National Broadband Network	Health blog	<a href="http://www.nbnco.com.au/blog/health">http://www.nbnco.com.au/blog/health</a>
News aggregators		
Computer World	Healthcare IT news section	<a href="http://www.computerworld.com/category/healthcare-it/">http://www.computerworld.com/category/healthcare-it/</a>
European EHealth News		<a href="http://www.ehealthnews.eu/">http://www.ehealthnews.eu/</a>
Healthcare IT News		<a href="http://www.healthcareitnews.com/">http://www.healthcareitnews.com/</a>
Information Week	Healthcare IT news section	<a href="http://www.informationweek.com/healthcare.asp">http://www.informationweek.com/healthcare.asp</a>
Pulse+IT Magazine		<a href="http://www.pulseitmagazine.com.au">http://www.pulseitmagazine.com.au</a>
Industry interest groups		
Australasian TeleHealth Society		<a href="http://www.aths.org.au">http://www.aths.org.au</a>
Health Informatics Society of Australia		<a href="http://www.hisa.org.au">www.hisa.org.au</a>
Health Information and Management Systems Society		<a href="http://www.himss.org">http://www.himss.org</a>

Deshazo JP, Lavallie DL, Wolf FM (2009) Publication trends in the medical informatics literature: 20 years of "medical informatics" in MeSH. BMC Med Inform Decis Mak 9:7. doi:10.1186/1472-6947-9-7

Gallivan M, Tao Y (2014) Value of co-citation analysis for understanding a field's intellectual structure: An application to healthcare information technology (HIT) research. Paper presented at AMCIS 2014: Twentieth Americas Conference on Information Systems, Savannah, Georgia, USA. Retrieved from <http://aisel.aisnet.org/amcis2014/ResearchMethods/GeneralPresentations/3/>

Guisse JM, Chang C, Viswanathan M, Glick S, Treadwell J, Umscheid CA, Whitlock E, Fu R, Berliner E, Paynter R, Anderson J (2014) Systematic reviews of complex multicomponent health care interventions. Report 14-EHC003-EF. Agency for Healthcare Research and Quality, Rockville, MD

Pfadenhauer L, Rohwer A, Burns J, Booth A, Lysdahl KB, Hofmann B, Gerhardus A, Mozygemba K, Tummers M, Wahlster P, Rehfuss E (2016) Guidance for the assessment of context and implementation in health technology assessments (HTA) and systematic reviews of complex interventions: The context and implementation of complex interventions (CICI) framework project report. Retrieved from <http://www.integrate-hta.eu/downloads>

Urquhart C, Currell R (2016) Systematic reviews and meta-analyses of health it. In: Ammenwerth E, Rigby M (eds) Evidence-based health informatics. IOS Press, Amsterdam, p 262-274. doi:10.3233/978-1-61499-635-4-262

Weigel FK, Rainer RK, Hazen BT, Cegielski CG, and Ford FN (2013) Uncovering research opportunities in the medical informatics field: A quantitative content analysis. Communications of the Association for Information Systems 33:15-32. Retrieved from <http://aisel.aisnet.org/cais/vol33/iss1/2>

### 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://ereseach.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 (Rosenbloom 2016). In general, research methodologies are still immature in this area, and thought-provoking accounts are worth weighing up before you wade in (for example Clark et al. 2015; Gray 2016; Lupton 2016; Taylor and Mandl 2015; Winickoff et al. 2016). 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 Ajorlou et al. 2015; Gachet Paez et al. 2016). A few analytics research approaches envisage fuller engagement with the patients whose data are under study (for example Khan et al. 2015). There are particular challenges in enabling active patient participation in analytics research (touched on by Cohen et al. 2014; Koster et al. 2016; Weiser et al. 2015; and the subject of a popular work by Tailor 2015).

