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D2.1 Brazil Interviews - Annex

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Abstract

This annex presents the findings from the interviews that were conducted in Brazil as a part of Task T2.3 – State of play in socio-economic and policy frameworks. As an annex, it is supplementary to the deliverable D2.1 State of Play in Mobile Healthcare.

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List of Participants

No.	Participant organisation name	Participant short name	Country
1	Atos Research and Innovation	ATOS	ES
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1 Executive Summary

This annex presents the findings from the interviews that were conducted in Brazil as a part of Task T2.3 – State of play in socio-economic and policy frameworks. As an annex, it is supplementary to the deliverable D2.1 State of Play in Mobile Healthcare.

Brazil is the largest country in South America and is today one of the world's fastest growing economies. However, Brazil is characterised by substantial health and wealth inequalities. The public health system is highly decentralised and access to and quality of healthcare services and treatment are still very much dependent on the patient's socio-economic status; the private healthcare sector offers high quality care and services to the very limited part of the population who can afford it.

mHealth is still very much in its beginning phases in Brazil. The main focus is still on providing online links between medical centres aimed at healthcare professionals and medical students. In relation to the public, focus is mainly on providing public health information and education particularly in schools.

In general, the users' attitude (professionals and patients) towards eHealth and mHealth is considered to be quite positive. Respondents were also quite confident that eHealth and mHealth services and applications will become more widespread in Brazil once the main challenges are overcome. These challenges or barriers include the instability of the Internet and mobile networks and the costs, in particular the core cost of using a mobile phone or accessing the Internet.

Regulatory frameworks and policies directed specifically at eHealth and mHealth were not known and this lack was mostly seen as a barrier. Uncertainty about regulatory issues and methods for approval for mHealth services and application did not necessarily mean a ready acceptance of anything out there, but rather instigated a hesitancy in adopting mHealth because there was no way of knowing if it violated any regulation and thus risked disapproval later on.

2 Target audiences

The target audience for this annex are anyone who have read or are intending to read the deliverable D2.1 State of Play in Mobile Healthcare. To be more specific, the target audience include stakeholders who are involved in the different aspects related to mHealth solutions, including:

- Medical, clinical and other care professionals
- Technology manufacturers, services, application providers and developers
- Policy, regulatory and other related actors
- Research, industry and academic stakeholders
- Patient support groups at national and international level.

3 Introduction

This annex presents the findings from the interviews that were conducted in Brazil as a part of Task T2.3 – State of play in socio-economic and policy frameworks and it should be read in connection with the deliverable D2.1 State of Play in Mobile Healthcare.

Four interviews (with two women and two men) were conducted in Brazil, each lasting between 45 minutes and 1½ hours. Interviews were conducted face-to-face and via the telephone and Skype (to avoid excessive travel). The interviewees represented a wide group from industry, academia and the medical domain. Each interviewee had different experiences and roles in the eHealth and mHealth context in Brazil as they represented doctors, a patient, and mobile technology researchers and developers. The particular focus of the interviews was to collect information on socio-economic issues relevant to the current state and experiences of mHealth in Brazil.

4 Brazil

Brazil is the largest country in South America and is today one of the world's fastest growing economies. However, Brazil is characterised by substantial health and wealth inequalities. The Southeast and South regions of Brazil are the most developed and wealthiest, while the North and the Northeast regions are the poorest and least developed. The public health system is highly decentralised and access to and quality of healthcare services and treatment are still very much dependent on the patient's socio-economic status; the private healthcare sector offers high quality care and services to the very limited part of the population who can afford it. Mobile healthcare technologies and services have great potential in improving access to healthcare services, especially for people in rural and remote areas, and the first steps in this direction have been taken with the establishment of Telehealth networks and clusters (the Telehealth Brazil programme, see below) in several states.

4.1 Healthcare issues

When discussing public health in Brazil, it became clear that both chronic diseases and communicable infectious diseases represent health problems, but also the lack of basic health education and healthcare professionals and access to health clinics particularly in remote areas constitute significant challenges. There are thus a wide range of healthcare issues that all could benefit from the implementation of eHealth and mHealth solutions and services in various ways.

With respect to communicable or infectious diseases dengue fever, malaria and tuberculosis (TB) were mentioned as representing serious public health problems in Brazil. These diseases were highlighted also because they usually occur as epidemics. As epidemics the attention they receive and the efforts spent trying to control them is naturally proportionate to the course of the outbreak. Thus, the priority given to this type of communicable diseases or epidemics depends on the current situation and outbreak. In contrast, the focus and priority on chronic conditions is more fixed and does not fluctuate in the same way.

