

Home Monitoring in Portugal

An Overview on Current Experiences

Ana Dias¹, Madalena Vilas Boas¹, Daniel Polónia¹, Alexandra Queirós² and Nelson Pacheco Rocha³

¹*Department of Economics, Management, Industrial Engineering and Tourism, University of Aveiro, Campo Universitário de Santiago, 3810-193 Aveiro, Portugal*

²*Health Sciences School, University of Aveiro, Campo Universitário de Santiago, 3810-193 Aveiro, Portugal*

³*Department of Medical Sciences, University of Aveiro, Campo Universitário de Santiago, 3810-193 Aveiro, Portugal*

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Abstract: This paper aims to be a contribution to the discussion on the issue of innovation in healthcare since, in the author's perspective, the health sector, and particularly the Portuguese National Health Service, needs changes in its "business model". There is a need of redirecting care provision to the citizen's natural environment, namely considering the opportunities offered by information and communication technologies. For this purpose the authors surveyed projects already implemented in Portugal, within the Portuguese National Health Service, related to home monitoring, in order to make a critical analysis of the state of the art of ongoing projects. In this study, the authors identified four pilot experiences of home monitoring, all targeted at chronic disease. In spite of some results of these experiments are already known, there is a shortage of available information and scientific evidence, both about the implementation processes themselves and about their clinical, technical and economic evaluation, which, in the opinion of the authors, also hinders their assessment and dissemination.

1 INTRODUCTION

The Portuguese National Health Service (Serviço Nacional de Saúde - SNS) presents difficulties in the coordination between levels of care, particularly among primary healthcare and hospital care, which has an impact on patient access to healthcare (Barros and Simões, 2007).

Traditionally, acute diseases were the main concern of health systems, a situation that has changed over the last century, as a result of advances in biomedicine and public health, with a significant impact on the eradication of certain infectious diseases. What is questioned today is whether, with regard to the organizational model of health systems, they fit the current reality where chronic diseases are predominant (Dias, 2015).

Data from the National Health Survey (INS, 2014) are indicative of the new challenges of the Portuguese SNS. In 2014, more than half (52.8%) of the population aged 18 years, was overweight (50.9% a decade ago). The symptoms of depression also worsened, affecting more the retired population (36.5% of the retired population had symptoms of

depression, compared to 18,5% of the employed population). Also the percentage of people who reported consuming prescribed drugs increase sharply with age: more than 90% of the population over 65 years. Comparing the results for chronic diseases collected in two surveys (2005-2006 and 2014) it is clearly an increase of the percentage of population affected by these diseases (INS, 2014).

The aging process that the Portuguese population is suffering further enhances this scenario. The National Statistics Institute (Instituto Nacional de Estatística - INE) forecasts that the potential sustainability index (i.e. the ratio between the number of people aged between 15 and 64 and the number of people aged 65 and over) may decrease abruptly: in Portugal, between 2012 and 2060, this index, in one of the most likely scenarios can change from 340 people in working-age for every 100 elderly to 149 people in working-age for every 100 elderly, a value that can decrease to 111 people in working-age for every 100 elderly in the worse-case scenario (INE, 2014a).

We are at a very particular moment of our history in which a "demographic transition" is

combined with "an epidemiological transition" and "this combination of phenomena is confronting us with a crisis (...) which comes as an opportunity to look critically at what has been done and, based on that, project us in the future with more appropriate tools and skills to new circumstances." (OPSS, 2016, p. 31).

This study thus seeks to contribute to the discussion on the theme of innovation in healthcare in Portugal, taking advantage of the opportunities offered by information and communication technologies. In particular, given the home monitoring potential, which is supported on the progress achieved in mobile technologies, as well as its relevance to chronic diseases, this study aims to analyze the viability of experiences already implemented in Portugal related to home monitoring of patients with chronic diseases.

2 RELATED WORK

In Portugal, via the 3571/2013 Order, published in the Official Gazette on March the 6th, 2013, the Ministry of Health, assuming that the use of telemedicine allows the observation, diagnosis, treatment and monitoring in a more convenient place for patients, particularly at home, states that "the services and facilities of the National Health Service (SNS) should increase the use of information and communication technologies in order to promote and ensure the provision of telemedicine services to [its] users" (p.8326).

According to INE, on its Survey on the Use of Information and Communication Technologies in Hospitals (INE, 2014b), one third of the Portuguese hospitals developed telemedicine activities in 2014, an increase of 16 percentage points in ten years (12 percentage points in the last four years) (Figure 1). However, the degree of implementation of telemedicine is quite different in public hospitals (51%) and private hospitals (15%).

