WOMEN AND EHEALTH 2010 – 2015. FROM THE STUDY TO THE WOMEN OBSERVATORY FOR EHEALTH

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Abstract

Improving access to information and communication technologies (ICT) and making these services affordable to all are prerequisites to their efficient and sustainable use in healthcare and eHealth. Women worldwide still face barriers that keep them away from innovation and limit their taking full advantage of eHealth and telemedicine. To help address these barriers, Millennia2015, an initiative of the Destree Institute, conducted the Women and eHealth Study 2010 – 2012 (*We*Health) to identify barriers and trends in the emerging arena of Women, Health and ICT. The study proposed a set of solutions to the identified barriers, including a mapping of Women's involvement in eHealth. Forging ahead on the Study's proposals, the new Millennia2025 Foundation "Women and Innovation", a Public Utility Foundation, and its partners, have developed Action Plans to ensure the full participation of women in eHealth and telemedicine. These Plans include diverse initiatives, such as the *We*Observatory, which provides support to 15 *We*Health projects in 11 countries, *We*Telemed, *We*Blog, *We*MOOCs, *We*Patients, *We*Library, and two mobile multilingual applications: UniversalNurses and UniversalWomen, available in six languages. Improving the role of women in eHealth requires commitment and effort, and the Millennia2025 Foundation is committed to accelerating women's access to innovation and technologies for health around the world.

Keywords: eHealth; women; telemedicine; mHealth; innovation.

Introduction

The Foundation Millennia2025 Women and Innovation, PuF, is the pursuance of the Millennia2015 "Women actors of development for the global challenges", a foresight research process launched in 2007 by the Destree Institute, a European pluralist research centre, based in Wallonia, Belgium. The Institute is an NGO official partner of UNESCO (the United Nations Educational, Scientific and Cultural Organization) with consultative status and has had a special consultative status with the United Nations Economic and Social Council since August 2012. The Millennia2025 Foundation is committed to highlight the crucial role of women in global health, eHealth and telemedicine, as well as their unrecognized capacity as builders of alternative futures.

What is "Women and eHealth" at Millennia2015?

In August 2010, Millennia2015 created the International Working Group "Women and eHealth" to explore the area at the intersection of Women, Health and Information and Communication Technologies (ICTs), named *We*Health (Figure 1).[1] Since its launch, *We*Health has grown steadily to include more than 800 members from 65 countries.

The topic of women and eHealth has been gaining international recognition through various presentations at international conferences and publications. To better understand women's access to ICT and the use they make of these technologies for health, the Working Group conducted a study on these topics among its members, covering the 2010-2012 period.
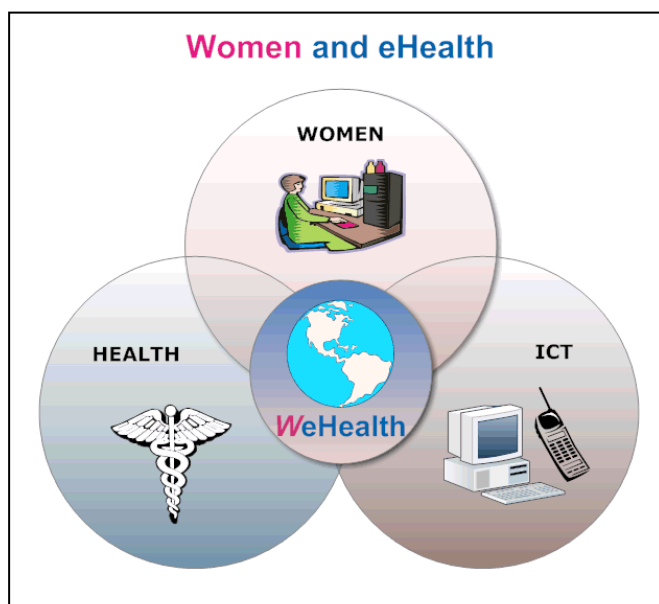
Figure 1: Research areas covered by *We*Health.

Why "Women and eHealth"?

The information provided by *We*Health members in the study acknowledges that access to and use of ICTs for health by women is a fundamental need and an essential factor contributing to their empowerment. One of the drivers is to promote the idea that it is a human right for women to benefit from mobile and mHealth applications during pregnancy and the early ages of their children. Non-economic benefits of these technologies include more rapid and effective communication in areas of conflict, during disasters, and support to women during their pregnancies.