Ajorlou S, Shams I, Yang K (2015) An analytics approach to designing patient centered medical homes. *Health Care Manage Sci* 18 (1):3-18. doi:10.1007/s10729-014-9287-x

Clark K, Duckham M, Guillemin M, Hunter A, McVernon J, O'Keefe C, Pitkin C, Prawer S, Sinnott R, Warr D, Waycott J (2015) Guidelines for the ethical use of digital data in human research. University of Melbourne, Parkville, Vic.

Cohen IG, Amarasingham R, Shah A, Xie B, Lo B (2014) The legal and ethical concerns that arise from using complex predictive analytics in health care. *Health Aff (Millwood)* 33 (7):1139-1147. doi:10.1377/hlthaff.2014.0048

Gachet Páez D, Morales Botello ML, Puertas E, de Buenaga M (2016) Health sensors information processing and analytics using big data approaches. In: Mandler B (ed) Internet of things. IoT infrastructures: Second international summit. Revised selected papers, part 1. Springer International Publishing, Cham, p 481-486. doi:10.1007/978-3-319-47063-4\_52

Gray K (2016) Like, comment, share: Should you share your genetic data online? *Australasian Science* 37 (6):24. Retrieved from <http://www.australasianscience.com.au/article/issue-julyaugust-2016/comment-share-should-you-share-your-genetic-data-online.html>

Khan WA, Idris M, Ali T, Ali R, Hussain S, Hussain M, Amin MB, Khattak AM, Weiwei Y, Afzal M, Lee S, Kang BH (2015) Correlating health and wellness analytics for personalized decision making. Paper presented at 17th International Conference on E-health Networking, Application & Services (HealthCom). doi:10.1109/HealthCom.2015.7454508

Koster J, Stewart E, Kolker E (2016) Health care transformation: A strategy rooted in data and analytics. *Acad Med* 91 (2):165-167. doi:10.1097/ACM.0000000000001047



Lupton D (2016) Digital health technologies and digital data: New ways of monitoring, measuring and commodifying human bodies. In: Olleros FX, Zhegu M (eds) Research handbook on digital transformations. Edward Elgar Publishing, London, p 85-102. doi:10.4337/9781784717766.00011

Rosenbloom ST (2016) Person-generated health and wellness data for health care. J Am Med Inform Assoc 23 (3):438-439. doi:10.1093/jamia/ocw059

Tailor K (2015) The patient revolution: How big data and analytics are transforming the health care experience. Wiley, Hoboken, NJ

Taylor PL, Mandl KD (2015) Leaping the data chasm: Structuring donation of clinical data for healthcare innovation and modeling. Harvard Health Policy Rev 14 (2):18-21

Weiser P, Ellis A, Silicon Flatirons Center (2015) The information revolution meets health: The transformative power and implementation challenges of health analytics. SSRN. doi:10.2139/ssrn.2593879

Winickoff DE, Jamal L, Anderson NR (2016) New modes of engagement for big data research. Journal of Responsible Innovation 3 (2):169-177. doi:10.1080/23299460.2016.1190443

### 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 Bergmo 2015; Eslami Andargoli et al. 2017; Jacobs and Graham 2016; Kumar et al. 2013; McGee-Lennon et al. 2017; Murray et al. 2016; WHO 2016). Less abundant but equally important are methods for doing implementation research (for example Chaudoir et al. 2013; Ross et al. 2016).

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](http://www.nihpromis.com). The many other ways of eliciting patient health effects include narratives (Grob et al. 2016) and activation measures (Hibbard et al. 2004). 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 Barell et al. 2013; Sawesi et al. 2016).

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 Albert and Tullis 2013; Klein 2013; Sauro 2016).