In relation to chronic diseases, diabetes was highlighted by the interviewees as a chronic condition where patients as well as doctors can benefit tremendously from mHealth solutions. In addition heart disease and obesity were also mentioned as other chronic conditions where mHealth can make a difference.

When discussing diabetes the importance of focusing on the patient as an individual was stressed. Also, healthcare professionals, whether working in primary, secondary or tertiary care, should

remember that although they operate in different care sectors, the disease and the patient are the same.

4.2 mHealth for Public Health Education, Prevention and Control

One of the priorities of the telehealth networks that have been established is to provide public health information and education. One project in one of the networks is targeted at schools, providing interactive information and education on TB and preventative measures. This project is just one example of the considerable efforts have been made in recent years to reduce the number of TB cases and TB deaths in Brazil.[1]

When it comes to dealing with outbreaks of for example dengue fever, the main tool for control is information, education and access to healthcare services. While mobile information technologies certainly could be very useful, the most effective media in Brazil are still radio and television. No matter how poor, households will have at least a radio. In other words, spreading information about an outbreak, how the public should act, symptoms, precautions etc. is today done via television and radio.

Likewise, public health campaigns continue to be most effectively spread via radio and television because everyone has at least a radio and very often a television. Even in very remote and rural areas families will have a radio and/or television, or they will gather in the household where a television set is available. Although today most people also have mobile phones and one could therefore imagine a text messaging public service to either complement or replace television public service messages there is a crucial problem with this: the costs of sending out messages. Thus, although respondents were clear that text messaging could be very useful because information could reach the public instantly, the problem of costs and who would (should) pay for it, as well as the instability of the Internet and mobile networks, are simply so great that it is still not seen as worthwhile to really promote or implement especially because using radio and television for public health information works just fine (for more detail on the issues of cost and connectivity, see below).

In Brazil an estimated 75% of diabetes patients do not have good glycaemic control. In other words, their diabetes is not being managed and treated adequately thus leading to long-term complications. This puts a strain on the healthcare system as these patients require more medical services (than the average patient) and this is also costly; costs that could be prevented with better management and therapy. How effectively a patient manages his/her diabetes appears to be related to socio-economic status; the higher the status the better the management. As several respondents pointed out, eHealth and mHealth solutions and services can specifically help to provide better management and thus prevent costly long-term complications and hospitalisation. This would not only alleviate the burden on the public healthcare system but it could also improve the patient's quality of life. However, the question remains if mHealth services would broaden the socio-economic divide in terms of effective diabetes management or help decreasing it.

4.3 Telehealth projects in Brazil

In Brazil there are two key government-based telehealth projects: 1) RUTE – Rede Universitária de Telemedicina (Telemedicine University Network) and 2) Telessaúde Brasil (Telehealth Brazil). These two projects will eventually be employed throughout the country, connecting the healthcare system

[1] Although the number of cases of tuberculosis in Brazil has decreased over the past years and the TB death rate has been reduced by half between 1990 and 2010, TB continues be a significant public health problem in Brazil. According the WHO, the prevalence of reported TB cases in Brazil in 2011 was 47 per 100,000 population. TB is primarily found in large cities particularly among the poorest population who live in "favelas" (densely populated slums) and cases of TB in Rio de Janeiro are particularly prevalent.

online. As Brazil's National Broadband Plan develops so will the country's healthcare system develop and become more and more online.

RUTE

The Telemedicine University Network (RUTE) is an initiative of the Ministry of Science and Technology, coordinated by the National Network of Education and Research (RNP), which aims to support the improvement of existing telemedicine projects and encourage the emergence of future inter-institutional work. The initiative provides the infrastructure for communication services, as part of computer and communication equipment for the research groups, promoting integration and connectivity and disseminating R & D activities of the participating institutions.

The use of advanced network services aims to promote the emergence of new applications and tools to explore innovative mechanisms in health education, remote cooperation for pre-diagnosis and remote assessment of medical data.

In this first step, RUTE makes it possible to use applications that require large network resources and data sharing for telemedicine services at university hospitals and educational institutions and research participants. In a second step, RUTE brings the services developed in university hospitals to professionals located in remote areas through remote file sharing of medical records, consultations, examinations and second opinion.

Telehealth Brazil

Telehealth Brazil aims to improve the quality of Primary Care services in the Unified Health System (SUS), integrating education and services through information technology tools that provide the conditions required to promote Tele-care and Tele-education. It is coordinated by the Secretariat of Management of Labour and Education in Health (SGTES) and the Health Care Secretariat (SAS), in articulation with other Ministries, Public Universities, Technical Health Schools and entities in the field of Health and Education.