The Women and eHealth Study 2010 – 2012

The Millennia2015 Women and eHealth study 2010-2012 highlights a set of barriers, solutions and trends in the emerging arena of Women, Health and Technologies.[2] The study considered various dimensions of the roles of women in ICT such as beneficiaries, health care providers and advocacy workers. Data gathered were generated through a two-year intensive information exchange among a network of 534 voluntary members in 62 countries, 2,500 emails, 82 Skype conferences, 175 publications, 15 conferences, 99 online interviews in 13 countries, and collaborations with 27 organizations. A list of 99

selected publications covering the themes of Women, Health and ICTs has been published. The study results were presented at Medetel, 10 April 2013, the annual conference organized by the ISfTeH in Luxembourg. Some of the key findings are discussed below.

Barriers and challenges include educating and training women on ICT usage, addressing illiteracy and disability, and ensuring that services are delivered in their own languages and dialects. The cost and complexity of devices can also be a hindrance to usage. ICT solutions cannot solve overall health issues, particularly for those living in more isolated areas. These technologies are still unaffordable and often too complex for the level of education and technical skills of many potential users. In addition, continued service after a pilot project has been completed and is no longer subsidized is problematic. These technologies must be adapted to conditions such as refugee camps, conflict situations, natural disasters, and areas with unreliable power supply.

Most women who received health related SMS messages on their mobile phones preferred to have messages delivered by voice, using voice commands. Long-term sustainability remains problematic, as devices and ICT applications are constantly evolving and proliferating. For women in developing countries, having access to the appropriate technology with basic functionalities, such as SMS, might be more effective in the long-term, than ensuring their access to the latest innovations. In the absence of continuous education and empowerment, this has major consequences on the access and use of new solutions by women.

Telemedicine remains a "male" dominated sector at all levels: medical, technical, and engineering. Women are beneficiaries as patients where such services are made available, yet just a few female doctors, nurses or midwives are trained and active in telemedicine services.

Local solutions where energy is scarce or unreliable have been found, such as using solar or wind power generation. Young girls in Africa have found a urine-based solution to provide enough energy for mobile phones. Women appreciate and use traditional technological tools that prove practical. For example, radios and television continue to play a major role in the dissemination of health information and should be incorporated with mobile phones and Internet services to reach more women. Mobiles, tablets, and other

electronic devices show interesting results, but remain limited to pilot projects that hardly expand at national and regional levels.

Free Call Lines were also emphasised as a need to enable women to reach health centres and health service workers. These lines can in particular to support women living in difficult situations, such as domestic violence, natural disasters, conflict areas, and as refugees. Access to broadband and eHealth services, available through cloud computing systems, is considered key to women to facilitate the exchange of digital images, accelerate diagnostics, and decision-making in urgent contexts, particularly during pregnancy.

The most cited health areas of interest for women receiving regular health information via ICTs were: maternal and child health, family health, disease control, HIV/AIDS, malaria, cancer and vaccination. Access to ICTs can have a profound effect on women with disabilities or who experience issues related to aging and mobility.

As major emerging trends, women are recognised to be active users of social media and blogs to gain access to health information, even prior to consulting health professionals. Technologies are causing an impressive shift into a new paradigm where women, whatever their roles, have better access to health information. As a result, doctors are no longer the sole repositories of medical information.

Who are the "Women in eHealth"? – Mapping Women's involvement in eHealth

Based on the data collected, the study has considered four dimensions of the roles of women in eHealth:

- *Women as Beneficiaries*: Women are at the core of family healthcare in communities and have the greatest need to have access to and use ICTs for their personal health and that of their family members.
- *Women as Healthcare Professionals*: Women are at the frontline of family care in their role as healthcare workers in communities. They require ICTs to facilitate effective communication with other healthcare workers, with doctors, and patients.
- *Women as ICT professionals*: Women are among the engineers and technicians who develop innovative and adapted devices and applications to help reach the most isolated environments and communities.

- *Women as Leaders*: Women advocate at all levels, from raising new opportunities to partnering with the private sector, collaborating and networking, improving funding mechanisms, and leading eHealth initiatives in communities.

Since 2013, two new dimensions were proposed at various international conferences to be taken into consideration:[3]

- *Women in Media as journalists,* in particular those active in social media: Women are influential on the web, and 85% of Pinterest users are women. They are active bloggers, sharing opinions and stories, shaking ideas and communicating new solutions.
- *Women as Educators or Mentors,* to educate young girls in technologies: Education and mentoring are very powerful instruments to motivate girls to study engineering, telecommunication or informatics. Women reaching high-level positions in the industry provide an incentive for young girls by giving the positive image of exciting jobs.