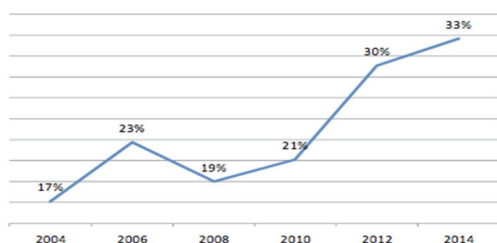


Figure 1: Proportion of hospitals with telemedicine, Portugal, 2004-2014 (Source: INE, 2014b).

Telemedicine activity can take many forms, ranging from remote diagnosis (teleradiology and telepathology) to remote care provision, such as teleconsultation or home monitoring. Within telemedicine activities, the most used was teleradiology (i.e. the exchange of images to discuss cases and for diagnosis), being reported by 84% of hospitals that refer having telemedicine. On the other hand, only 31% of hospitals that report having telemedicine provide teleconsultation (i.e. 10% of the total hospital's number) (INE, 2014b).

As a result of the telemedicine development, Portugal is involved in several international projects to promote the cooperation between healthcare professionals. In particular, there are some projects with the African Countries with Portuguese as an Official Language (Países Africanos de Língua Oficial Portuguesa - PALOP) (Borja-Santos, 2013). In October 2013 it was launched a telemedicine platform between Portugal and several PALOP (Noronha, 2013) but, previously, there were other projects. For example, in 2012 a project between Portugal and São Tomé and Príncipe allowed an estimated saving of 180,000 euros in the transfer of patients to Portugal and allowed to save one million euros to the Portuguese Ministry of Health (Noronha, 2013). Portugal is also part of a telemedicine network with Angola and the University Hospitals of Geneva that allows technical support for diagnosis and treatment of Angolan patients.

In addition to the experiences within the PALOP, there are others being carried out between Portugal and Spain. Since 2003 the southern region of the Algarve has participated in a telemedicine project in conjunction with the Spanish region of Andalusia, with the aim of creating new communication channels between the Algarve and Andalusia and, inside the Algarve, between the health centers and the hospitals in the region, with the installation of telemedicine equipment in all health centers (Portal da Saúde, 2005).

With regard to teleconsultation, in 2007, it was launched in Portugal the "Linha de Saúde 24", which provides counselling and referral in a disease situation, accessible through the phone (or chat for people with special needs) as well as therapeutic counselling to clarify particular questions and provide support related to matters as medication (Saúde 24, s.d.).

Within a group of other innovative projects in this area, out of the governmental sphere, the authors highlight two: the "Patient Innovation", a social network for patients who, sharing experiences about

their illness, can develop solutions to their real problems, from therapeutic support to proper medical equipment (Pinho, 2013) and a private service that allows traveler teleconsultations (Consulta do Viajante, 2016).

Specifically, in the region of Alentejo (one of the most aged and sparsely populated regions of the country) several teleconsultation experiments (Oliveira et al., 2014) were reported, dating back to 1998, in order to respond to challenges such as desertification, isolation, low population density, poverty, lack of medical resources in several specialties as well as poor public transports, all of which have acted as barriers to access to healthcare in the region. It should be noted that the Alentejo region represents approximately one-third of Portugal's continental territory, but it is home to only 5% of its population. Teleconsultations are available in 15 medical specialties, ranging from Neurology to Pediatric Surgery. The network includes 20 primary care units and five hospitals, covering almost 30,000 km² and around 500,000 people. A comprehensive assessment of the costs and consequences of the program is currently underway, since it is stated that there is a lack of evidence of its cost-effectiveness, which, according to Oliveira et al. (2014), hinders the sustainment and realization of the promise of innovative solutions, wherever it is implemented.

Regarding the autonomous islands, the Azores already belongs to several networks, which allows the realization of teleconsultation to determine the clinical need of the patient's displacement to mainland to carry out consultations and exams (Mourato, 2014). In the Azores the use of teleconsultation in Nursing is also frequent, particularly in decision support in the treatment of wounds. Furthermore, there is already teleconsultation in various health centers in the archipelago in the following specialties: Nephrology, Pediatric Cardiology, Neonatology and Endocrinology.

Home monitoring can improve disease prevention, facilitate chronic disease management, including disease self-management, enable personalization of care, and improve productivity in healthcare, thus allowing a more rational use of health services (Queirós et al., 2013; Queirós et al., 2017). In Portugal, according to the Order 8445/2014 of June the 30th, 2014, the Ministry of Health stressed the need to improve the capacity of health monitoring, prevention, detection and treatment of disease in innovative ways, including through models of care in order to maintain people

in their homes, promoting their autonomy and encouraging personal responsibility by adopting healthy lifestyles. However, there are no studies reporting the current experiences of home monitoring in Portugal.

3 METHODS

Considering the lack of evidence of current Portuguese home monitoring experiences, the present study has the following main objectives:

- To make an inventory of projects already implemented in Portugal, within the SNS in the area of home monitoring, particularly focused on the chronically ill, and preferably projects involving primary healthcare, which is believed that will assume an increasingly central role in the management of chronic disease.
- To make a critical analysis of the state of the art of ongoing projects.