The Telehealth Brazil programme was launched in 2007. It started with the implementation of a pilot project establishing nine Telehealth Centres located at the universities in the states of Amazonas, Ceará, Pernambuco, Goiás, Minas Gerais, Rio de Janeiro, São Paulo, Santa Catarina and Rio Grande do Sul. Each of these Telehealth Centres has a local coordinator. The programme aims to establish Telehealth Centres all over the country, and work to establish centres in other states is currently in process.

The telehealth projects under the Telehealth Brazil programme that some of the interviewees participate or had participated in are designed specifically for a particular care sector, i.e. the primary and the tertiary sector, and not for specific diseases. For the time being there are no projects in the secondary sector, but this is expected to change in time.

These projects focus on how technology can be used within the specific care sector and may be used for any disease. Thus, for the primary care sector this includes technologies that help provide information and basic health education. An example of a primary care eHealth project is one that deals with childhood obesity. Its objective is to create a basis for the online interaction and exchange of information and communication between healthcare professionals and schools with the aim to promote health education and prevention.

There have also been projects that develop games aimed at promoting health education and prevention of dengue and TB. All of these projects develop online applications which foster interaction rather than simply provide information and this is considered much more effective.

Another project that one of the interviewees had participated in used mobile phones and smartphones to collect data during home visits to patients.[2] Providing home care and family health in Brazil is a significant challenge, not least because of the lack of well-educated healthcare professionals and because of the vast distances in the country (remote areas). The problem is also that there are different types of health professionals who have very different levels of education and skills. The healthcare workers who visit families at home have the lowest level of education and skills. They often live near where they work, are familiar with the area and this is why they carry out home visits. These healthcare workers would benefit tremendously from mHealth solutions; if they had a smartphone with online access to health information, tele-support and tele-consultation with experts etc. the healthcare that they provide would improve. The healthcare worker and the community would feel that they are providing and receiving better care.

In addition, mHealth services and solutions would not only improve the healthcare provided but it would be a step towards promoting digital inclusion for communities and patients who are usually excluded as they are often poor, have low literacy levels and low ICT literacy. In other words, offering mHealth services and solutions to these communities may actually provide a path towards general digital inclusion.

In terms of apps for mobile phones/smartphones, this is only just beginning to develop in Brazil; development and user interest is slowly beginning and the few applications that are used are mainly developed in the US. In fact, an environmental scan only revealed one mobile phone application developed and used in Brazil; an app for diabetes management that can be used by both patients and doctors.[3] It can be used via the mobile phone and/or the Internet. The system allows the users to record their blood glucose level, meals and doses of insulin. It basically enables an automatic calculation of carbohydrates and of the insulin doses that should be administered. In 2002, when developers first introduced their idea for this system to investors in Brazil, the US and Europe, they were up against a wall. People simply did not understand what they were talking about or see the need for such a system. Today, the situation is very different as there is not only much more awareness about the potential of mobile technologies and applications, but also the focus on chronic conditions such as diabetes and their strain on the healthcare systems are more widely recognised as a real challenge globally.

[2] This project finished in 2010 but a follow-up is currently being developed which will address some of the problems encountered in the initial project. This follow-up will develop a much simpler system which allows doctors (independent of their IT skills) to easily change the parameters and configurations.

[3] One of the founders behind this system and application is a MD who has diabetes I. The system was thus developed (started in 2002) to provide an easier way to manage her condition. An updated version is currently planned for release in September 2012 which will add diet control to its functionalities. At the time of the interview, the system had a total of 4129 registered users (3831 patients and 298 doctors).

4.4 User acceptance and usability

As several interviewees stressed, however, mHealth solutions, devices and applications must be intuitive and easy to use, for example with supportive images and other visualisations. This point is particularly important because many patients and healthcare professionals may have little or no ICT skills, including unfamiliarity with devices such as smartphones. All too often developers fails to recognise this or simply cannot imagine how even simple functions may actually cause problems for inexperienced users. An example from a trial of a mobile system for monitoring and managing diabetes is very telling:

During a clinical trial with end users, the developers would occasionally call participants to hear how they were getting on. They called participants on the smartphone they had been given and that had the system installed. One of the participants never answered her phone despite numerous phone calls. This led the developing team to worry that there was some kind of technical problem with her smartphone and the system. However, during a face-to-face meeting with all the participants, it transpired that this particular patient's smartphone was working perfectly and she had been able to use the system without any problems. The reason why she had never answered the phone when it rang was simple: she didn't know how to! She had been taught how to use the diabetes management system on the smartphone but she had not been trained in using the smartphone as a normal phone, or in any of its other functionalities; she could use the system but she could not pick up the phone.