From the Women and eHealth Study 2010 – 2012 to the Women Observatory for eHealth

The Women and eHealth study highlighted barriers and challenges to take into consideration after 2012. The creation of the Women Observatory for eHealth at the Millennia2025 Foundation (*We*Observatory hereafter) encouraged development of specific Action Plans for the 2012–2017 period, with the objective to provide concrete eHealth solutions to women, in partnership with Connecting Nurses and Connecting Midwives. Some of these specific activities are highlighted below.

Education and Training

Educating and training women on ICT usage are two main areas of concern mentioned often in interviews and reports. Other major impediments that limit the ability of women to use ICTs are illiteracy and disabilities. In order to expand education and learning, the Intelligence MOOCs Commons for Women and eHealth of the WeObservatory (*We*MOOCs) provides an annual selection of free Massive Online Courses (MOOCs) in English, French and Spanish, developed by the most famous universities and academics.[4] The MOOCs included in the *We*MOOCs are scanned and selected by specialized advisors and members of the

Foundation, and cover three of the six UN official languages: English, French and Spanish.

In 2014, the advisors identified and selected 72 MOOCs in English, and a handful of courses in the Other two languages, covering various topics of interest to women, such as nutrition, nanotechnologies, diabetes, epidemics, AIDS, and nursing. In 2015, the number of selected courses increased to a total of 340, of which 276 were in English, 28 in French and 36 in Spanish. The courses were selected from 21 different MOOC platforms and are being imparted by diverse institutions from 18 countries in America (6), Europe (8), Asia (2), the Middle East (1), and Oceania (1). Through the WeMOOCs, the WeObservatory offers a unique platform to improve education and training in eHealth and telemedicine.

Languages and Dialects

It is important for women that eHealth services are delivered in their own languages and dialects. This encompasses all kind of eHealth activities, including but not limited to mHealth, telemedicine, EMR, and SMSs. In partnership with UniversalDoctor, the WeObservatory has developed mobile applications for nurses, midwives and pregnant women. The applications UniversalNurses and UniversalWomen are available in six languages to support multilingualism and common understanding between nurses, midwives and their patients.[5,6] UniversalDoctor was recently awarded at the UN World Summit Award in Abu Dhabi.

Cost, Complexity and Sustainability

In most instances, ICT solutions do not satisfy women's needs, particularly for those living in rural communities or remote areas. Long-term sustainability remains problematic, as devices and ICT applications are constantly evolving and proliferating.

To help address these issues, the WeObservatory is committed to support projects on the Care Challenge platform, and provides technical and financial support for digital inclusion solutions.[7] Cost, complexity and sustainability are integrated at each level of project development and implementation. Selected projects cover various health areas and topics, such as mental health, HIV, ePrevention programs, mWounds apps, foot diabetes, video training, child diabetes, maternal health, emergencies during natural disasters, research

on the elderly and telehealth, as well as mobile multilingual applications.[8] They cover all ages of patients' lives, from birth, childhood, adolescence, adulthood to the elderly. With 15 eHealth projects in

10 countries in 3 languages, 2 mHealth applications in 6 languages, the WeObservatory constitutes a unique platform of innovation driven by nurses and midwives for their patients. To date, 7 projects have developed innovative tools and services.[9] The Blog of the WeObservatory (WeBlog), launched in October 2014, provides regular news on the projects, publications and international events.[10]

Telemedicine

Telemedicine remains an area with an insufficient number of women health professionals, leaders, IT designers, and beneficiaries. To address this gap, the Global Network of Women in Telemedicine (WeTelemed) was initiated as an Action Plan with the vision to constitute a powerful demonstration of women empowerment for Millennia2015.[11] WeTelemed was launched in Panama, at the conference on "Digital Inclusion for Health and Sustainable Development".[12] Since the launch, 251 members from 38 countries have registered, and constitute a dynamic group of women and men involved in telemedicine.

WeTelemed gives particular attention to women addressing the needs of women living in remote areas, refugee camps or in areas of conflict where telemedicine services may constitute an alternative to local health centres, which are often non-operational under such conditions. Medical specialties such as gynaecology, maternal and children health, dermatology, reproductive health, neurology, radiology, dermatology, infectious diseases, emergency surgery and services are primarily targeted, as an increased number of female health care providers are needed to deliver healthcare to women via telehealth.

