Informatics for Health: Connected Citizen-Led Wellness and Population Health R. Randell et al. (Eds.) © 2017 European Federation for Medical Informatics (EFMI) and IOS Press. This article is published online with Open Access by IOS Press and distributed under the terms of the Creative Commons Attribution Non-Commercial License 4.0 (CC BY-NC 4.0). doi:10.3233/978-1-61499-753-5-283

# Global *e*Health, Social Business and Citizen Engagement

Siaw-Teng LIAW<sup>a,b,c,1</sup>, Mahfuz ASHRAF<sup>a,b</sup>, and Pradeep RAY<sup>a,b</sup> <sup>a</sup> UNSW Medicine Australia <sup>b</sup> WHO Collaborating Centre (eHealth), Sydney Australia <sup>c</sup> Ingham Institute of Applied Medical Research, Sydney Australia

Abstract. The UNSW WHO Collaborating Centre (WHOCC) in eHealth was established in 2013. Its designated activities are: mHealth and evidence-based evaluation, including use case analyses. The UNSW Yunus Social Business Health Hub (YSBHH), established in 2015 to build on the Yunus Centre/Grameen Bank eHealth initiatives, added social business and community participation dimensions to the UNSW global eHealth program. The Grameen Bank is a social business built around microcredit, which are small loans to poor people to enable them to "produce something, sell something, earn something to develop self-reliance and a life of dignity". The vision revolves around global partnerships for development, Millennium Development Goals (MDGs) and Sustainable Development Goals (SDGs). The scope includes mHealth implementation and evaluation in the context of the Internet of Things (IoT), with a growing focus on social business and citizen engagement approaches. This paper summarises a critical case study of the UNSW WHOCC (eHealth) designated activities in collaboration with Bangladesh institutions (International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDRB) and Yunus Centre). Issues and challenges are highlighted..

Keywords. Global eHealth, mHealth, social business, citizen engagement

## 1. Introduction

The World Health Organisation Collaborating Centre (WHOCC) in eHealth was established in UNSW Medicine in 2013, to implement evidence-based evaluation of eHealth and guide mHealth solutions, including the Internet of Things (IoT). The Yunus Social Business Health Hub (YSBHH) was established in 2015 to build on the Yunus Centre/Grameen Bank eHealth initiatives. The vision revolves around global partnerships for development, United Nations Millennium Development Goals (MDGs) and Sustainable Development Goals (SDGs). The scope includes implementation and evaluation of integrated information systems and data and the Internet of Things (IoT).

The MDGs [1, 2] aim to eradicate extreme poverty and hunger; achieve universal primary education; promote gender equality and empower women; reduce child mortality; improve maternal health; combat HIV/AIDS, malaria, and other diseases; ensure environmental sustainability; and develop a global partnership for development. The SDGs replaced the MDGs in 2016 [3]. Relevant SDGs include:

#8. Decent, full and productive Work and Economic Growth;

<sup>&</sup>lt;sup>1</sup> Corresponding author, Academic General Practice Unit, School of Public Health & Community Medicine, UNSW Australia, Randwick, NSW 2049 Australia. E-mail: siaw@unsw.edu.au

#9. Resilient and sustainable Industry, Innovation and Infrastructure

#10.Reduced income inequality within and among countries

#11.Sustainable Cities and Communities - inclusive, safe, resilient and sustainable

#12.Responsible and sustainable Consumption and Production patterns

This paper is a critical case study of the WHOCC (eHealth) activities and social business approaches to global eHealth in collaboration with Bangladesh institutions.

The social business paradigm was initiated by Nobel Peace Prize Laureate Professor Yunus as part of the theory and practice of microcredit/microfinance. The Grameen Bank, or "*village bank for the poor*", is a social business built around microcredit or tiny loans to poor people. There is no collateral; the microcredit system is based on trust with no legal documents involved! Grameen Bank now has 9 million borrowers who are "owners" of the bank. Currently, Grameen Bank lends out over one and a half billion US dollars each year. Almost all (97%) borrowers are women who use the loan to start a business: "by producing something, selling something, earning something, she starts to develop self-reliance and a life of dignity" [4].