[Albert W, Tullis T \(2013\) Measuring the user experience: Collecting, analyzing and presenting usability metrics, 2nd edn. Morgan Kaufmann, Burlington, MA](#)

[Barello S, Triberti S, Graffigna G, Libreri C, Serino S, Hibbard J, Riva G \(2016\) eHealth for patient engagement: A systematic review. Front Psychol 6:2013. doi:10.3389/fpsyg.2015.02013](#)

[Bergmo TS \(2015\) How to measure costs and benefits of eHealth interventions: An overview of methods and frameworks. J Med Internet Res 17 \(11\):e254. doi:10.2196/jmir.4521](#)

[Chaudoir SR, Dugan AG, Barr CH \(2013\) Measuring factors affecting implementation of health innovations: A systematic review of structural, organizational, provider, patient, and innovation level measures. Implement Sci : IS 8:22-5908-5908-5922. doi:10.1186/1748-5908-8-22](#)

[Eslami Andargoli A, Scheepers H, Rajendran D, Sohal A \(2017\) Health information systems evaluation frameworks: A systematic review. Int J Med Inform 97:195-209. doi:10.1016/j.ijmedinf.2016.10.008](#)  
[Grob R, Schlesinger M, Parker AM, Shaller D, Barre LR, Martino SC, Finucane ML, Rybowski L, Cerully JL \(2016\) Breaking narrative ground: Innovative methods for rigorously eliciting and assessing patient narratives. Health Serv Res 51 Suppl 2:1248-1272. doi:10.1111/1475-6773.12503](#)

[Hibbard JH, Stockard J, Mahoney ER, Tusler M \(2004\) Development of the Patient Activation Measure \(PAM\): Conceptualizing and measuring activation in patients and consumers. Health Serv Res 39 \(4 Pt 1\):1005-1026. doi:10.1111/j.1475-6773.2004.00269.x](#)

[Jacobs MA, Graham AL \(2016\) Iterative development and evaluation methods of mHealth behavior change interventions. Curr Opin Psychol 9:33-37. doi: 10.1016/j.copsyc.2015.09.001](#)

[Klein L \(2013\) Ux for lean start-ups: Faster, smarter user experience research and design. O'Reilly Media, Sebastopol, CA](#)

[Kumar S, Nilsen WJ, Abernethy A, Atienza A, Patrick K, Pavel M, Riley WT, Shar A, Spring B, Spruijt-Metz D, Hedeker D, Honavar V, Kravitz R, Lefebvre RC, Mohr DC, Murphy SA, Quinn C, Shusterman V, Swendeman D \(2013\) Mobile health technology evaluation: The mHealth evidence workshop. Am J Prev Med 45 \(2\):228-236. doi:10.1016/j.amepre.2013.03.017](#)

[McGee-Lennon M, Bouamrane M, Grieve E, O'Donnell CA, O'Connor S, Agbakoba R, Devlin A \(2017\) A flexible toolkit for evaluating person-centred digital health and wellness at scale. In: Duffy VG, Lightner N \(eds\) Advances in Human Factors and Ergonomics in Healthcare: Proceedings of the AHFE 2016 International Conference on Human Factors and Ergonomics in Healthcare, Walt Disney World, Florida, USA. Springer International Publishing, Cham, p 105-118. doi:10.1007/978-3-319-41652-6\\_11](#)

[Murray E, Hekler EB, Andersson G, Collins LM, Doherty A, Hollis C, Rivera DE, West R, Wyatt JC \(2016\) Evaluating digital health interventions: Key questions and approaches. Am J Prev Med 51 \(5\):843-851. doi:10.1016/j.amepre.2016.06.008](#)

[Ross J, Stevenson F, Lau R, Murray E \(2016\) Factors that influence the implementation of e-health: A systematic review of systematic reviews \(an update\). Implement Sci 11\(1\):146. doi:10.1186/s13012-016-0510-7](#)

Sauro J (2016) The challenges and opportunities of measuring the user experience. J Usability Stud 12 (1):1-7. Retrieved from <http://uxpajournal.org/challenges-opportunities-measuring-user-experience/>

Sawesi S, Rashrash M, Phalakornkule K, Carpenter JS, Jones JF (2016) The impact of information technology on patient engagement and health behavior change: A systematic review of the literature. JMIR medical informatics 4 (1):e1. doi:10.2196/medinform.4514

World Health Organisation (2016) Monitoring and evaluating digital health interventions: A practical guide to conducting research and assessment. WHO, Geneva. Retrieved from <http://www.who.int/reproductivehealth/publications/mhealth/digital-health-interventions/en/>

### 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 Peterson 2015). 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>.

