

CONSORTIUM UPDATE



Highlights

- Both clinical studies launched across all participating sites in June 2026.
- First participants recruited to the randomised controlled trial (RCT).
- Validation of the initial EDS results.

OUR JOURNEY SO FAR

JUN 2026

✓ Studies launched

EDS Stage 2 and RCT started at all sites

JAN-JUN 2026

● Preparation & approvals

Study preparation and approvals
Digital platform ready
Final HexCom-Ped & IMPACT tools

2025-EARLY 2026

● Core tools & frameworks

Development of EDS, HexCom-Ped & IMPACT

ONGOING ACTIVITIES

● Public engagement

Activities across all clinical sites

AUG-DEC 2024

● Design & co-creation

Two co-creation rounds
EDS concept & deployment plan

JUL-AUG 2024

● Governance & ethics

External boards established
EDS Stage 1 approved

FEB-APR 2024

● First foundations

ACP capacity-building
Visual identity & website

DEC 2023

● Project launch

Scale-up and policy work underway

Progress

WP1 - PROJECT MANAGEMENT

The second reporting period ends on 30 November 2026. WP leaders should submit their technical reports by the first week of November, covering progress, achievements, deviations and outstanding work. The financial reporting template will follow once the amendment is approved. For guidance, please contact Elizabeth.

WP2 - PPI ENGAGEMENT

Ten Young People and Family Advisory Boards are active across the clinical sites and provided feedback on the RCT intervention through 30 sessions. We are happy to report that a review of accessible information and consent materials has been completed. The next steps include preparation of the leaflet and survey which will examine experiences of participating in the RCT.

WP3 - EDS DEVELOPMENT

The conceptual design, predictive model, dashboard and technical implementation of the EDS have been completed. The Stage 2 protocol foresees validation with 385 participants across four clinical sites. Both ethical and regulatory approvals have now been obtained, with the exception of MEYER, which remains pending. The EDS stage 2 validation study has begun in HSJD and will shortly be followed in HUS and REGIONH.

WP4 - ACP IN PPC

The HexCom-Ped needs-assessment tool was delivered, and 17 professionals participated in training. Feedback and suggested changes will be collected during the RCT. The IMPACT tool was adapted to strengthen family-centred care, personal agency, sibling involvement and sensitive communication.

WP5 - RCT

The RCT protocol was registered, with ethical approval obtained in all study sites! The XR-based training milestone is still pending. Clinical-site training and accessible participant materials are finalised and available in the protocol. Current priorities include reaching the outlined milestone and beginning participant recruitment.

WP6 - EVALUATION

The evaluation framework for the PALLIAKID intervention and EDS has been defined, covering effectiveness, feasibility, engagement, implementation and cost-effectiveness. Outcomes for children, families and professionals have been selected. WP6 is now preparing protocol amendments, the statistical analysis plan, data collection procedures and study visits ahead of the start of recruitment.

WP7 - POLICY & DISSEMINATION

The third version of the Dissemination and Communication Plan was submitted. Communication activities continued through the website, social media, conferences and partner networks. Work has now started on scale-up and transferability, policy recommendations, implementation guidelines, communication training standards and exploitation pathways. Coordination with clinical sites and other WPs will support these new tasks. WP7 montly meetings are now starting to work on KVC and ICPCN tasks.

WP8 - ETHICS & DATA

The GDPR documentation, DPIAs for EDS Stages 1 and 2, and the Ethics Checklist were completed. The Joint Controllership Agreement is progressing towards signature. Consent forms, privacy notices and protocols were also reviewed. The next priorities are completing the DPIA for the intervention and monitoring the implementation of the agreed mitigation measures.

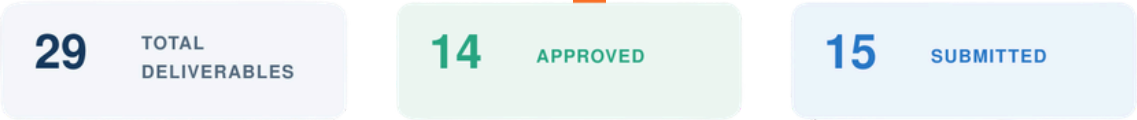
WP9 - ETHICS REQUIREMENTS

The Ethics Advisory Board held its second meeting and submitted its annual report. Recommendations were shared with the technical teams, with several already addressed. The third meeting is now being prepared. We estimate Living Labs will take place between March-May 2026.

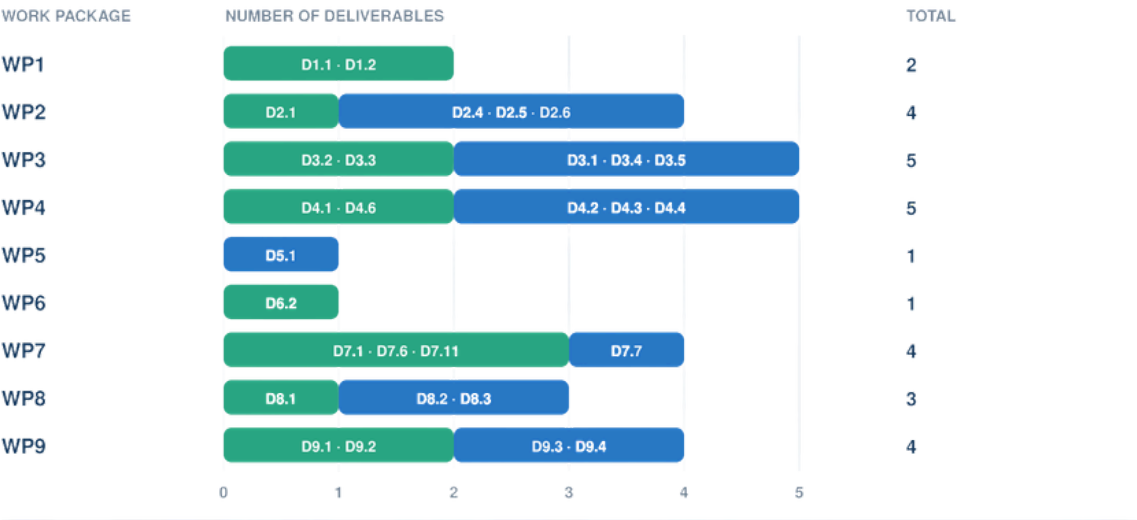
Deliverables & Milestones submitted

Deliverables status

Current overview across the nine PALLIAKID work packages



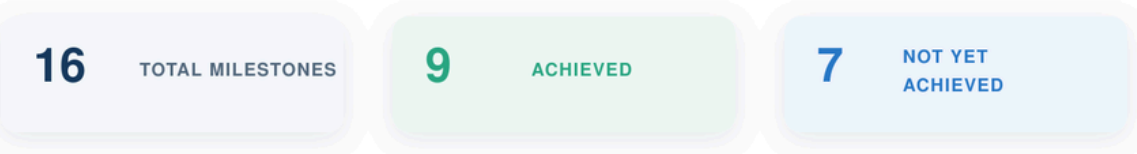
● Approved ● Submitted



Internal PALLIAKID project overview

Milestones status

Current overview across the PALLIAKID work packages



● Achieved ● Not yet achieved



Internal PALLIAKID project overview