Social business is defined as a non-dividend business entity established to solve human problems [5]. It can co-exist with money-making business. Successful social businesses in health include selling vegetable seeds at affordable prices to make vegetable growing easy for the citizenry. This business has become the largest seed retailer in Bangladesh and, more importantly, is associated with a marked reduction of night blindness, a common disease among the poor children in rural Bangladesh. Malnutrition is being addressed by a joint venture in 2005 with a global company (Danone) to establish a social business to manufacture an affordable fortified yogurt for poor families. This successful social business continues as part of Danone's corporate social responsibility within a for-profit construct.

The key characteristics of a social business are that it must address a social problem and poverty, operate sustainably, and re-invest profits to expand business and social goals. The social business company adapts business principles to use a market-based solution to alleviate issues caused by poverty, poor health, unhealthy food, smoking, alcohol, gambling, risky behaviour, unemployment, poor literacy, etc. Most of the successful social businesses created in Bangladesh are owned and managed by non-profit organizations. Multi-national companies and non-profits tend to own joint ventures, which may or may not be social businesses.

The Grameen Village Phone Program, started in 1997, provided a good incomeearning opportunity to more than 210,000 mostly women Village Phone operators living in rural Bangladesh through facilitating universal access to telecommunication services by the poor in remote, rural areas. The phone was used mainly for financial discussions and social calls with family and relatives living and working in urban areas, resulting in real savings through avoidance of and reduction in trips to the city [6].

In 2006, Grameenphone initiated *HealthLine 789* for its 10 million subscribers, who are charged US\$0.38/call for 5 minutes. A range of medical information facilities (e.g. SMS-based laboratory reports), emergency and ambulance services, and real-time medical consultations is provided via mobile phones. A panel of skilled health professionals is available 24/7 through the physician's interface; support is provided by a back office and network manager [7] [8, 9].

High smartphone penetration and strong user and patient demand for mobile phone apps are strong drivers for mHealth initiatives [10]. Health professionals often resist this potential power shift to patients and community. Regulations of the industry do not appear to be a barrier, but, uncertainty exists around the lack of data security and standards. A general barrier is *"discoverability"*, where it difficult to discover the required app from among the estimated 100,000 mHealth apps available online.

Community readiness for eHealth is important globally, as in rural Bangladesh [11, 12]. Community members, leaders and healthcare providers would use mHealth tools and services. However, awareness of existing services is low, especially among the poor and less educated. While face-to-face consultations are preferred, the community is attracted by the timely access to qualified healthcare providers, time savings and lower costs associated with mHealth. Low literacy, lack of English language proficiency, lack of trust and technological incapability were barriers to mHealth use. A sense of ownership, evidence of utility, a positive attitude and intention to use mHealth were drivers of adoption of mHealth services. Implementation strategies must focus on gaining trust, through training and support of users. This requires citizen engagement to inform and empower consumers and ensure transparency and accountability.

The key construct in citizen engagement is public participation. Unlike public communication to inform the public and public consultation, public participation is characterised by 2-way flow of communication in an iterative fashion. It involves the public in collaborative ways and emphasises empowerment. However, barriers exist including poverty and a decreased sense of worth associated with disability and disadvantage such as age, female gender and belonging to minority groups [13].

Global eHealth implementation and evaluation requires social business strategies, targeted at both clinical and population issues, underpinned by citizen engagement if they are to succeed.

