Digital Health Research Review

Making Education Easy

Issue 4 - 2017

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Abbreviations used in this issue app = application GP = general practitioner OR = odds ratio PAEHRs = patient-accessible electronic health records

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MERRY CHRISTMAS AND A HEALTHY, HAPPY 2018!



Welcome to the fourth issue of Digital Health Research Review. First up we take a look at an interesting study analysing national patient-accessible electronic health records policy and services in Australia,

look at an interesting study analysing national patient-accessible electronic health records policy and services in Australia, Denmark, Estonia, Finland, France, the Netherlands, New Zealand, Norway, Sweden and the United States, and discover that all 10 countries regulated some level of patient access to medical records, but policies, systems and technological processes were highly variable. Following on, we discover that connecting with and leveraging social media provides an opportunity to enhance health care, drug development, clinical trial recruitment, and drug therapy administration and adherence. Also in this issue we review studies on a smartphone app that maps social connectivity and mental health, mapping health events during travel, determinants of sustained activity tracker use, app records of menstrual cycle and ovulation timing, support for families caring for a child with cancer, MapMe body image scales, global reach and value of a provider-facing healthcare app, and framework to inform and evaluate technology-supported health programmes. We hope you find our selection for Digital Health Research Review stimulating reading and we welcome your feedback. Furthermore, if you have discovered or been involved with what you think is significant global research in this area, please let us know and we will consider it for inclusion next time.

I would like to thank Karen Day, Rosie Dobson and Gayl Humphrey for their contribution to this issue of Digital Health Research Review.

Kind regards, Dr Robyn Whittaker

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Patient access to electronic health records: Differences across ten countries

Authors: Essén A et al.

Summary: This study analysed national patient-accessible electronic health records (PAEHRs) policy and services in Australia, Denmark, Estonia, Finland, France, the Netherlands, New Zealand, Norway, Sweden and the United States. All 10 countries regulated some level of patient access to medical records; however, policies, systems and technological processes were highly variable. Particularly variable were login procedures (security), adolescent access to data (user rights), and medical data types available to the patient (data sets).

Comment (RW): This paper provides an interesting insight into the different ways patients get access to their digital health records in 10 countries. Not only are there differences in mandatory requirements, access methods, and the data that are made accessible, but some of the other learnings are also useful. Provider adherence to policy on providing data is a key issue regardless of whether this is mandatory or opt in, automatic data transfer from electronic health records (EHRs) to PAEHRs facilitates systematic engagement in other countries. Not deliberately considering access of parents and children to their records in adolescence can lead to issues in managing their health. Sweden has developed forums where healthcare professionals and patients can provide input into the development of PAEHR systems and regulations. This paper calls for more open dissemination of practices and collaboration between countries, as New Zealand commences the journey towards a national electronic health record, learning from the successes and difficulties experienced in other countries will be extremely valuable and may prevent us from making mistakes.

Reference: Health Policy Tech. 2017;Nov 20 [Epub ahead of print] Abstract

Independent commentary by Karen Day, Robyn Whittaker, Rosie Dobson and Gayl Humphrey

Dr Robyn Whittaker is an Associate Professor at the National Institute for Health Innovation at the University of Auckland, where her research has been about developing and trialling mHealth (using mobile communications technologies) interventions. She is also a Public Health Physician leading the implementation of innovations, including digital health technologies at Waitemata District Health Board.

Karen Day, PhD, FACHI, is Programme Director for postgraduate studies in health informatics. Her research spans telehealth, patient portals, evaluation of digital health implementations, and focuses on the patient's experience of using information technologies for self-care of long-term health issues.

Rosie Dobson is a Health Psychologist working at the National Institute for Health Innovation at the University of Auckland. Her research looks at the use of mobile technology to support behaviour change and disease management. Currently she is involved in SMS-based programmes in the fields of maternal health and diabetes.

Gayl Humphrey is the Co-Lead for the Health Informatics and Technology Programme at the National Institute for Health Innovation, University of Auckland. Gayl's interest and experience in research and evaluation is on the use of technologies as enablers to support and enhance health outcomes across the health continuum.

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"I'm home(screen)!": Social media in health care has arrived

Authors: Housman LT

Summary: This commentary suggests that healthcare app usage is increasing, with 32% of US consumers having at least one health app on a smartphone or tablet. Mobile health care apps are used for managing health care services and health and wellness. Connecting with and leveraging social media provides an opportunity to enhance health care, drug development, clinical trial recruitment, and drug therapy administration and adherence.

