

Update EPICARE Registry

London 2019

Status presents

- Excel version distributed to 28 centres (July 2018)
- Local use: about 400 patients included (5 centres)
- Feedback from local users to optimise registry (meeting Feb 22)
- January 2019 : start IT manager (Arunganesh Velurajah)

Action points 2019

Content changes

FAIRification of the Registry (Findable, Accessible, Interoperable, Reusable)

Pseudonymization / identification (EUPID)

Ethical committee approval guidance



Action points 2019

RedCapisation of the registry

Implementation RedCap (central server GOSH)

- *uploading from excel*
- *data entry RedCap*

Governance structure

Terms of Reference

Business Requirements Specifications

Training centres / structured feedback

