Executive Summary

Clause 20.7 of the Project Agreement provides that a template “Associated Scientific Collaborator Agreement” (ASCA) will be developed as a deliverable by the EPAD Legal & IP Committee in collaboration with WPs 3 and 5 and approved by the Steering Committee. This template has been included as deliverable 3.2 in the Description of Work. The Associated Scientific Collaborator Agreement’s main purpose is to provide a legal framework for involving (external) Parent Cohorts in the enrolment of subjects into the EPAD Project as well as possible data contribution by those Parent Cohorts.

Early in the Project, the EPAD Legal & IP Committee initiated work on this template, which became more complicated (and time consuming) as initially expected for the following reasons:

- Input was needed from WP 3 on how Parent Cohorts would be approached and how patients would be enrolled in EPAD.
- The templates involved an important ethical/privacy aspect, which is why WP 8 was closely involved.
- The template should be fit for use in the various jurisdictions of relevance to EPAD.

In many cases Associated Scientific Collaborators would actually not really contribute (raw) data to the Project but rather be (solely) involved in patient recruiting and enrolment within EPAD (including fingerprinting/subject discovery activities). The only “data” which would likely be transferred in such case are aggregate counts/summary level data. This is why it was opted to work with two different templates: one for Associated Scientific Collaborators who are (solely) involved in patient recruiting and enrolment within EPAD and another one for those Associated Scientific Collaborators who also agree to contribute (raw) data to EPAD (the latter being more legalistic and longer).

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