The authors consulted the Central Administration of the Health System (Administração Central do Sistema de Saúde - ACSS) in order to retrieve information on projects related to home monitoring already implemented by the SNS.

Subsequently, an additional survey was conducted to analyze if there were publications that best described these experiences and others in the same area, and possible results already obtained.

Finally, the authors conducted a survey on the web pages of SNS hospitals to search for innovative projects in general, and home monitoring in particular. For this purpose, the web pages of 41 hospitals were identified and analyzed.

4 HOME MONITORING EXPERIENCES IN PORTUGAL

With data provided by the ACSS it was possible to identify three projects related to home monitoring already implemented by the Portuguese SNS. In the area of Pulmonology, a home monitoring pilot program of chronic obstructive pulmonary disease was developed, funded by the ACSS and supported by Shared Services of the Health Ministry (Serviços Partilhados do Ministério da Saúde - SPMS), the government agency for eHealth, in partnership with five hospitals, covering a total of 75 patients with severe disease (15 per hospital). These patients were selected in each hospital by their attending

physician, based on their prior history of chronic obstructive pulmonary disease. This home monitoring pilot program began in 2013 and was implemented in a phased manner in the five institutions, namely: Hospital of Faro (Algarve) - beginning in August 2013 (Phase 1); Hospital Pêro da Covilhã (Cova da Beira) - beginning in March 2014; Hospital and University Center of Coimbra - beginning in May 2014; Hospital of Viana do Castelo (Alto Minho) - beginning in October 2014 and Hospital of Portalegre/Elvas (North Alentejo) - beginning in October 2014. Five private companies were also involved in the project and were responsible for the installation of the monitoring devices and their maintenance and for the process of gathering information and transfer it to health professionals. Each patient was assigned the following monitoring devices: blood pressure measuring device, pulse oximeter, thermometer, odometer, device monitoring heart rate and mobile phone. The clinical teams of the hospitals were actively involved in the monitoring of patients integrated in the program and also in their education. According to SPMS (2014), under this pilot program, patients are monitored in their homes. The respective data are then analyzed twice a day by the Pulmonology teams of involved hospitals, trying to reduce the aggravation of their clinical situation, thus avoiding new hospital admissions.

The objectives and results to be achieved in 2016 within the home monitoring program for chronic obstructive pulmonary disease include (ACSS, 2016): raising the quality of services provided to citizens, promoting the continuous monitoring of their health condition; reducing at least one episode of annual hospitalizations as a result of the deterioration of the patients medical condition; reducing at least three episodes of urgency per year; reducing at least two episodes of outpatient consultation per year, and follow, proactively and continuously, the fluctuations of the health conditions of each patient.

In terms of preliminary results of this pilot program, according to Pereira (2016), these have been encouraging, both in terms of satisfaction and health indicators, having already been released some results of an evaluation carried out in the Local Unit of the Alto Minho, namely the reduction in 50% of visits of these patients to emergency services, as well as a decrease in the number of hospitalizations (70%). Pereira (2016) also states that in these five hospitals, 61% of patients considered the quality of the service as "very good or excellent". Although the final overall results are not yet available due to the

late start in one of the hospitals, interim evaluations reveal both a reduction in the number of hospital admissions or visits to the urgency services of patients, more evident in some hospitals.

More recently, in November 2015, the "Home Monitoring Plan" was adopted for the definition of sites for the realization of home monitoring and its articulation with the rules of the SNS.

In this context, and for the year 2016, it was contracted activity for the implementation of other two home monitoring pilot programs: a Pilot Program for Home Monitoring of Acute Myocardial Infarction and a Pilot Program for Chronic Heart Failure. Like the pilot program of chronic obstructive pulmonary disease, it was planned that the program would be implemented in five hospitals covering a group of 75 patients (15 per hospital).

In the case of the chronic heart failure, and in the absence of results which can be explained due to the program's newness, it should be noted that from conventional remote monitoring to more recent strategies, using cardiac devices or implantable hemodynamic monitors, this is a topic under active investigation, but, despite previous meta-analyses of small studies have documented the potential benefit of home monitoring, major randomized clinical trials have failed to demonstrate the positive impact of this strategy. In addition, data on the value of the latest monitoring devices are contradictory, since some studies have documented potential prognosis benefit while others cannot confirm it (Sousa et al., 2014).

As a result of the literature review carried out in scientific databases, the authors found a concrete example in Portugal of assessment of a home monitoring experience in cardiac patients, with four hospitals involved. This study, of 2013, indicates that the introduction of home monitoring has the ability to reduce in 25% the costs of monitoring the patients (Costa et al., 2013).