The fact that many patients may not know how to use mHealth devices and applications was stressed by several respondents. Experience has shown that the technologies give good clinical results and improve patients' quality of life but for many patients they may be too difficult to use. This is related to the distinct rural-urban divide that exists in Brazil which also affects access to and the quality of medical services and medical technologies. Doctors and even basic medical services are concentrated in big cities and capitals. In terms of diabetes, one of the goals behind the mobile system developed by one of the respondents was to also reach those patients who do not live in the capitals or big cities.

The issue of user acceptance was also seen as directly related to costs; if patients were able to pay and considered the cost to be reasonable they would more readily accept mHealth applications and services. Costs, rather than issues of trust or privacy, were considered to be the main factor affecting user acceptance.

Connectivity issues were considered by one respondent as a major factor to consider when discussing user acceptance. There are two dimensions to this issue: the cost and the reliability. Internet connection is still very expensive in Brazil and therefore excludes a large part of the population from being online. Furthermore, the poorer part of the population may often have very limited or no experience in using the Internet. In terms of reliability, those users who have Internet connection either at home or via their mobile/smartphone often experience poor connectivity, i.e. no signal, low speed, a weak signal, and this of course frustrates many users and certainly does not promote online services. The instability of Internet connections throughout the country, albeit most noticeable in rural and remote areas (which, as a respondent pointed out, ironically would be those areas where people could benefit tremendously from eHealth and mHealth), is the most basic problem that must be solved. Neither patients nor healthcare professionals will be inclined to adopt Internet-based services if their experiences with connectivity are negative.

On the other hand, when it works, patients and doctors alike have responded very positively. The different small-scale pilot projects that some of the respondents have been involved in have all had very positive response from users. This was explained very simply: If people can avoid travelling long distances to the hospital or clinic for a check-up or diagnosis, but instead get the doctor to check symptoms using a webcam they will happily do so. This is particularly true for the poorer people who

have to travel very far and who may find it difficult to pay for this travel. It makes their lives easier and actually provides healthcare access to a part of the population who otherwise would not have access simply because they cannot afford to travel to the clinic or hospital.

Experiences with a mobile system for diabetes management have also been very positive and show improvements in the patients' health status and quality of life and time savings for doctors.

4.5 Regulatory frameworks

While there are general laws regarding medical practice, protection of data and technology which can be seen as affecting telehealth, the interviewees were not aware of any regulatory frameworks or policies specifically aimed at mHealth. The existing general laws ensure proper and ethical conduct (particularly in terms of medical practice) and they protect both the practitioner and the patient. In terms of mobile applications and technologies aimed at healthcare, the regulatory framework that is applied depends how the technology is classified, e.g. if it is classified as a medical device. However, when it comes to systems or applications that are not used for diagnosis or for providing specific medical treatment, the consensus was that there are no regulations so far because eHealth services still constitute a new area that the authorities have yet to figure out how to regulate.

One respondent mentioned the National Regulatory Agency for Private Health Insurance and Plans (Agência Nacional de Saúde Suplementar - ANS) which is in charge of the health plans sector in Brazil. It is linked to the Ministry of Health. The challenge of dealing with the growing group of patients with chronic conditions has motivated the ANS to more and more regard eHealth and mHealth as an important part of the solution and to promote the development of online and mobile tools for chronic disease management.

When discussing the absence of (specific) regulatory frameworks, interviewees suggested that this could be regarded as positive thing as regulatory frameworks might work to hinder the development and deployment of mHealth solutions. Obtaining funding and carrying out field trials for mHealth solutions and services can already be quite difficult and if specific mHealth regulatory frameworks were in place it could mean more obstacles in the way.

One respondent described how the process in securing funding for the development of a mobile solution for monitoring diabetes had run into barriers due to some regulatory issues. These barriers were considered unnecessarily cumbersome and with no real purpose, but rather were examples of how bureaucracy and inflexible regulatory constraints create obstacles to progress and development.

On the other hand, the absence of regulation for eHealth and mHealth services may also prevent some healthcare authorities and providers from adopting these services because there is no formal approval in place for them. The same may apply when trying to secure funding for a project. Investors are not willing to invest if the regulatory framework is either unclear or absent; they simply become worried that some unforeseen regulatory instance is going to stop the product from entering the market. Clear regulatory frameworks may impose certain requirements that may be difficult to meet, but an unclear or absent regulatory framework invokes uncertainty about how to ensure the product will be approved.

