A Digital Platform for Paediatric Palliative Care

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Abstract. Around 21 million children worldwide require Pediatric Palliative Care (PPC), yet access remains scarce, with only 5.7% of countries offering adequate services. In Portugal, despite ongoing efforts, timely referral to PPC is limited, though tools like the PaPaS Scale help identify children needing specialized care. The country's hospitals vary in capacity, but lack a formal system to coordinate PPC across centers. Unidade Local de Saúde Santa Maria is leading research to better understand PPC needs and improve service organization nationally. To address data challenges, we propose a secure, user-friendly digital platform that encloses a Clinical Data Registry for PPC clinical data and will enhance PPC coordination across hospitals.

Keywords: Pediatric Palliative Care · Clinical Data registry · Cybersecurity · Digital Platform.

1 Introduction

In 2018, the World Health Organization estimated that 21 million children needed Pediatric Palliative Care (PPC) annually. While medical advances have improved survival rates for children with Chronic Complex Diseases (CCD), this has led to more frequent and costly hospitalizations with higher mortality. Despite the growing need, only 5.7% of countries have adequate PPC services [5].

In 2018, an estimated 7,828 children and young people in Portugal needed PPC, with around 200 dying annually from CCD — half within their first year, mostly in hospitals (`https://icpcn.org/`) [1]. Despite efforts, access to PPC and timely referrals remain limited. The PaPaS Scale [1, 8] is a validated tool that helps to identify 1- to 19-year-olds with CCD and palliative needs, supporting earlier referral to PPC specialists [2, 6].

Hospitals in Portugal are categorized into levels based on their capabilities, with level III being the most advanced, including five major university hospitals. Smaller level I and II hospitals offer limited services but can support patient care locally, easing the burden on larger hospitals. Better coordination between hospitals could improve resource use, but currently, there is no formal system for coordinating palliative care across hospitals.

The *Unidade Local de Saúde Santa Maria* (ULS SM), a level III center, is developing a strong PPC team and leading a multicenter study to profile children and youth with CCD and palliative care needs in Portugal. The study aims to determine the required levels of PPC and support improvements in PPC structure and organization, potentially forming a national PPC network.

In Portugal, while many medical specialties use advanced Clinical Data Registries (CDRs), PPC still relies on individual Excel files to manage patient data. These basic CDRs, maintained separately by physicians, hinder data integration, scalability, accessibility, and usability. This fragmented system complicates data entry, access, and analysis, making it difficult to understand patient populations and monitor their clinical progression.

At INESC-ID, in collaboration with the PPC leader at ULS SM, we are developing a digital platform to enhance PPC in Portugal. It includes: (i) a clinical data repository (CDR) for storing comprehensive patient data from multiple hospitals; (ii) cybersecurity measures like role-based access control and data anonymization; and (iii) a user-friendly interface to help physicians easily input, access, and visualize data, improving efficiency and reducing errors.

This paper is organized as follows: Section 2 summarizes the existing clinical data registries in Portugal; Section 3 briefly details the digital platform we are developing; finally, Section 4 concludes by listing ongoing work.

2 Related Work

In 2022, Portugal had a total of 108 patient registries, including 76 national and 32 international registries, covering 19 different medical specialties or diseases. All these registries collect data on the Portuguese population. Some of the most frequently mentioned registries in scientific literature, according to [7] usually cover one medical specialty or part of it. The most cited include Reuma.pt (`https://reuma.pt/`), RON (`https://ron.min-saude.pt/`), and ProACS (`https://spc.pt/`). The primary aim shared by all these registries is to collect data and support analysis to improve patient care.

None of the 108 existing registries in Portugal specifically address PPC, which is currently marked by isolated, centralized interventions, poor coordination, and limited home and psychosocial support. Given the proven value of CDRs in other specialties, this highlights a critical need for a dedicated PPC CDR to support better care for children with CCD.

3 Digital Platform for Paediatric Palliative Care

3.1 Architecture and PPC CDR

The proposed PPC platform is structured in a basic client-server architecture: a relational database, a web server, and one or more web clients.

The platform's relational database, called the **PPC CDR**, stores all data collected through the platform and was designed based on input from the PPC physician at ULS SM. Centered around the Patient entity, it includes key attributes like name, health service number, gender, and birthdate, along with

additional details such as education level, disease characterization, current therapies, palliative needs group, referral information, PPC interventions, and family caregiver data.

3.2 Data privacy / Access control

The platform uses **Attribute-Based Access Control** (ABAC) [4] for data access, a fine-grained model that evaluates access requests based on attributes of the subject (e.g., hospital, medical speciality), the resource (e.g., hospital, data group) and the environment (e.g., IP address, time of access). In this model, policies are evaluated to determine if the combination of these attributes satisfies the defined access rules, with the policy decision point applying the appropriate algorithm to grant or deny access.

In line with the ABAC model, the CDR for PPC defines two roles: the *Super Administrator*, who manages platform-wide tasks like adding hospitals and assigning Local Managers to hospitals, and the *Local Manager*, who manages users and resources within a specific hospital, including linking physicians to hospitals and setting access rules.

To protect sensitive data, the system uses client-side encryption and adopts **Attribute-Based Encryption** [3] for end-to-end security, ensuring only users with the right attributes can decrypt and access the data.

3.3 PaPaS scale

Currently, the platform offers basic functionality, allowing physicians to register patients and manage user access within their hospital.

The **PaPaS Scale**, integrated into the platform, assists physicians from different specialties in identifying children with CCD who may benefit from PPC, promoting timely referrals. After referral, the scale is used every six months to monitor clinical progression, with each assessment timestamped and linked to the patient's record (see Figure 1). This enables tracking changes over time and adjusting care plans.

4 Conclusion and Future Work

This paper briefly presents a project curently under development at INESC-ID that aims at building a digital platform for PPC, first in cooperation with ULS SM and then extensible to other Portuguese Hospitals with PPC teams.

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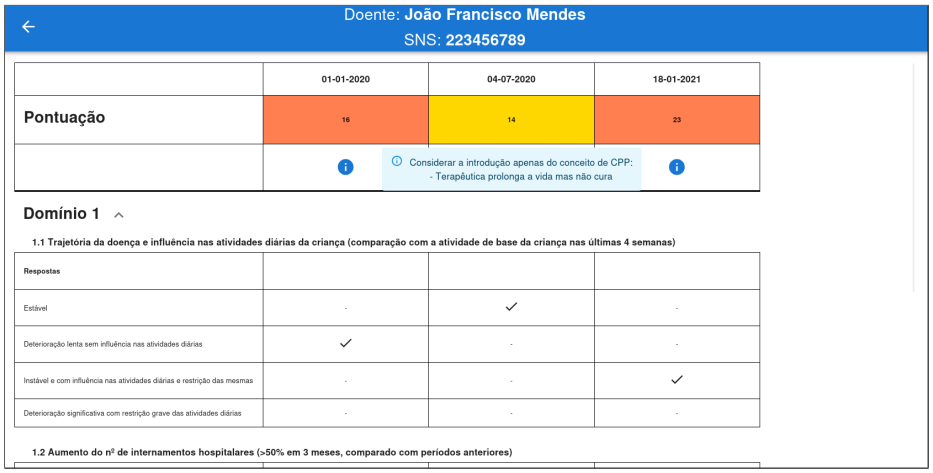


Fig. 1. Longitudinal visualization of a patient's PaPaS Scale scores displaying total scores and detailed responses for Domain 1 questions across three assessment dates. Alongside the score, a recommendation is available via the *i* button—shown here for the second assessment date.

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