EPAD Deliverable 3.8

Final version of data discovery software and related infrastructure for the EPAD Register

Executive Summary

The EPAD Registry is built from a collaborating set of Parent Cohorts (PCs) across Europe that remain independent and secure, but simultaneously cooperate to provide a 'virtual' total collection of subjects from which suitable participants can be discovered and selected to be put forward for potential enrolment into the EPAD trial-ready 'Longitudinal Cohort Study' (LCS).

Making this work in practise has required the creation and optimisation of an array of software tools and processes for federated discovery of suitable subjects [called 'Participant Registry in EPAD' (PREPAD)], ID encryption and matching (called 'DerID Input Output Management' (DerIDIOM)], rapid controlled registration of high-value subjects [called 'VElocity for EPAD' (VEEPAD)], semi-real-time and historical visual exploration of the Registry and enrolment activities [called 'Subject Enrolment in EPAD' (SEEPAD)], batch-level tracking of all pre-screening steps [Aridhia App], comprehensive tracking, checking and integration of all Registry activities at the subject level ['Central Archive' and 'Current Status' databases], and custom scripts for data transformation. These are now all fully operational, effective, and flexible enough to meet cohort-specific and generic needs in EPAD enabling large-scale pan-European subject enrolment into a novel trial-ready cohort. As of the end of 2018, 14 cohorts were connected to the PREPAD software, totalling around 34,000 participants of which >21,000 meet the minimum requirements for consideration for the LCS.

For more information: info@epad.org