Since its launch, WeTelemed has been presented at various conferences, including the Millennia2015 International Conference, held at UNESCO in Paris in December 2012. Each conference provides an opportunity to expand the network, include new members and enrich our work. In 2013 and 2014, WeTelemed was presented at the OCAPROCE NGO's Forum in Geneva (September 2013), the Women's

Leader Forum in New York (September 2013 and 2014), in partnership with Advanced Development for Africa Foundation, and the *We*Observatory Round Table, Geneva, in May 2014.[12]

Emerging Trends

Among the emerging trends identified in the study, the use of social media was the most prominent in the area of eHealth. As noted above, women are active users of social media, blogs, and twitter to gain access to and share health information, even prior to consulting health professionals. This is a new paradigm where doctors are no longer the sole repositories of medical information.

Other trends have emerged since 2013, such as Patient Empowerment and eHealth. The *We*Observatory developed the Patients Commons for eHealth (*We*Patients), to support Patient Empowerment in Self-Management of Chronic Conditions in three languages, English, French and Spanish. The objective is to raise awareness of behavioural change models and tools that can be applied to improve patient adherence and health outcomes. *We*Patients includes a selection of eHealth projects focused on Patient Empowerment along the ages of life, resources, publications and patient's stories.[13]

The future Women Library for eHealth (*We*Library, under development) will provide access to articles and publications related to women involved in eHealth and telemedicine. Currently, access to 99 selected publications listed in the Women and eHealth Study 2010-2012, as well as links to recent publications are already made available.[14] This section will be periodically updated and worthy of being consulted.

Conclusion

The Women and eHealth Study 2010 – 2012 (*We*Health) contributed to explore a new area of investigation, at the intersection of Women, Health and ICTs, and has highlighted a set of barriers and challenges, innovative solutions and emerging trends. The *We*Observatory, the *We*Blog, *We*Telemed and the *We*MOOCs constitute the initial Action Plans of the Foundation Millennia2025, PuF, to support access to and use of eHealth and telemedicine for and by women around the world. In 2015 – 2016, the Library for Women and eHealth (*We*Library) and the Patients Commons for eHealth (*We*Patients) will ensure that all women receive special attention in the access to and use of eHealth and telemedicine.

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Conflict of Interest
The authors declare no conflicts of interest.

References

1. Millennia. International Working Group "Women and eHealth". Available at: http://www.millennia2015.org/Women_and_eHealth accessed 8 March 2015.
2. Thouvenot VI, Holmes K. Closing the Gender and Digital Gaps to Improve Women's Health. Results of the Women and eHealth Study 2010 – 2012: 14 Key Findings and 6 Action Plans. Namur, Belgium: Millennia2015.org; 2013. Available at: http://www.millennia2015.org/files/files/M15_Documents/Millennia2015_WeHealth_Key_Findings_and_Action_plans_2012.pdf accessed 8 March 2015.
3. Millennia. Women and eHealth study 2010-2012. Available at: http://www.millennia2015.org/Women_and_eHealth accessed 8 March 2015.
4. The Intelligence MOOCs Commons for Women and eHealth of the *We*Observatory (*We*MOOCs). Available at: http://www.millennia2015.org/moocs accessed 8 March 2015.

5. UniversalNurses. Multilingual patient communication tool for nurses and maternal health issues. Available at: http://www.u-nurses.com/ accessed 8 March 2015.

6. UniversalWoman. Multilngual communication for pregnancy, childbirth. Available at: http://www.u-women.com/ accessed 8 March 2015.

7. The Care Challenge platform. Available at: http://www.care-challenge.com/ accessed 8 March 2015.

8. Millennia2015. Selected projects. Available at http://www.millennia2015.org/WeObs_Selected_Projects accessed 8 March 2015.

9. Millennia2015. Achievements. Available at: http://www.millennia2015.org/weobs_achievements accessed 8 March 2015

10. WeObservatory Blog. Available at: www.weobservatory.com accessed 8 March 2015.

11. WeTelemed, Global Network of Women in Telemedicine Available at: http://www.millennia2015.org/WeTelemed accessed 8 March 2015.

12. Millennia2015. Digital Inclusion for Health and Sustainable Development. Available at: http://www.millennia2015.org/Mujeres_ICTs_Panama accessed 8 March 2015.

13. Millennia2015. The Patients Commons for eHealth (WePatients) Available at: http://www.millennia2015.org/WePatients accessed 8 March 2015.

14. Millennia2015. Women and eHealth Study 2010 - 1012. List of selected references. Available at: http://www.millennia2015.org/files/files/WeHealth_Research/wehealth_list_of_references.pdf accessed 8 March 2015.