**MyPal**: Fostering Palliative Care of Adults and Children with Cancer through Advanced Patient Reported Outcome Systems

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Project Overview Presentation
Presentation Overview

- Project identity & Consortium synthesis
- Positioning in palliative care
- Key Elements & mission statement
- Intervention main pillars
- Objectives and strategy
- Implementation highlights
- Contact information
MyPal Identity

- **Title:** MyPal - Fostering Palliative Care of Adults and Children with Cancer through Advanced Patient Reported Outcome Systems
- **Call Identifier:** SC1-BHC-23-2018 - Novel patient-centred approaches for survivorship, palliation and/or end-of-life care
- **Work Programme Objective:** Better Health and care, economic growth and sustainable health systems
- **Grant Agreement No:** 825872
- **Start Date:** 01/01/2019
- **Duration:** 42 Months
- **Total Budget:** 3,999,308.75€
- **Coordinator:** Institute of Applied Biosciences (INAB) | Centre for Research & Technology Hellas (CERTH)
Consortium Synthesis

- 16 partners
- 7 countries
- 6 research/academia
- 6 clinical sites
- 2 SMEs
- 2 palliative care associations
MyPal Position on Palliative Care

What Is Palliative Care?

**Definition**

Palliative care (pronounced pal-lee-uh-tiv) is specialized medical care for people with a serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. **It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.**

https://getpalliativecare.org/whatis/
MyPal Position on Palliative Care

Release: December 2018

What’s Different About The New Edition Of The National Consensus Project For Quality Palliative Care Guidelines?

The 4th Edition calls for delivery of palliative care for all people living with serious illness, regardless of diagnosis, prognosis, care setting, or age, and for the first time calls on all health professionals to improve care during serious illness. To achieve this objective requires two changes. First,
MyPal Position on Palliative Care

Taxonomy of palliative care-related terms

Model of concurrent palliative cancer care

Doi: 10.1182/asheducation-2015.1.471

MyPal Focus

✓ Palliative care for cancer patients at any point along the disease trajectory, regardless of prognosis
“Patient Reported Outcome”: Definition

✓ A measurement based on a report that **comes directly from the patient** about the status of a patient’s health condition without amendment or interpretation of the patient’s response by a physician or anyone else

✓ Reports may come from a **proxy** (that is, a spouse, significant other, or formal or informal caregiver)

[Link]
MyPal **Basis: electronic** Patient Reported Outcome (PRO) Systems

The "**Quantified-Self**" paradigm

Personal devices and tools for implicit/explicit self-reporting and tracking of health and well-being
MyPal Mission Statement

Mission Statement

✓ Foster palliative care for cancer patients by leveraging existing PRO systems through their adaptation to the personal needs of the cancer patient and his/her caregiver(s)

✓ Empower cancer patients and their caregivers in capturing more accurately their symptoms/conditions, communicate them with a seamless and effective way to their healthcare providers and, foster the time for action through the prompt identification of important deviations in the patient’s state & QoL

✓ Move from conventional PRO approaches to active patient engagement and a closed-loop approach (bridging the gap between patient reporting and timely as well as personalised actions performed by healthcare providers to address the varying patient needs) to cope with the palliative care for cancer
MyPal Intervention in a Nutshell

- Digital health, personalized (MyPal) intervention exploiting the value of patient-generated health-related data
- **Target users**: Adults (hematologic cancers) and children (hematologic cancers or solid tumors) as well as their families and healthcare providers
- Assessment in 6 clinical sites across 5 European countries via 2 clinical studies:
  - MyPal-ADULT (RCT)
  - MyPal-CHILD (observational study)
MyPal Intervention Design: Main Pillars

✓ No “one size fits all” solution ➔ Personalization/adaptation of the intervention according to the needs of the patient and his/her caregiver(s)

✓ No “passive reporting” - Exploit PROs to offer tangible added value to the care of the patients, their families and healthcare providers ➔ *paradigm shift*

✓ “Solid evidence” ➔ Assess the effectiveness and cost-effectiveness of MyPal systematically
MyPal **Objectives**

- Design a comprehensive, patient-centred intervention for palliative care in cancer by adapting and advancing PRO systems
- Reduce symptom burden for cancer patients in need of palliative care
- Reinforce patient participation and empowerment in palliative care
- Close the loop between PRO systems and patient-centred palliative care in cancer
- Reinforce the evidence-base of the effectiveness and cost-effectiveness of PRO systems for the palliative care of cancer patients
- Prove the feasibility of integrating the proposed intervention in palliative care regimes and healthcare systems across Europe
MyPal Conceptual Framework
MyPal Strategy

1. **Employ existing ePRO tools from previous research projects, e.g.:**
   - Personal Health Record (PHR) with tools for reporting via questionnaires and/or portable devices
   - a “gamification” approach for reporting by children

2. **Adapt** the tools to the targeted population and the personal user needs

3. **Reinforce the value** of patient reporting by developing **tools to exploit the reported data**, i.e.:
   - early detection of deviations in the patient’s state
   - better communication between patient and healthcare providers
   - integrated care for better symptom management
   - shared decision making
   - psychological support

4. **Evaluate the intervention** in well-designed, clinical studies across **diverse population and healthcare settings**
MyPal Implementation Approach: 4 Phases

Phase A: Intervention Design
- Definition of Clinical Study Protocols & User Requirements
- Continuous Interaction (User-Centred Design)
- Adaptation of PRO Components and Tools
- Pre-Study Testing

Phase B: Technical Implementation
- M1-M9
- M10-M15
- M16-M36

Phase C: Clinical Studies of the MyPal Intervention
- Preparations of Clinical Studies
- Conduction of Clinical Studies
- M9-M16

Phase D: Impact Assessment
- Intervention Assessment
- Refinement of MyPal Components
- M37-M42

MyPal Overview Presentation
### MyPal Structure (Work packages)

<table>
<thead>
<tr>
<th>WP</th>
<th>Leader</th>
<th>Work package Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>WP1</td>
<td>ESDY</td>
<td>Ethical Framework &amp; Drivers for Leveraging Patient Reported Outcome Systems</td>
</tr>
<tr>
<td>WP2</td>
<td>CERTH</td>
<td>Intervention Design</td>
</tr>
<tr>
<td>WP3</td>
<td>FORTH</td>
<td>Patient Reported Outcome Tool for Adults</td>
</tr>
<tr>
<td>WP4</td>
<td>PSW</td>
<td>Patient Reported Outcome Tool for Children</td>
</tr>
<tr>
<td>WP5</td>
<td>FRAU</td>
<td>Tools for Exploiting PROs and Advancing ePRO systems</td>
</tr>
<tr>
<td>WP6</td>
<td>USAAR</td>
<td>Clinical Studies Implementation, Evaluation and Impact Assessment</td>
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<tr>
<td>WP7</td>
<td>ULANC</td>
<td>Dissemination &amp; Exploitation</td>
</tr>
<tr>
<td>WP8</td>
<td>CERTH</td>
<td>Project Management</td>
</tr>
<tr>
<td>WP9</td>
<td>CERTH</td>
<td>Ethics Requirements</td>
</tr>
</tbody>
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The MyPal Consortium
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