



Patient engagement in clinical research through mobile technology

Keywords: clinical research • mHealth • mobile applications • mobile devices • patient engagement • telehealth • wireless technology

Rapid innovation and the adoption of mobile, cellular and digital technologies are dramatically changing the face of the global healthcare industry. With the ubiquity of mobile devices in today's society, the impact of wireless technology in healthcare is multifaceted – promoting patient engagement, information sharing, and enhancing communication with providers. Perhaps most significant in wireless technology use in health is patient engagement. Patient engagement is defined as the active participation and actions patients take to reap the greatest benefits from the healthcare services and providers with whom they interact [1]. With the advent of mHealth, mobile and electronic health information technology that emphasizes shared decision-making and personal responsibility [2], mobile applications and devices are becoming well suited for use in chronic illnesses where patterns of health change may be gradual and subtle, but also often the best means of long-term management. As the application of the quantified self, a movement aiming to improve health and self through daily self-monitoring and recording [3], takes roots in the era of mobile health, the role of patient engagement and clinical research through mobile technology will blossom.

Researchers and patients have been increasingly engaged by the advent of wearable monitoring devices and the scope offered by these. Personal devices available for health and fitness maintenance and monitoring are changing the face of fitness in today's society, engaging participants daily [4], and form-

ing a platform for the launch of new clinical research projects. Extension of wearable monitoring devices for health applications in clinical research is now a growing sector. With this technology, a plethora of medical parameters can be measured, monitored and recorded remotely by the patient himself, physicians, or third party researchers [2]. Building patient registries to accelerate clinical research is now potentially faster and more feasible. Additionally, the patient can become his or her own researcher, actively participating in self-experimentation with monitoring and tracking of behavior, lifestyle and health changes. Conversely, patients can engage in larger scale clinical trials, seeking to gain active participation in clinical trials with more patient-centered feedback as patient empowerment and engagement in his or her healthcare and clinical research develops [5].

With growth in this area of data collection, increasing development of this software and device technology, and expanding use by the population and patients, the wealth of information available is immense. Health researchers are increasingly able to access and analyze electronic health data, insurance claims and other kinds of traditional health information; however, they are largely restricted from the growing mounds of health and fitness data, courtesy of these personal fitness bands, devices and mobile applications. Perhaps tapping into this vast sea of data is the future of clinical research in areas of fitness, behavioral change, health monitoring and chronic illness management,

Melissa LoPresti

Author for correspondence:
Neuro+Digital Initiative, The Neurological Institute, Columbia University Medical Center, New York, NY, USA
Tel.: +1 212 305 4697
mlopresti01@gmail.com

Geoff Appelboom

Neuro+Digital Initiative, The Neurological Institute, Columbia University Medical Center, New York, NY, USA

Olivier Bruyère

Department of Public Health, Epidemiology & Health Economics, University of Liège, Liège, Belgium

Jean-Yves Reginster

Department of Public Health, Epidemiology & Health Economics, University of Liège, Liège, Belgium

Eric Klug

Department of Cardiology, Heart Failure Clinic, Johannesburg, South Africa

E Sander Connolly Jr

Neuro+Digital Initiative, The Neurological Institute, Columbia University Medical Center, New York, NY, USA

and perhaps the use of wearable monitoring devices is the future of both inpatient and outpatient symptom management and treatment. Regardless of the future of this electronic health technology sector, one thing is for certain, and that is the plethora of clinical research untapped thus far in the population growing in patient engagement through mobile health technology.

Growth of wireless technology

Mobile health (mHealth) is the emerging area of mobile communication devices such as smartphones and tablets for health information, with electronic health (eHealth) as a subset referring to communication technology [2]. As technology advances in the 21st century, so do developments in the sector of health monitoring devices and mobile applications [6]. They allow for wireless communication regardless of time and place, only limited by access, and allow for collection of community and clinical health data and dissemination of health information to providers, patients, and researchers [7]. Exponential growth in the mobile phone penetration rate globally, coupled with increasing use of smartphones and mobile applications, are large contributors to the burst of this technology. Additionally, the advent of monitoring devices linked to or incorporated in this technology allow for real-time vital signs monitoring. Fitness devices allow people to set goals, motivate them for achievement, provide tracking abilities and real-time monitoring [2]. This couples patient-reported outcomes with daily logs of activity, fitness, intake and quantifiable outcomes. While the growth in this technology holds tremendous promise for improved health, the research supporting their efficiency is behind [8]. There are challenges in verifying and validating accuracy of these devices in comparison to existing standards of care, and with limits to wireless networks, digital data plans, and access to this technology, the breadth of widespread application is limited.

Patient engagement

Technology not only allows for enhanced communication and information exchange, but it promotes it. Serving as a motivation source, goal setting forum, and feedback network, many of these applications and devices allow patients to form teams and networks with others aiming to achieve similar health goals, as well as providing feedback and encouragement in proportion to application utilization and engagement [6]. In essence, they act as mobile phone games for health, and patient engagement through gaming could revolutionize the way patient perceive medicine and interact with their own healthcare. Promotion of patient engagement in their fitness, nutrition, activity and health bridges wellness with the clinical world.

