EPAD Deliverable 3.6

Interim report on Parent Cohort fingerprinting, selection and use of data discovery software

Executive Summary

In this deliverable 3.6, we describe engagement with Parent Cohorts (PCs) for the EPAD Register, presenting both the current status and the short and medium term goals. Most of the work presented was led and conducted by the EPAD partners VUmc, ULEIC, Pfizer and SYNAPSE.

The deliverable builds on previous deliverables of WP3, most importantly Deliverable 3.4 (Data discovery software for EPAD Register v1) in which the content and technical details of the EPAD Register are described and Deliverable 3.5 which described the first version of the EPAD Register.

In 2016, the Register was used for the first time to select potential participants for the EPAD-LCS. Up to now 6 Parent Cohorts have invited participants via the EPAD Register procedures, a number which we expect to expand during the course of the project. Around 17,000 potential participants were in the EPAD Register by January 2017, of which 1,000 were already selected for the LCS.

It is the aim to increase the numbers to over 24,000 in 2017. The EPAD Register will be fine-tuned further to stay fit for purpose.

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