

Executive Summary

In this deliverable we describe engagement with Parent Cohorts (PCs) for the EPAD Register, presenting both the current status and the short and medium term goals. The deliverable builds on previous deliverables of WP3 and the LCS protocol, 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.

Procedures for connecting PCs to the EPAD Register are described. An initial set of nine PCs have been selected for inclusion in the Register, of which four are already connected to the 'Participant Register for EPAD' (PREPAD) software tool, and hence the present day Register encompasses >4000 potential research participants without dementia. The other five PCs will be incorporated in the next few months by work that is already underway. In total 23 PCs have been fingerprinted, representing >500,000 participants.

The PREPAD system comprises several software modules, including the main discovery software, a 'DerIDIOM' tool for one-way encryption of local IDs, and a customisable data harmonisation script. Extensions and enhancements to this are planned, including potential federation with other system components.

In this document, we present the process of collaboration with the PCs to implement the Register and provide information on the data elements the system employs. We also provide information on which variables have been available in the PCs selected thus far, give the results of example queries and describe the querying process. Finally we discuss the next steps for further development of the EPAD Register, both in terms of the content and the software.

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