Accepted wisdom for transforming the quality and costs of healthcare includes as a central pillar the concept of ‘patient engagement’, the need to involve patients more fully in their health and wellness [6]. As wireless technologies assist with that, better chronic disease management and the evolution of preventive care are main areas of healthcare that will benefit. Providers can work with patients, using these ubiquitous electronic health records to identify areas for intervention, behavior modification and enable meaningful patient engagement. Patients who are truly engaged make positive choices for their health and wellness every day, enabling the system to move to a culture of prevention as opposed to treatment. The capabilities of eHealth can help patients follow an engagement path that leads to a wellness equivalent of self-actualization in Maslow’s pyramid.

Implications in research

As use of this technology spreads, the data it yields will grossly enhance observational data. Like never before, the development of patient engagement tools, technologies, social platforms and mobile applications have improved our way to conduct studies to assess the effectiveness of treatments. Clinical trials can now take place with a new body of samples, pending patient preference with goal setting, application usage or treatment plans. As patients become more comfortable sharing their health information online, in forums and databases, self-reported qualitative and quantitative data and feedback at every stage of a clinical trial are becoming feasible in online communities [9]. This allows for the development of large online patient communities, linked with this technology, via mobile applications, wireless registries, and online networks and forums. mHealth better defines and measure outcomes, yielding more accurate qualitative and real-time quantitative data. Using daily data collection, sensors of multiple parameters, and logging of symptom frequency, patients can better advocate for their needs and wants of healthcare.

Being so pervasive, with independent and networked use, this technology generates patient communities, with the potential to create patient registries and tailored research networks using specific technology, applications, groups or parameters, creating a large volume of patient-powered registry networks in the research [10]. Suddenly the sample population for clinical trials is instantaneously present, ample in number, and ready, willing, and able to provide feedback. While observational studies inherently cannot meet the gold standard of randomized clinical trials, they provide an opportunity to collect useful early-phase data by capturing patients’ self-experimentation [11]. With the

use of self-reported patient data, coupled with patient-matching algorithms, clinical discovery can parallel that of randomized clinical trials, as demonstrated by Wicks *et al.* [12]. Clearly, this resource is a budding development and hugely untapped well of data for clinical research. As this field continues to grow, it is important to consider the ethical regulation of the use of self-reported data, or participant-led research, as it is unclear and varies from standard research [10,13].

Conclusion

Advancements in wireless technology have created the field of mobile health, a sector growing in devices and applications, as well as potential. With the ability to instantaneously share information, provide self-tracking and monitoring applications, establish support networks and forums, and enhance communication between providers, patients, and researchers, mobile and electronic health hold much promise for restructuring and bolstering the concept and application of patient engagement and clinical research data

collection. These perceived benefits of sharing health data cannot be underestimated. The potential that improved patient engagement holds for healthcare globally could alter standards for treatment and prevention of chronic illnesses as well as generate high volumes of data and large patient populations to sample in clinical studies, furthering our understanding of this technology in health, as well as providing us with engaged patients, not only in individual health, but in broader research registries and online patient networks.

Financial & competing interests disclosure

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

No writing assistance was utilized in the production of this manuscript.

References

- Center for Advancing Health. A New Definition of Patient Engagement: What is Engagement and Why Is It Important? www.cfah.org/pdfs/CFAH_Engagement_Behavior_Framework_current.pdf
- Dobkin BH, Dorsch A. The promise of mHealth: daily activity monitoring and outcome assessments by wearable sensors. *Neurorehabil. Neural Repair* 25(9), 788–798 (2011).
- Rettner R. The Quantified Self: How data-obsessed trackers push toward healthier lives. www.livescience.com/44618-quantified-self-culture.html
- LiveScience Staff. Best Fitness Tracker Bands. LiveScience. www.livescience.com/41556-best-fitness-trackers.html
- Mullins CD, Vandigo J, Zheng Z, Wicks P. Patient-centeredness in the design of clinical trials. *Value in Health* (2014). <http://dx.doi.org/10.1016/j.jval.2014.02.012>
- Wicks P, Stamford J, Grootenhuys MA, Haverman L, Ahmed S. Innovations in e-health. *Qual. Life Res.* 23, 195–203 (2014).
- Germanakos P, Mourlas C, Samaras G. “A Mobile Agent Approach for Ubiquitous and Personalized eHealth Information Systems” Proceedings of the Workshop on ‘Personalization for e-Health’. Presented at: *10th International Conference on User Modeling (UM’05)*. Edinburgh, UK, 29 July 2005.
- Reynolds G. Activity trackers don’t sense everything. *The New York Times*. <http://well.blogs.nytimes.com>
- Wicks P. Could digital patient communities be the launch pad for patient-centric trial design? *Trials* 15, 172 (2014).
- Workman TA. Engaging patients in information sharing and data collection: the role of patient-powered registries and research networks. In: *AHRQ Community Forum White Paper. AHRQ Publication No. 13-EHC124-EF*. Agency for Healthcare Research and Quality, MD, USA (2013).
- Lauer MS, D’Agostino RB. The randomized registry trial—the next disruptive technology in clinical research. *N. Engl. J. Med.* 369(17), 1579–1581 (2013).
- Wicks P, Vaughan E, Massagli MP, Heywood J. Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm. *Nat. Biotechnol.* 29, 411–416 (2011).
- Vayena E, Tasioulas J. Adapting standards: ethical oversight of participant-led health research. *PLoS Med.* 10(3), 1–5 (2013).