## 2. Progress and Challenges in an Environment of Ongoing Change

#### 2.1. Infrastructure and Building Blocks Activities with International Agencies

- Legal and business analysis of e-Authentication and e-Authorisation [14] as part the EU 7th Framework project called AU2EU {www.au2eu.eu}.
- Collaborative work on natural language processing to improve quality of routinely collected data as part of clinical practice [15-18].
- Collaborative multidisciplinary projects to establish the infrastructure and tools to support an Internet of Things approach to the smart built environment.
- Collaborative projects with the Australian Collaborative Research Centre on Spatial Information (CRC-SI) to geocode and spatially enhance the eHealth evaluation methodology to understand integrated health neighbourhoods [19].

#### 2.2. Collaborative mHealth Activities

- with International Centre for Diarrhoeal Disease Research, Bangladesh (ICDDRB) to assess community readiness for mHealth [11, 12, 20].
- with EU partners to assess market adoption, cost, maturity and user acceptance of robotic mHealth services for vulnerable groups [21].
- PhD research into cloud-based mHealth systems for disaster management [22].
- PhD research on mHealth for the primary care of cancer patients [23].

• Indian Aboriginal health agencies on the use of tablets for health checks of independent-living elders, within the Silvercare model where a young retired person supported up to ten elderly people in their neighbourhood [24].

# 2.3. Evaluation Methodologies and Optimizing the Use of EHR Data for Research

- Data analytics of observational and measurement data from electronic health records from Integrated Health Neighbourhoods (IHNs), which are referral networks across primary and secondary care, supported by an informatics infrastructure and record linkage across clinical and population health information systems, traditional research data sets, social media and personalised appliances [19]. Data quality assessment, management and governance [15, 25-30] are ongoing strategic activities to ensure fitness for purpose for comparative effectiveness research to understand variations in quality of data and care and how eHealth improves self-management, equity and access to health care and social capital across health neighbourhoods.
- EHR data is the core longitudinal data source for quality improvement, evaluation and research; supplemented by specific quantitative and qualitative methods and tools.

## 3. Conclusions

The WHO CC social business and citizen engagement approach to implementation and evaluation gives meaning to global eHealth infrastructure and tools as sociotechnical mechanisms to achieve access, equity, safety, quality and continuity and comprehensiveness of health care. Individual and community readiness of consumers and providers to adopt and use eHealth tools is central to building a community of citizens that use digitally-enhanced social business approaches to innovate, facilitate and sustain the utility and relevance of global eHealth programs. The highly contextual nature of implementation and evaluation is re-affirmed. The expectations and needs of global eHealth are constantly being met and evolving. The WHOCC (eHealth) research and development program must also evolve with ongoing adaptation and innovation to ensure global eHealth programs and tools contribute meaningfully to meeting the SDGs.

## References

- [1] United Nations. The Millennium Development Goals Report 2015. New York: 2015.
- [2] United Nations. Millenium Development Goal 8: Global Partnership. New York: 2015.
- [3] United Nations. Sustainable Development Goals: 17 goals to transform our world 2016.
- [4] Dowla A. In credit we trust: Building social capital by Grameen Bank in Bangladesh. The Journal of Socio-Economics. 2006;35(1):102-22.
- [5] Yunus M. Creating a world without poverty. Social business and the future of capitalism. New York, USA: Public Affairs; 2007.
- [6] Richardson D, et al. Grameen Telecom's Village Phone Programme in Rural Bangladesh: a Multi-Media Case Study. TeleCommons Development Group, Can Int Dev Agency, 2000.
- [7] Akter S, Ray P, D'Ambra J. Continuance of mHealth services at the bottom of the pyramid: the roles of service quality and trust. Electron Mark. 2013;23(1):29-47.