Petersen C, DeMuro P (2015) Legal and regulatory considerations associated with use of patient-generated health data from social media and mobile health (mHealth) devices. *Appl Clin Inform* 6 (1):16-26. doi:10.4338/ACI-2014-09-R-0082

### 3.6 Writing up and reporting digital health research

The range of journal, conference and monograph resources cited in this paper 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. The following papers may help you to describe formally all of the important elements of your digital research project:

Agarwal S, LeFevre AE, Lee J, L'Engle K, Mehl G, Sinha C, Labrique A, WHO mHealth Technical Evidence Review Group (2016) Guidelines for reporting of health interventions using mobile phones: Mobile health (mHealth) evidence reporting and assessment (mERA) checklist. *BMJ* 352:i1174. doi:10.1136/bmj.i1174

Ammenwerth E, de Keizer NF (2016) Publishing health IT evaluation studies. In: Ammenwerth E, Rigby M (eds) *Evidence-based health informatics: Promoting safety and efficiency through scientific methods and ethical policy*. IOS Press, Amsterdam, p 304-311. doi:10.3233/978-1-61499-635-4-304

Brender J, Talmon J, de Keizer N, Nykanen P, Rigby M, Ammenwerth E (2013) STARE-HI - statement on reporting of evaluation studies in health informatics: Explanation and elaboration. *Appl Clin Inform* 4 (3):331-358. doi:10.4338/ACI-2013-04-RA-0024

Eysenbach G (2004) Improving the quality of web surveys: The checklist for reporting results of internet e-surveys (CHERRIES). *J Med Internet Res* 6 (3):e34. doi: 10.2196/jmir.6.3.e34

Eysenbach G, Group C-E (2011) CONSORT-EHEALTH: Improving and standardizing evaluation reports of web-based and mobile health interventions. *J Med Internet Res* 13 (4):e126. doi:10.2196/jmir.1923

Khanal S, Burgon J, Leonard S, Griffiths M, Eddowes LA (2015) Recommendations for the improved effectiveness and reporting of telemedicine programs in developing countries: Results of a systematic literature review. *Telemed J E Health* 21 (11):903-915. doi:10.1089/tmj.2014.0194

Niederstadt C, Droste S (2010) Reporting and presenting information retrieval processes: The need for optimizing common practice in health technology assessment. *Int J Technol Assess Health Care* 26 (4):450-457. doi:10.1017/S0266462310001066

#### 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

Apple HealthKit. Retrieved from <https://developer.apple.com/healthkit/>

Armstrong S (2016) What happens to data gathered by health and wellness apps? *BMJ* 353:i3406. doi:10.1136/bmj.i3406

Australia. Therapeutic Goods Administration (2013) Regulation of medical software and mobile medical 'apps'. Retrieved from <https://www.tga.gov.au/node/4316>

BinDhim NF, Trevena L (2015) Health-related smartphone apps: Regulations, safety, privacy and quality. *BMJ Innov* 1 (2):43-45. doi:10.1136/bmjinnov-2014-000019

Boulos MN, Brewer AC, Karimkhani C, Buller DB, Dellavalle RP (2014) Mobile medical and health apps: State of the art, concerns, regulatory control and certification. *Online J Public Health Inform* 5 (3):229. doi:10.5210/ijphi.v5i3.4814

Cerner CODE (2016). Retrieved from <http://www.healthcareitnews.com/news/cerner-launches-open-platform-spur-development-smart-fhir-apps>

Chindalo P, Karim A, Brahmbhatt R, Saha N, Keshavjee K (2016) Health apps by design: A reference architecture for mobile engagement. *Internat J Handheld Comput Res* 7 (2):34-43. doi:10.4018/IJHCR.2016040103