To broaden the scope of this research, and to identify innovative projects, in general, and home monitoring, in particular, the authors decided to search for information on the web pages of the SNS hospitals. From the 41 organizations identified six refer teleconsultation activities on the following areas: Dermatology (referred by three organizations), Pediatric Cardiology (two organizations), Internal Medicine, Endocrinology, Rheumatology, Oncology, Neurosurgery, Pediatrics, Gynecology, Ophthalmology, Genetics, Imaging and Pathology (all referred only by one organization).

However, no organization mentions any home monitoring experiment.

5 DISCUSSION

The main purpose of this study was to give visibility to the experiences already implemented in Portugal related to home monitoring of patients with chronic conditions, which the authors believe could permit not to repeat known errors as well as to replicate successes, after being properly evaluated and contextualized. However, it is clear that, although some results of these experiments have been reported in this paper, there is a shortage of scientific evidence regarding, on one hand, the implementation process and, on the other hand, the evaluation of these experiences, what is conflicting to what is defended in the eHealth Action Plan 2012-2020 - Innovative healthcare for the 21st century (Commission of the European Union, 2012), namely: “It is essential to measure and assess the added value of innovative eHealth products and services to achieve wider evidence-based eHealth deployment and create a competitive environment for eHealth solutions.” (p.13)

Regarding the home monitoring pilot projects identified in this work the authors would like to stress that the pathologies covered by the pilot projects correspond to chronic diseases and that they are also within the group of priority areas identified by the Portuguese government in 2013.

Concerning these same projects the authors also want to highlight the fact that in the group of institutions covered by these projects, there are no institutions coming from primary healthcare, at least not in an explicit and formal way. As mentioned before, the authors consider that the primary healthcare services must increasingly be involved because of their close proximity to the patient and their informal careers as well as due to their abilities in the management of chronic disease, even because one of the main purposes of home monitoring is to reduce the number of admissions or visits to the hospital emergency services. It is important to emphasize the significance of primary healthcare in the organization of health systems, recalling what in 1978 was stated in the Declaration of Alma Ata (WHO, 1978) on the importance to be given to this level of care: “Primary healthcare is essential healthcare based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford (...) It is the first level of contact of individuals, the family and community with the national health system bringing healthcare as close

as possible to where people live and work, and constitutes the first element of a continuing healthcare process.” (p.1-2)

Concerning the results obtained from the research on the hospital’s web pages, the authors would like to highlight the scarce information available with regard to innovative experiences, as well as the complete lack of publicizing information about home monitoring. This, from the author’s point of view, can raise questions in particular regarding the opportunities created for patients to participate in these experiences and create obstacles to ensure the equity required in healthcare provision. Despite the fact that, as it has also been demonstrated in this work, home monitoring experiences in Portugal are still small, in number and in size, still the authors would like to discuss the importance of what is (or not) revealed to the public: whether information regarding the experiences as a whole whether information on the criteria for inclusion of patients in these experiments. Another purpose of this advertising is, from the author’s point of view, to emphasize the need to make the whole process more transparent, with particular interest to patients and also to other health professionals and institutions, a similar progress that what has been achieved with respect to clinical trials since 2011. Since then, the information on clinical trials with medicines for human use, which are underway in the European Union, is accessible to all European citizens from the portal “EU clinical trials Register” and, more recently, through the international network of clinical trials registers of the World Health Organization. In Portugal, Law 21/2014 of the 16th April, amended by Law 73/2015 of the 27th July, envisages the creation of the National register of clinical trials. Still, and going back to experiences that are developed within the SNS in Portugal, and highlighting once again the difficulties, specifically in this study, on the collection of information on ongoing initiatives, the authors would like to discuss the pertinence of creating a platform for registering, monitoring and disseminating results of these experiences, similar to what is already being done in the clinical trials domain.

6 CONCLUSION

In Portugal, within the SNS, the authors identified four pilot experiences of home monitoring, all targeted at chronic disease, but with no direct involvement of primary healthcare, at least explicit

in contracts that were made between the ACSS and the primary healthcare services. This somehow contradicts the need to direct primary care for the prevention, with a view to achieve further gains in health outcomes as well as improvements in terms of efficiency.

The authors would also like to point out the difficulty in getting information related to home monitoring experiences taking place in the SNS, from one source, which, from our point of view, should be either the ACSS or the SPMS. In the author's point of view, if this information is not somehow centralized, the evaluation and subsequent dissemination of these experiences will be more difficult to achieve.

It should also be noted that it was not possible to identify evaluation methods with the purpose of, systematically, evaluating experiences, so that the decisions can be based on accurate information, it can be possible to learn from mistakes as well as to innovate by sharing and replicating successful experiences, although this is one of the EU guidelines for the eHealth Action Plan 2012-2020 (Commission of the European Union, 2012).

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