Comment (KD): In this commentary the author not only claims that social media has arrived in health, but that it takes many forms and users are ahead of healthcare professionals and application developers in adoption, adaptation, and persistent use. Some tools, such as WebMD (a website also available on smart phones as an app) and MediSafe (a medication app for smartphones), have become predicable aspects of a person's search for a diagnosis and assistance in applying a treatment. The boundaries are blurring between websites, microblogs (e.g. Twitter), image apps (e.g. Instagram), social connecting tools (e.g. Facebook) and the Internet of Things. What are the implications of this massive adoption of technologies in the health arena? How people interact with their healthcare professionals is changing, they check their symptoms, look up information, and try to make sense of their health issue before discussing with their GP. Telemonitoring has traditionally been initiated by health services, but will in the future be initiated by people who perceive a need for their own monitoring. Apps, websites and blogs need to be maintained and evaluated better, and medical grade wearables should be made available at affordable prices for people to select with or without guidance from their healthcare professionals. This could be the closest we can get (for now) to patient-centred care.

Reference: Clin Ther. 2017;39(11):2189-95

Abstract

Smartphone app to investigate the relationship between social connectivity and mental health

Authors: Boonstra TW et al.

Summary: This feasibility study used passive smartphone monitoring in 63 participants to map social networks based on proximity (Bluetooth data), in order to analyse relationships between social-network metrics and mental health. Social networks estimated from Bluetooth data suggested that 95% of the edges were scanned every 30 minutes. Most participants accepted this data collection method and indicated they would participate in future studies using this app.

Comment (KD): This research article presents a social network tracking app that can be downloaded onto smartphones to track interactions between people in close proximity with one another (0-5 m), using Bluetooth. Social interaction (or isolation) influences a person's experience of depression. Self-reporting about social interaction is often biased and flawed. The app was built to measure the degree of interaction for people affected by depression, without the user having to report anything or enter any data other than to complete the Patient Health Questionnaire 9-item depression scale (PHQ-9) and 7-item Generalised Anxiety Disorder scale (GAD-7). This article reports on the validation of the app for research. This app could open up new insights into how people who are affected by depression and/or anxiety interact with others as their mental health ebbs and flows. These new insights could influence how healthcare professionals and patients co-design treatment and crisis plans, and prevent social isolation that could lead to suicidality.

Reference: Conf Proc IEEE Eng Med Biol Soc. 2017;287-90 Abstract

Streaming data from a smartphone application: A new approach to mapping health during travel

Authors: Farnham A et al.

Summary: This prospective cohort study describes spatial and environmental patterns in health using smartphone data from 101 travelers to Thailand. 74.3% of participants completed the study and completed 940 daily questionnaires; 796 geolocated to Southeast Asia. 20.0% of participants experienced accidents, mainly occurring in the Thai islands, while mental health events self-rated as "severe" (21.3%) occurred most often in Bangkok. Health events occurred more frequently in Chiang Mai (OR 2.34; 95% Cl 1.08-5.08) and on rainy days (1.86; 95% Cl 1.03-3.36).

Comment (KD): This research study outlines how travel medicine can be expanded by means of an app on a smartphone. Since the phone is usually on and usually with a person, geotagging and surveys can be done in real time, enabling the collection of nuanced contextual environmental and personal health data, e.g. where a traveller is, information about accidents, drug use, and symptoms of illness (stomach cramps, itchy mosquito bites). This enables travel advice on a much more granular level and in real time. The app was tested unidirectionally (collecting data), but in the future can be used to respond with advice or guidelines to reported health issues. What does this mean for everyday healthcare practice? On a population health level, the nuanced data collection and analysis could inform travel guidelines, providing evidence about aspects of health that are currently not available, e.g. why certain areas are deemed safe by common sense. When a traveller returns home and seeks medical assistance that relates to an illness acquired while travelling, the data collected in the app can be used to assist with diagnosis and treatment in ways not currently available. For now, the app promises to provide new insights into environmental and personal health factors that affect the experiences of travellers.

Reference: Travel Med Infect Dis. 2017;Nov 15 [Epub ahead of print] Abstract

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Determinants for sustained use of an activity tracker: **Observational study**

Authors: Hermsen S et al.

Summary: This French study in 711 participants examined determinants of sustained use of an activity tracker (Fitbit Zip) in the first year after purchase. A slow exponential decay in activity tracker use was identified; 73.9% of participants were still tracking activity after 100 days and 16.0% after 320 days. Participants used the tracker for an average of 129 days. The most common reasons for tracking failure were technical issues (empty batteries, broken or lost trackers) which occurred in 21.5% (130/601) of respondents after 232 days. Machine learning analysis (Random Forest) identified the most influential predictors of continued use were age, user experience-related factors, mobile phone type, household type, perceived effect, and goal-related factors.