- [8] World Health Organization. mHealth New horizons for health through mobile technologies Geneva, Switzerland: World Health Organization, 2011.
- [9] Al Mamoon I, Khan S. Performance Analysis of a Nationwide Telemedicine Call Center. J Telecommunications. 2011;8(2):10-3.
- [10] Zhao J, Freeman B, Li M. Can Mobile Phone Apps Influence People's Health Behavior Change? An Evidence Review. J Med Internet Research. 2016;18(11).
- [11] Khatun F, Heywood A, Ray P, Bhuiya A, Liaw S. Determoinants of readiness to adopt mHealth in a rural community of Bangladesh. Int J Med Informatics. 2015.
- [12] Khatun F, Heywood AE, Ray PK, Bhuiya A, Liaw S-T. Community readiness for adopting mHealth in rural Bangladesh: A qualitative exploration. Int J Med Inform 2016;93:49-56.
- [13] Sheedy A, MacKinnon MP, Pitre S, Watling J. Handbook on Citizen Engagement: Beyond Consultation. Canadian Policy Research Networks, 2008 March. Report No.
- [14] Ghorai K, Smits J, Ray P, Kluitman M. European Health Data Privacy and eHealth Rules in Aged Care Coordination. Amsterdam Privacy Conference; 2015; Amsterdam, Netherlands.
- [15] Jonnagaddala J, Liaw S, Ray P. Impact of data quality assessment on development of clinical predictive models. Studies in health technology and informatics. 2015(216):1069.
- [16] Jonnagaddala J, Liaw S, Ray P, Kumar M, et al. Coronary artery disease risk assessment from unstructured electronic health records using text mining. J Biomed Inform. 2015.
- [17] Jonnagaddala J, Liaw S, Ray P, Kumar M, Dai H. HTNSystem: Hypertension information extraction system for unstructured clinical notes. Tech & App Art Intell. 2014:219-27.
- [18] Jonnagaddala J, Liaw S, Ray P, et al. Identification and Progression of Heart Disease Risk Factors in Diabetic Patients from Longitudinal EHRs. BioMed Res Int. 2015(10).
- [19] Liaw S, de Lusignan S. An 'integrated health neighbourhood' framework to optimise the use of EHR data. J Innovation in Health Informatics. 2016;23(3):547-54.
- [20] Khatun F, Heywood et al. Prospects of mHealth to improve the health of the disadvantaged in Bangladesh. In Adibi, S (Ed) *mHealth multidisciplinary verticals*. Taylor & Francis 2015.
- [21] Ariani A, Kapadia V, Talaei-Khoei A, Li J, Ray P. Challenges in Adoption of Assistive Robots among Seniors. Int Technology Management Review (in press). 2016.
- [22] Guempana Y, Rabhi F, Lewis J, Ray P, Zhu L, editors. Mobile Cloud Computing for Disaster Emergency Operations. IEEE ISTAS2015; 2015 Nov; Dublin, Ireland.
- [23] Lewis J, Ray P, Liaw S-T. Recent worldwide developments in eHealth and mHealth to more effectively manage cancer and other chronic diseases. Int Yrbk Med Inform. 2016:11-26.
- [24] Blake J, Ray P, editors. Facilitating Digital Communication in Seniors. IEEE International Symposium on Technology and Society (ISTAS2016); 2016 Oct 21-22; Trivandrum, India.
- [25] de Lusignan S, Liyanage H, Di Iorio C, et al. Using routinely collected health data for surveillance, quality improvement and research. J Innov Health Inform. 2015;22(4):426–32.
- [26] de Lusignan S, Liaw ST, et al. Key concepts to assess the readiness of data for International research. Int Yrbk Med Inform. 2011;2011:112-21.
- [27] Kahn M, Callahan T, al e. A Harmonized Data Quality Assessment Terminology and Framework for the Secondary Use of Electronic Health Record Data. eGEMS 2016.
- [28] Liaw S, Rahimi A, Ray P, et al. Towards an ontology for data quality in integrated chronic disease: a realist review of the literature. Int J Med Informatics. 2013;82(1):10–24.
- [29] Rahimi A, Liaw S, et al. Ontological specification of quality of chronic disease data in EHRs to support decision analytics: a realist review. Decision Analytics. 2014;1(1):5.
- [30] Taggart J, Liaw S-T, Yu H. Structured data quality reports to improve EHR data quality. Int J Med Informatics. 2015;84:1094-8.