

mHealth and Citizen Science







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Document Information

GRANT AGREEMENT NUMBER 824666		ACRONYM: FAIR4Health	
Full title	Improving Health Research in EU through FAIR Data		
Horizon 2020 Call	SwafS-04-2018: Encouraging the re-use of research data generated by publically funded research projects		
Type of action	Research and Innovation Action		
Start Date	1st December 2018	Duration	36 months
Website	www.fair4health.eu		
Project Officer	Raluca lagher		
Project Coordinator	Carlos Luis Parra Calderón, Andalusian Health Service		
Report	mHealth and Citizen Science		
Related task	Report: mHealth and Citizen Science		
Release date	May 2019		
Dissemination Level	Public		
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Keywords	Digital health, citizen, digital technologies, innovations.		



Improving Health Research in EU through FAIR Data



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List of acronyms

WHO World Health Organization

ICU Intensive Care Unit

CSQ Client Satisfaction Questionnaire

SUS System Usability Scale







Review: mHealth and citizen science

In recent years, there has been a change in health care systems due to an increase of developments in technology. Recent figures published by WHO (World Health Organization), show that the health care systems of most countries are becoming increasingly dependent on digital health [1]. It is expected that medical practice will become more reliant on the aid of algorithms produced by artificial intelligence in order to make diagnostic and therapeutic decisions. It is expected that progress will be made in this area by considerably improving the quality of the health care provided currently.

Digital health owes its rapid expansion to an increase in access to patients' clinical history. This includes a wide range of new digital technologies such as health information technology, electronic medical records, telemedicine, patient portals, mobile applications and personalized medical services.

Citizens are the driving force behind this rapid development of digital health. Health systems are continuously looking for new ways to increase the level of patient participation and satisfaction [2,3]. In this way, citizens can participate more actively alongside technology and providers in order to receive a completely personalized experience when it comes to their health. This in turn has a high probability to lead to an increase in patient satisfaction, a better understanding of overall health status, and an improvement in the reception of results while reducing costs [4]. These technologies allow patients to input and search for information such as test results, scheduling of appointments, and communication with medical providers thus improving the patient-medical relationship and improving the management of diseases and illnesses.

Additionally, the surge of mobile applications related to health in recent years will provide citizens the ability to better understand their health and achieve their







overall goals related to their well-being. Having said that, it comes of no surprise that of the more than one million applications available, over 325,000 are health related [5].

In recent years, several studies have been conducted that analyse the use of smart phone applications in relation to the health benefits of citizens, the vast majority of which show a positive effect on overall health. Similarly, there are studies which analyse other indicators related to these devices, including viability, usability, acceptability, trust, security and satisfaction. We cite one particular literature review by Maramba et al. [5] that aimed to identify and explore the current methods related to the usability of health applications. As with other digital instruments, ease of use is one of the key factors in successful implementation. Authors concluded that questionnaires are the most prevalent method used to evaluate the usability and ease of these types of applications. Other methods that were analysed were qualitative methods, use of multiple methods and automated methods.

One randomized clinical trial was conducted on patients after discharge from ICU due to respiratory failure, in order to test the feasibility, acceptability, and usability of a mobile, self-directed mindfulness training app in comparison to both used methods: a therapist-led telephone-based mindfulness program as well as a web-based critical illness education program. Feasibility was assessed by comparison of observed frequencies to a priori-specified targets of informed consent among eligible patients (70%); randomization of consented participants (60%), retention (80%); and among participants who neither dropped out nor died, who completed all interviews (75%), completed all weekly surveys (60%; mobile group only), and completed all intervention sessions (50%). Acceptability was measured by an adapted Client Satisfaction Questionnaire (CSQ) which assessed credibility and satisfaction (range 9 [low] to 36 [highest]). Usability of the mobile app was assessed with open-ended participant feedback and with the 10-item System





Usability Scale (SUS); O [lowest] to 100 [highest]). The study concluded that the majority preferred the mobile app as a method of delivery. More importantly, mobile mindfulness performed similarly to therapist-led mindfulness training program and generally better than an education program [6].

Innovations in digital health face several ethical and political challenges. We have argued that in order for digital health products and applications to produce tangible innovation and health impacts, either at individual or population level, four conditions must to be met [3]. First, data is of paramount importance for digital health: access to sufficient amounts of data is thus a primary requirement for the development of innovative diagnostic and therapeutic. Second, alignment with existing legal provisions regarding data protection, data security and privacy are key to digital health innovation. Legal frameworks can thus have a major impact in facilitating or hindering progress in this field. Nonetheless, legal provisions do not address the full range of ethical issues in data processing. Nor do they cover the full spectrum of legitimate concerns of data subjects. Third, robust and transparent accountability mechanisms should ensure the precise identification of responsibility for data uses and their consequences on individuals, families and communities. What is more, accountability also sets up mechanisms for communicating health relevant information to data subjects. Fourth, evidence of safety and efficacy is a significant condition for the success of digital health. Licensed digital health products and applications will have to go through extensive assessment processes.

We conclude that health systems are slowly moving towards digital health. Research and support for health information technologies related to patient participation for its potential benefits is important. In this sense, it seems reasonable and advisable to include accessible, legally compliant, accountable and safe mobile technologies as an effective method for boosting citizen science in health research.





References

- [1] World Health Orgnizatión. Global diffusion of eHealth: making universial health coverge achievable. Report of the third global survey on eHealth. Geneva: WHO Document Production Services; 2016.
- [2] Kouroubali A, Katehakis DG. The New European Interoperability Framework as a Facilitator of Digital Transformation for Citizen Empowerment. J Biomed Inform. 2019; 9:103-166. doi: 10.1016/j.jbi.2019.103166.
- [3] Vayena E, Haeusermann T, Adjekum A, Blasimme A. Digital health: meeting the ethical and policy challenges. Swiss Med Wkly. 2018; 16:14-18. doi: 10.4414/smw.2018.14571
- [4] Walker DM, Sieck CJ, Menser T, Huerta TR, McAlearney AS, et al. Information technology to support patient engagement: where do we stand and where can we go?. J Am Med Inform Assoc. 2017; 1;24(6):1088-1094. doi: 10.1093/jamia/ocx043.
- [5] Maramba I, Chatterjee A, Newman C. Methods of usability testing in the development of eHealth applications: A scoping review. Int J med Inform. 2019; 126: 95-104. doi: 10.1016/j.ijmedinf.2019.03.018
- [6] Cox CE, Hough CL, Jones DM, Ungar A, Reagan W, Kew MD. Effects of mindfulness training programmes delivered by a self- directed mobile app and by telephone compared with an education programme for survivors of critical illness: a pilot randomised clinical trial. Thorax. 2019;74(1):33-42. doi: 10.1136/thoraxjnl-2017-211264.