Dialogue Consulting. (2015). Guidelines for developing healthy living apps. VicHealth. Retrieved from <https://www.vichealth.vic.gov.au/media-and-resources/app-developers>

Heffernan KJ, Chang S, Maclean ST, Callegari ET, Garland SM, Reavley NJ, Varigos GA, Wark JD (2016) Guidelines and recommendations for developing interactive ehealth apps for complex messaging in health promotion. *JMIR Mhealth Uhealth* 4 (1):e14. doi:10.2196/mhealth.4423

Hillebrand U, von Jan U, Albrecht UV (2016) Concepts for quality assurance of health related apps. *Stud Health Technol Inform* 226:209-212. doi:10.2196/mhealth.4423

Martinez-Perez B, de la Torre-Diez I, Lopez-Coronado M (2015) Privacy and security in mobile health apps: A review and recommendations. *J Med Syst* 39 (1):181-014-0181-0183. doi:10.1007/s10916-014-0181-3

Research2Guidance. (2016). mHealth app developer economics 2016: The current status and trends of the mHealth app market. Retrieved from <http://research2guidance.com/r2g/r2g-mHealth-App-Developer-Economics-2016.pdf>

Schnall R, Rojas M, Bakken S, Brown W, Carballo-Dieguez A, Carry M, Gelaude D, Mosley JP, Travers J (2016) A user-centered model for designing consumer mobile health (mHealth) applications (apps). *J Biomed Inform* 60:243-251. doi:10.1016/j.jbi.2016.02.002

SMART - an app platform for healthcare. Boston Children's Hospital Computational Health Informatics Program; Harvard Medical School Department for Biomedical Informatics, Boston. Retrieved from <http://smarthealthit.org/an-app-platform-for-healthcare/about/>

Stoyanov SR, Hides L, Kavanagh DJ, Zelenko O, Tjondronegoro D, Mani M (2015) Mobile app rating scale: A new tool for assessing the quality of health mobile apps. *JMIR mHealth uHealth* 3 (1):e27. doi:10.2196/mhealth.3422

UK National Health Service (2014) App development: An NHS guide to developing mobile healthcare applications. NHS Innovations South East. Retrieved from [http://www.innovationsoutheast.nhs.uk/index.php/download\\_file/view/45](http://www.innovationsoutheast.nhs.uk/index.php/download_file/view/45)

#### **4.3 Health social media**

Abbasi A, Adjero D, Dredze M, Paul MJ, Zahedi FM, Zhao H, Walia N, Jain H, Sanvanson P, Shaker R, Huesch MD, Beal R, Zheng W, Abate M, Ross A (2014) Social media analytics for smart health. *IEEE Intelligent Systems* 29 (2):60. doi:10.1109/MIS.2014.29

Ben-Harush O, Carroll J-A, Marsh B (2012) Using mobile social media and GIS in health and place research. *Continuum* 26 (5):715-730. doi:10.1080/10304312.2012.706460

Bond CS, Ahmed OH, Hind M (2014) Implications for research methods when conducting studies with the users of online health communities. *Comput Inform Nurs* 32 (3):101-104. doi:10.1097/CIN.0000000000000049

Bradley M, Braverman J, Harrington M, Wicks P (2016) Patients' motivations and interest in research: Characteristics of volunteers for patient-led projects on PatientsLikeMe. *Research Involvement and Engagement* 2 (1):33. doi:10.1186/s40900-016-0047-6

Capurro D, Cole K, Echavarria MI, Joe J, Neogi T, Turner AM (2014) The use of social networking sites for public health practice and research: A systematic review. *J Med Internet Res* 16 (3):e79. doi:10.2196/jmir.2679

Cyrus JW (2014) A review of recent research on internet access, use, and online health information seeking. *J Hosp Librariansh* 14 (2):149-157. doi:10.1080/15323269.2014.888630

Ekberg J, Gursky EA, Timpka T (2014) Pre-launch evaluation checklist for online health-promoting communities. *J Biomed Inform* 47:11-17. doi:10.1016/j.jbi.2013.10.004

