

# Supporting Palliative Care Services

## *An IS System to Monitor the Patients and Manage the Mobile Support Team*

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**Abstract:** The health centers group (ACES) “Douro Sul II” is creating a Community Support Team for Palliative Care (ECSCP) in order to provide palliative care services for the ACES’s population of 73,713 registered users. The team comes as a follow-up from a strategic plan, recently issued by the health ministry, in order to serve the patients in their own homes, providing the necessary support to them, to their families, and their caregivers. This approach has several benefits for the patients and their families, as well as for the healthcare system itself. To further promote the effectiveness of the ECSCP team, it was planned to develop an information system (IS), comprising several application modules, with the main objective to monitor the patients in their homes and deliver information to support the planning and execution of the ECSCP team activities. The system is based on an electronic services platform and several mobile and web applications, to be used by the patients, team’s staff and coordination. This way, we expect to overcome the geographic issues of the ACES territory, as well as the team’s human resources constraints, while remotely monitoring the patients and providing the necessary support, if and when needed, contributing to maintaining the conditions for the patients to live with dignity and quality in the comfort of their own homes.

## 1 INTRODUCTION

The Portuguese Health Ministry published, in 2017, a strategic plan for the development of palliative care for the 2017/2018 biennium (MS, 2016). This plan includes a framework for the implementation of Community Support Teams for Palliative Care (ECSCP). These teams are composed of specialized staff, including: medicine doctors, nurses, psychologists, and social assistants. The main objective is to monitor and support the population in need of palliative care, creating the conditions for them to live in their own homes, autonomously or with support from the family or a caregiver.

The strategic plan document recognizes that when applied early in the diseases progression, the palliative caring has benefits for the patients and for their families. It reduces the problems associated with the symptoms as well as diminishes the physical, psychological and emotional burden imposed to the patients and their families. The benefits for the health care system are also significant, including the reduction of: the hospitalization durations; the

number of hospital readmissions; the unnecessary treatments; the usage of emergency services; thus, prompting a general reduction of the global healthcare costs (ANCP, 2006).

The ECSCP teams can be described as:

- A multidisciplinary team with their own resources and managed at a regional level;
- A provider of specific support and counselling regarding palliative care for all the regional health units;
- A provider of home palliative care for patients with complex palliative necessities, their families and caregivers;
- A provider of training in palliative care for the families, health professionals, and for the home caregivers;

The creation of the ECSCP teams meets the basic principle of palliative care by respecting the patient right to choose the place where he wants to live at the final stage of his life and, in case the patient choses his own home, creating the conditions for the patient to have all the necessary support to continue to live

with dignity and quality in the comfort of his own home. These teams are particularly important in territories where the population is geographically scattered and the patients need to travel great distances to access the health services.

## 2 THE SOUTH DOURO CASE

This paper addresses the case being developed by the health centers group (ACES), named “Douro Sul II” after their geographic location.

### 2.1 The Douro Sul II ACES Area

The Douro Sul II area of influence is the combined areas of the following counties: Armamar, Lamego, Moimenta da Beira, Penedono, São João da Pesqueira, Sernancelhe, Tabuaço, and Tarouca. The Figure 1 represents a map of this area, south of the Douro River, which corresponds to a large area of 1,366.7 square kilometres with a scattered population of 70,803 inhabitants, accounting for a population density ratio of 51.8 inhabitants per square kilometre (ARSN, 2012). In this area, the weather is mainly continental with very cold winters and very hot summers.



Figure 1: The geographic area of ACES Douro Sul II (source: [http://portal.arsnorte.min-saude.pt/ARSNorte/dsp/ACES/PLS2012\\_1923\\_DouroSul.htm](http://portal.arsnorte.min-saude.pt/ARSNorte/dsp/ACES/PLS2012_1923_DouroSul.htm)).

Consider the aging index defined as the ratio between the elder (65 or plus years old) and the youth (14 or less years old) populations.

According to recent data, from April 2017, the Douro Sul II ACES has 73,713 registered users (SIARS, 2017), representing an aging population, which, according to Figure 2, has an increasing aging

index, from 76,7% in 1991 to 164,0% in 2011 (Pordata, 2011). This increase over the years is mainly due to the decrease of the birth rate, the increase of the life expectancy, and the reduction of mortality.

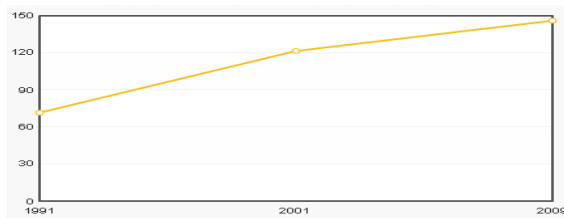


Figure 2: Evolution of the aging index (1991 to 2009). (source: ACES Douro Sul II).

In short, it is a large area, with a wide weather temperature range, and geographically scattered and aging population.

### 2.2 The ECSCP Team

The ECSCP team will serve all the 73,713 users, registered in the health units of the area of the ACES Douro Sul II, and has the following operational objectives:

- Provide home support to patients and caregivers with the help of a remote monitoring system.
- Control the patient’s symptoms.
- Increase the ratio of patients living in their homes with the team’s support.
- Reduce the need for hospital admissions and the usage of emergency services.
- Support the patients’ families and caregivers.