Comment (RD): This is an interesting paper on the predictors of sustained use of activity trackers. Fitbit type trackers are popular throughout the population and provide an accessible tool for monitoring and feedback of exercise behaviour, which in turn can promote positive behaviour change. Like many behaviour change interventions sustainability is a key factor in their success in improving the health of their users. This study of over 700 users found that only about 50% were still using the device 6 months later and only 16% were still using it nearly a year later. Although exponential decay in use was seen, this was much slower than what has been reported with mobile apps. Factors such as age, personal behavioural goals and user experience were key predictors of sustained use. The most commonly reported reasons contributing to not using the device were technical problems including flat batteries, highlighting the importance of technological reliability for sustained use of this type of technology. The reliability of the technology needs to be considered before activity trackers and other similar devices are used in health research or recommended in clinical practice to ensure end users not only engage correctly with the devices, but get the intended benefits.

Reference: JMIR Mhealth Uhealth 2017;5(10):e164 Abstract

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Research Review publications are intended for New Zealand health professionals.

Relationship between the menstrual cycle and timing of ovulation revealed by new protocols: Analysis of data from a self-tracking health app

Authors: Sohda S et al.

Summary: This analysis of anonymised data from 7043 women with reliable menstrual and ovulation records (from 8,000,000 mobile phone app users), examined how to improve the accuracy of ovulation date prediction utilising the relationships between menstrual cycle length, follicular phase length, and luteal phase length fitted to a linear function and compared with the existing calendar-based methods. Length of menstrual cycle and length of follicular phase were more strongly correlated than length of menstrual cycle and length of luteal phase, and the lengths of past and future menstrual cycles were positively correlated. Mean length of past cycles and length of the follicular phase were also strongly correlated. The derived calendar-based optimised function method performed better that the Ogino method when predicting the next ovulation date and it was also superior to a prediction method using the middle day of a menstrual cycle as the ovulation date.

Comment (RD): For the many people using consumer apps to track and monitor their health, this paper provides insight into how their data can be (or may already be) used in research. The anonymised data from thousands of women using an app for tracking menstruation and ovulation has been used to improve the accuracy of ovulation predictions. The large dataset available from users of the app allowed for more detailed analysis than is usually possible from traditional methods. It highlights the opportunity that anonymised data from apps provide for researchers and clinicians. It also raises the question of how many consumers read the user agreements when downloading apps and are aware that their data will be used this way.

Reference: J Med Internet Res. 2017;19(11):e391 Abstract



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The Oncology Family App: Providing information and support for families caring for their child with cancer

Authors: Slater PJ et al.

Summary: This paper describes the process of developing and evaluating an 'Oncology Family App' mobile app in collaboration with parents, caregivers and clinicians in Queensland. The first version featured "Statewide Hospital Contacts"; When to Call" – symptoms to look for in a deteriorating child; "Blood Results Table"; and "Information" on websites, health care team contacts, appointments and notes.

Comment (RD): Finding cost-effective methods to link patients with support when they are at home is key, not only for reducing unnecessary stress and anxiety for patients and families, but also for reducing unnecessary visits to hospital. Apps are ideal for this purpose providing information and support wherever the person may be. The Oncology Family App provides management plans for a deteriorating child, patient-specific information, hospital contact information, and other resources. Although this has been provided previously in traditional methods (leaflets), having it available on a person's phone at all times is ideal in paediatric oncology where sudden onset of fever can require urgent medical input. Although not the only app available in this space, the positive feedback provided shows the value of these tools in providing convenient and accessible information and support.

Reference: J Pediatr Oncol Nurs. 2017;Nov 1 [Epub ahead of print] Abstract

Development of the MapMe intervention body image scales of known weight status for 4-5 and 10-11 year old children

Authors: Jones AR et al.

Summary: This study aimed to develop paediatric sex- and agespecific body image scales (BIS) using 3D surface body scans of children (4-5 years, n = 211; 10-11 years, n = 177), British growth reference (UK90) criteria from height and weight measurements, and qualitative sessions with 37 parents and health professionals. The BIS visual aid may help parents assess child weight status and support weight-management strategies.

Comment (GH): Finding ways to support parents, families and others to recognise when a child's weight is becoming unhealthy and how to make lifestyle changes is essential. The challenge is in correctly identifying overweight, especially in the context of a shifting normal towards heavier weight categories. Parents are more likely to use subjective approaches and visual assessments to judge their child's weight and health and are less able to see how that translates to objective measures such as growth charts, the normal tools used by health professionals to capture and track growth. This paper takes advantage of readily available technology and applies it to developing body image scales that are aligned to the evidence-based growth standards. The acceptability of these are seen as a first step in a new tool that could be used as a way to start conversations, raise awareness of the potential harms of a weight gain trajectory, and when aligned with other interventions, could be used as part of lifestyle change intervention. While this paper presents the beginning of a journey to explore body image scales as effective tools in influencing change, finding innovative solutions to address our growing obesity problem are needed. A possible outcome of this tool is that it has the potential to be personalised and customisable to the user, which, coupled with behavioural change, could help create opportunities for positive change.