4.6 Barriers and drivers

The economic aspect of mHealth technologies and services was considered to be one of the most – if not the most – important factor, acting as either a driver or an inhibitor of mHealth both in terms of research and development, testing, implementation, deployment and user acceptance. As one respondent pointed out, the technologies enabling mHealth is available, but in the end the cost of using them (mHealth services and solutions) is what ultimately determines their fate. If costs were

less usage would be much higher overall. The possibility of having wireless and mobile access to the Internet is something most users would definitely opt for: it is easier and more practical for everyone. People would like to be more mobile (be online and mobile), however, the rates for accessing the Internet via the mobile phone continue to be very high and therefore most people simply opt out. As long as the number of wireless mobile online users remains low the use of mobile health application and services will also be low.

The technology to spread public health messages and basic health education (e.g., informing about a dengue outbreak and what symptoms to watch out for) via mobile phones, e.g. text messaging, is available and quite simple and easy to use, but the problem is who is going to pay for it. Payment and reimbursement issues are yet unresolved. The healthcare system cannot pay for it and patients cannot and should not pay it (public health information services should never be paid for by the public directly) and the tele-companies are not willing to pay for it. The tele-companies are only interested in making a profit and they are (to date) not interested in nor obliged to provide a public health service. However, as one respondent pointed out perhaps they ought to because they are making a lot of money and can certainly afford it.

The fees charged for regular mobile phone usage (calls and text messaging) is still very high in Brazil, effectively excluding a major proportion of the population from using their mobile phones for other than receiving calls and messages. In short, the problem is not necessarily getting funding for developing a mHealth service or solution, but the problem is the costs of maintaining it. One proposed solution, or a prerequisite for the solution, is to use (and provide) free software and use cloud computing; doctors and patients would then at least not need to worry about maintaining the system.

However, the issue of trust in connectivity was also mentioned as an important factor that works as a barrier. Currently, both fixed and mobile connections are still not stable enough particularly in areas outside the largest cities. Until this problem gets solved eHealth and mHealth cannot be fully exploited, even simple solutions like providing public health information via text messaging cannot be considered trustworthy because the network connection is too unstable and often fails. Therefore, television still remains the primary and most optimal media for public health information and education.

When discussing the issue of securing connectivity and bandwidth to eHealth and mHealth services this was considered something that would have an extremely positive effect on the future development and deployment of eHealth and mHealth in Brazil. Some respondents expressed the opinion that this issue was bound to be established and resolved in the near future (although no real or current initiatives for this purpose were known), simply because it will be necessary. RUTE and Telehealth Brazil were mentioned as having taken a first step in this direction by the establishment of a network infrastructure (online communication points) specifically for medical research and telehealth. One could envision a national plan that guarantees users fixed low prices for mobile networks and Internet connections used specifically to access and use eHealth and mHealth services, solutions and applications. This would help to overcome the cost barrier for the uptake and deployment of mHealth.

4.7 Conclusion

mHealth is still very much in its beginning phases in Brazil. The main focus is still on providing online links between medical centres aimed at healthcare professionals and medical students. In relation to the public, focus is mainly on providing public health information and education particularly in schools. General public health information on outbreaks of epidemics such as dengue or malaria is still transmitted via radio and television as these are the most effective media channels at

present, particularly when addressing rural and less literate (illiterate in general and ICT illiterate in particular) groups of the population.

However, the respondents agreed that in general many doctors and patients alike are quite positive towards eHealth and mHealth. Nevertheless, there are some very fundamental barriers that need to be overcome, mainly the instability of the Internet and mobile network and the costs, in particular the core cost of using a mobile phone or accessing the Internet). Regulatory frameworks and policies directed specifically at eHealth and mHealth were not known and this lack was mostly seen as a barrier. Uncertainty about regulatory issues and methods for approval for mHealth services and application did not necessarily mean a ready acceptance of anything out there, but rather instigated a hesitancy in adopting mHealth because there was no way of knowing if it violated any regulation and thus risked disapproval later on.

In conclusion, respondents were quite confident that eHealth and mHealth services and applications are the future and will become more widespread in Brazil if the main challenges of network infrastructure and costs are overcome. The possibilities of the internet are considered unlimited, but the problem is to tap into these possibilities because first of all this requires a stable and trustworthy connection. Respondents could easily envision using mobile phones for remote and instant medical assistance, such as for emergencies (remote consultation) or for chronic patients to receive medical advice or assistance.