As defined by a regulatory document from the Health Services Central Administration (ACSS), there should be a dedicated ECSCP team for each group of 150,000 inhabitants (ACSS, 2017). In the ACES Douro Sul II case, and considering its characteristics, the ACES proposes a ECSCP team formed by:

- Medical doctor (35 hours/week);
- Nurse (35 hours/week);
- Psychologist (8 hours/week);
- Social services (6 hours/week).

This team will provide services every day, from 8am to 8pm in the working days, and from 9am to 5pm on the weekends and holydays. A 24h permanent telephone support service will be available, providing coordination for urgent visits and proper cooperation with the hospitals units in order to support and follow-up the users to the most suitable hospital unit.

### 3 THE INFORMATION SYSTEM PROPOSAL

The University of Trás-os-Montes and Alto Douro (UTAD) has been deeply involved in researching and development projects related to the usage of information technologies (ICT) to support healthcare services, disable users and elderly people (Reis et al., 2016 a), 2016 b), 2017; Paulino et al., 2017). This proposal came as a natural follow-up to use ICT in order to maximize the efficiency and effectiveness of the Douro Sul II ACES's ECSCP team.

The information system has three main objectives:

1. To monitor the users served by the ECSCP team, proving information to the team about the evolution of the health status of each patient, and providing an access channel to communicate with the ECSCP team and have their best support.
2. To support the operation of the ECSCP team, e.g., interaction with the patients, data requests and collection from the patients, data visualization, planning and home visits registration, tracking and registering the patients' access to the healthcare services.
3. To support the management of the ECSCP team by compiling information and indicators related to the development of the team's activities.

#### 3.1 Architecture

The system is composed by five modules:

1. An electronic services platform, hosted on the cloud, including: a database system to store information; the application logic software modules to manage information and provide electronic services for the user's applications; an application programming interface (API) for further user's application development.
2. A monitoring mobile application (for mobile devices), to be used by the patients and their caregivers.
3. An operations mobile application to be used by the ECSCP team operative staff.
4. A management web application, to be used by the (and for the) management of the ECSCP team's activities.

The Figure 3 represents the system's architecture, including some of its functionalities and technological characteristics.

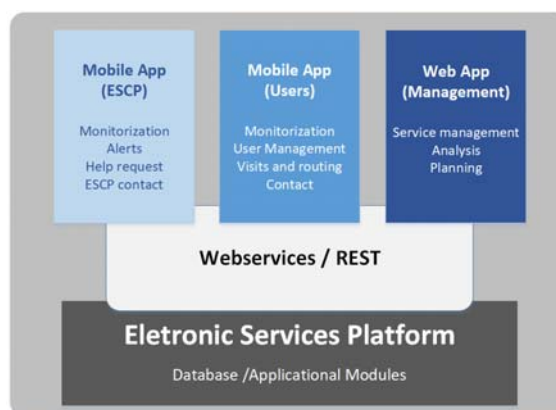


Figure 3: System architecture.

#### 3.2 Functional Description

##### 3.2.1 Electronic Services Platform

The electronic services platform is an online system, with the proper characteristic for the implementation of specific applications, by providing electronic services, accessible over the internet, using standard protocols for software integrations. It includes: database for persistency; software components for basic application logics; electronic interface, e.g., webservices, REST, for integration and interoperability.

##### 3.2.2 Monitoring Mobile Application

This application will be used by the patients and will acquire and collect information regarding the evolution of their health status, as well as other data, including their health related needs and routes on the healthcare system units. The application's user interface will be carefully designed and developed, according to the NO INTERFACE and adaptive interface paradigms (Carrol et al., 1991; Santos et al., 2011; Stephanidis, 2001; Kamberov et al., 2017), so it can be easily used by patients with physical or cognitive disabilities. Some data collection will be based on questionnaires surveying configured by the ECSCP team. Other forms of interaction (Marcelino et al., 2009; Felisberto et al., 2015; Abreu, 2017) are also accounted for although in this case we opted to keep it as simple as possible.

##### 3.2.3 Operations Mobile Application

This application will be used by the operative staff of the ECSCP team to: view the status of each patient; view the monitoring results as collected by the monitoring application; plan and register the home

visits to the patients; configure the individual monitoring parameters for each patient; provide an overall perspective of the patients' population while the team operates in a mobility context; support the coordination of forwarding the patients throughout the healthcare system units.

### 3.2.4 Management Web Application

The management application will be used by the ACES to plan and coordinate the program of palliative caring. It should provide information regarding: the evolution of the patients' support service; a view of the geographic localization of the patients and the team visits; a perspective of the routes of the patients thought the units of healthcare system; the management of the ECSCP visits routes.

## 4 CONCLUSION

This paper reports the inception of a project to use ICT as tool to further improve the results of a multidisciplinary palliative care team, about to be introduced by the national healthcare system. The case of Douro Sul II presents a context which is particularly appealing due to the geographic dispersion, isolation and aging of the population. This scenario might benefit from the introduction of remote monitoring and other telematics related tools. A first beta deployment is scheduled to early 2018 and the further developments will be incremental and based on the results of each successive iteration. That way, we expect to better understand the problem and to better design an ICT solution.

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