Heidelberg CA, El-Gayar O, Sarnikar S (2011) Online health social networks and patient health decision behavior: A research agenda. Paper presented at the 44th Hawaii International Conference on System Sciences, New York. doi:10.1109/HICSS.2011.328

Ho K, Peter Wall Workshop P (2014) Harnessing the social web for health and wellness: Issues for research and knowledge translation. *J Med Internet Res* 16 (2):e34. doi:10.2196/jmir.2969

Ji X, Chun SA, Cappellari P, Geller J (2016) Linking and using social media data for enhancing public health analytics. *J Inform Sci (Online First)*:1-25. doi:10.1177/0165551515625029

Kim Y, Huang J, Emery S (2016) Garbage in, garbage out: Data collection, quality assessment and reporting standards for social media data use in health research, infodemiology and digital disease detection. *J Med Internet Res* 18 (2):e41. doi:10.2196/jmir.4738

Martínez P, Martínez JL, Segura-Bedmar I, Moreno-Schneider J, Luna A, Revert R (2016) Turning user generated health-related content into actionable knowledge through text analytics services. *Natural Language Processing and Text Analytics in Industry* 78:43-56. doi:10.1016/j.compind.2015.10.006

McKee R (2013) Ethical issues in using social media for health and health care research. *Health Policy* 110 (2-3):298-301. doi:10.1016/j.healthpol.2013.02.006

Merolli MA (2015) Participatory health through social media in chronic disease: A framework for research and practice. Dissertation (PhD), Melbourne Medical School. Retrieved from <http://hdl.handle.net/11343/57017>

Merolli M, Sanchez FJM, Gray K (2014) Social media and online survey: Tools for knowledge management in health research. Paper presented at HKM '14 Proceedings of the Seventh Australasian Workshop on Health Informatics and Knowledge Management, Auckland, New Zealand pp. 21-29. Retrieved from [www.crpit.com/confpapers/CRPITV153Merolli.pdf](http://www.crpit.com/confpapers/CRPITV153Merolli.pdf)

Mitra S, Padman R, Yang H, Lee EK (2016) Understanding the role of social media in healthcare via analytics: A health plan perspective. In: Yang H, Lee EK (eds) *Healthcare analytics: From data to knowledge to healthcare improvement*. John Wiley & Sons, Hoboken, NJ, p 555-587. doi:10.1002/9781118919408.ch19

Murray PJ, Wright G Towards a research agenda for web 2.0 and social media in health and informatics. Paper presented at the 4th WSU – International Research Conference, East London, South Africa, 2014. Walter Sisulu University, p 89-98.



Myneni S, Iyengar S (2016). Socially influencing technologies for health promotion: Translating social media analytics into consumer-facing health solutions. Paper presented at the 49th Hawaii International Conference on System Sciences (HICSS). doi:10.1109/HICSS.2016.388

Neighbors C, Lewis MA (2016) Editorial overview: Status update: Current research on social media and health. *Curr Opin Psychol* 9:iv-vi. doi:10.1016/j.copsyc.2016.04.021

Smith BG, Smith SB (2015) Engaging health: Health research and policymaking in the social media sphere. AcademyHealth, Washington, DC. Retrieved from <http://www.academyhealth.org/publications/2015-04/engaging-health-health-research-and-policy-making-social-media-sphere>

Straton N, Hansen K, Mukkamala R, Hussain A, Grønli T, Langberg H, Vatrapu R (2016). Big social data analytics for public health: Facebook engagement and performance. Paper presented at HealthCom '16: 18th IEEE International conference on e-Health networking, applications and services, Munich, Germany, 2016. doi:10.1109/HealthCom.2016.7749497

Taylor HA, Kuwana E, Wilfond BS (2014) Ethical implications of social media in health care research. *Am J Bioeth* 14 (10):58-59. doi:10.1080/15265161.2014.947820

Thirumalai M, Ramaprasad A (2015) Ontological analysis of the research on the use of social media for health behavior change. Paper presented at the 48th Hawaii International Conference on System Sciences. doi:10.1109/HICSS.2015.103

