

HOME-C2P2

Supporting children with complex chronic conditions or palliative needs at home: Clinical Command Center to coordinate efforts with primary healthcare

ABSTRACT

The prevalence of children with complex chronic conditions or palliative care needs has increased, highlighting the urgency of improving care. While improved paediatric care has reduced infant mortality, it has also increased the survival of children with serious illnesses, leading to an increase in the number of children with life-limiting or life-threatening conditions. In Europe, the estimated prevalence is 20-66 per 10000 children. These children show severe frailty, functional limitations and dependence on technology such as ventilators. This highly specialised care is centralised in hospitals. A key challenge in these children's care is achieving effective and coordinated communication between different levels of care. This fragmentation extends to the exchange of essential patient information, which hinders the ability of the healthcare system to provide a continuum of care at home and limits the ability to implement a personalised care plan.

The HOME-C2P2 project aims to improve the quality of life and community-based and home-based care for C2P2 by implementing the HOME-C2P2 model. The specific objectives (SO) of HOME-C2P2 are:

- SO1. To identify the factors and measures that would facilitate the implementation of the HOME-C2P2 model (at clinical and technological levels) in different European countries, taking into account the differences in health and care systems and technological developments.
- SO2. To include end-users perspectives (healthcare professionals and family caregivers) in co-designing the model and technological approach to be tailored to their needs.
- SO3. To study the feasibility, logistics and acceptability of the HOME-C2P2 model in several European countries (Spain, Denmark, Netherlands and Slovenia) from a multi-stakeholder approach (professionals, patients, families, IT teams).
- SO4. To promote the future integration of the HOME-C2P2 model into the regular functioning (standard of care) of European health systems, including using relevant information and digital technologies to achieve better health outcomes.

The target population is children with complex chronic conditions and palliative care needs at home. HOME-C2P2 will provide family caregivers with home monitoring devices personalised to each patient's needs to perform the appropriate biomedical measurements at home. Healthcare professionals will develop a shared, individualised care plan for each patient, ensuring that care is participatory, focused on the patient's needs and comprehensive across different healthcare system levels.

Coordination between primary and specialist levels will be facilitated by a cloud platform that will receive real-time home monitoring data, process this data and generate appropriate alerts in the event of deviations in health parameters. Data from the cloud platform will be available to both levels of care, enabling early intervention to prevent exacerbations and complications according to the shared individualised care plan.

KEYWORDS

- Paediatrics Palliative Care
- Home monitoring
- Care coordination
- Alert management

DURATION

36 months

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