Reference: J Public Health 2017;Nov 28 [Epub ahead of print] Abstract

Assessing the global reach and value of a providerfacing healthcare app using large-scale analytics

Authors: O'Reilly-Shah V et al.

Summary: Users of a free anaesthesia calculator app (n = 31,173) from 206 countries, representing a spectrum of healthcare provider roles, were recruited for this study and traditional app analytics with in-app surveys utilised to collect user demographics and feedback. The app was used primarily for paediatric cases and it was used around the clock, peaking during times typical for first start cases. Participants in low-income countries had greater rates of app use (p < 0.001) and ascribed greater importance of the app to their practice (p < 0.001), and physicians from such countries were more likely to adopt the app (p < 0.001).

Comment (GH): mHealth apps are growing exponentially and this paper provides a nice insight into the extent that large scale analytics can be used to explore uptake and use of apps (in this case an anaesthetic app). The paper discusses the importance of using a survey of users at the outset plus the large scale app analytics can enrich the understanding of who, when, where and how an app is adopted and used. In this paper the uptake of the anaesthetic app was found to be highly adopted in low- and middle-income countries, by users in remote and rural areas, and by a spectrum of professionals with anaesthetist assistants and nurses the large proportion of users. This level of granularity would not have been possible without the combination of a survey and app analytics. The authors conclude that the sophistication of these tools is such that exploring patient-level outcomes to ascertain more closely the effect of app usage on individual outcomes should be the next stage of investigation. The extent to which NZ is digitalised and continuing to digitalise health suggests that measuring the impact of apps on outcomes should be a key focus for mHealth apps here.

Reference: BMJ Glob Health 2017;2(3):e000299 Abstract

Beyond adoption: A new framework for theorizing and evaluating nonadoption, abandonment, and challenges to the scale-up, spread, and sustainability of health and care technologies

Authors: Greenhalgh T et al.

Summary: These authors produced an evidence-based, theory-informed and pragmatic framework to help predict and evaluate the success of a technology-supported health or social care programme. Utilising data sharing for up to 3 years across more than 20 organisations, they studied six technology-supported programmes; video outpatient consultations, global positioning system tracking for cognitive impairment, pendant alarm services, remote biomarker monitoring for heart failure, care organising software, and integrated case management. Their empirical dataset comprised of >400 hours of ethnographic observation, 165 semi-structured interviews, and 200 documents. A literature review also identified 28 previous technology implementation frameworks, 14 of which had taken a dynamic systems approach (including two integrative reviews of previous work). Their final non-adoption, abandonment, scale-up, spread, and sustainability (NASSS) framework comprised questions in seven domains: the condition or illness, the technology, the value proposition, the adopter system (comprising professional staff, patient, and lay caregivers), the organisation(s), the wider (institutional and societal) context, and the interaction and mutual adaptation between all these domains over time. Their empirical case studies raised a variety of challenges across all seven domains, each classified as simple (straightforward, predictable, few components), complicated (multiple interacting components or issues), or complex (dynamic, unpredictable, not easily disaggregated into constituent components). It was apparent that programmes characterised by complicatedness proved difficult, but not impossible to implement, while those characterised by complexity in multiple NASSS domains rarely, if ever, became mainstreamed. They concluded that NASSS could be applied across a range of technological innovations in health and social care. Potential uses of NASSS include: to inform the design of a new technology; to plan the implementation, scale-up, or rollout of a technology programme; to identify technological solutions that (perhaps despite policy or industry enthusiasm) have a limited chance of achieving large-scale, sustained adoption; and to explain and learn from programme failures.

Comment (GH): This paper is an important piece in the ongoing discourse of health technology pilots presenting good evidence but still resulting in a lack of sustained uptake and adoption into business as usual. The authors have distilled a large amount of information through extensive methodology modes to create a framework (NASSS) that aims to help inform and evaluate the success of technology-supported health programmes. The paper lays out nicely questions to use to assess each of the seven domains. They place each response into a matrix of Simple, Complicated and Complex, which then helps set the tone for assessing the difficulty a health technology programme may have in becoming embedded and sustained into service delivery. The authors highlight that the framework could be used retrospectively and prospectively. However they advocate that prospectively using it can inform the implementation and help with lining up the wider system variables that would be needed to support success. However, it is not a deterministic or formulaic tool where if you tick all the boxes you will have success. The authors suggest that the framework is more iterative and should be used to help identify the challenging domains (which will be different depending on the implementation programme) at a (preferably) early stage and therefore set a realistic plan for adoption, spread and sustainability, or contrarily, whether to embark on the programme at all.

Reference: J Med Internet Res. 2017;19(11):e367 Abstract