#### **4.4 Healthcare wearables**

Almalki M, Gray K, Martin-Sanchez F (2016) Activity theory as a theoretical framework for health self-quantification: A systematic review of empirical studies. *J Med Internet Res* 18 (5):e131. doi:10.2196/jmir.5000

Almalki M, Gray K, Martin-Sanchez FJ (2017) Refining the concepts of self-quantification needed for health self-management. A thematic literature review. *Methods Inf Med* 56 (1):46-54. doi:10.3414/ME15-02-0007

Banaee H, Ahmed MU, Loutfi A (2013) Data mining for wearable sensors in health monitoring systems: A review of recent trends and challenges. *Sensors (Basel)* 13 (12):17472-17500. doi:10.3390/s131217472

Casper GR, McDaniel A (2015) Introduction to theme issue on technologies for patient-defined and patient-generated data. *Pers Ubiquitous Comput* 19 (1):1-2. doi:10.1007/s00779-014-0803-2

Chiauzzi E, Rodarte C, DasMahapatra P (2015) Patient-centered activity monitoring in the self-management of chronic health conditions. *BMC Med* 13:77-015-0319-0312. doi:10.1186/s12916-015-0319-2

Choe EK, Lee NB, Lee B, Pratt W, Kientz JA (2014) Understanding quantified-selfers' practices in collecting and exploring personal data. Paper presented at the SIGCHI Conference on Human Factors in Computing Systems, Toronto, Ontario. doi:10.1145/2556288.2557372

Custodio V, Herrera FJ, Lopez G, Moreno JI (2012) A review on architectures and communications technologies for wearable health-monitoring systems. *Sensors (Basel)* 12 (10):13907-13946. doi:10.3390/s121013907

De Mooy M, Yuen S Towards privacy-aware research and development in wearable health (2017) Paper presented at the 50th Hawaii International Conference on System Sciences (HICSS), 2017. Retrieved from <http://hdl.handle.net/10125/41600>

Deering MJ (2013) ONC issue brief: Patient-generated health data and health IT. Office of the National Coordinator for Health Information Technology. Retrieved from [https://www.healthit.gov/sites/default/files/pghd\\_brief\\_final122013.pdf](https://www.healthit.gov/sites/default/files/pghd_brief_final122013.pdf)

Gray K, Martin-Sanchez FJ, Lopez-Campos GH, Almalki M, Merolli M (2017) Person-generated data in self-quantification: A health informatics research program. *Methods Inf Med* 56 (1):40-45. doi:10.3414/ME15-02-0006

Kumara S, Cui L, Zhang J (2011) Sensors, networks and internet of things: Research challenges in health care. Paper presented at IIWeb '11: 8th International Workshop on Information Integration on the Web in conjunction with WWW 2011, Hyderabad, India. doi:10.1145/1982624.1982626

Piras EM, Ellingsen G (2016) International workshop on infrastructures for health care: Patient-centered care and patient generated data. *J Particip Med* 8:e4. Retrieved from <http://www.jopm.org/media-watch/2016/03/23/international-workshop-on-infrastructures-for-health-care-patient-centered-care-and-patient-generated-data/>

Rich E, Miah A (2017) Mobile, wearable and ingestible health technologies: Towards a critical research agenda. *Health Sociol Rev* 26 (1):84-97. doi:10.1080/14461242.2016.1211486

Shapiro M, Johnston D, Wald J, Mon D (2012) Patient-generated health data: White paper. RTI International, Research Triangle Park, NC. Retrieved from <https://www.rti.org/publication/patient-generated-health-data-white-paper>

Woods SS, Evans NC, Frisbee KL (2016) Integrating patient voices into health information for self-care and patient-clinician partnerships: Veterans Affairs design recommendations for patient-generated data applications. *J Am Med Inform Assoc* 23 (3):491-495. doi:10.1093/jamia/ocv199

[END]