

EDITH Project

WP6: Follow up Registry for Kidney Transplant Recipients

Workpackage 6

Led by ET and NHSBT



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Works closely with WP5

Broad Aims of WP6

- Establish a European kidney transplant follow up registry
 - Build on EFRETOS project
 - Provide for consistent and comprehensive data collection and reporting across MS
- Study of Quality of Life in transplant recipients
 - Small scale pilot study
 - Broader evaluation of transplant benefit

Objectives of WP6 (year 1)

- Review national arrangements for collection of kidney transplant recipient data
 - identify MS who may contribute to European Registry
- Identify support needed by MS for data collection
 - identify and help overcome obstacles
- Define data set to be used as basis for the registry
 - specify variables and provide data dictionary
- Specify technical needs of database
 - arrangements for governance, reporting, consent
 - requirements for data entry, file upload, data storage, validation, security

Objectives of WP6 (years 2, 3)

- Establish web based registry
 - functional design, architecture, proof of concept, user acceptance testing, deployment
- Carry out study on Quality of Life of transplant recipients
 - develop and implement a measure of QoL
- Devise a Sustainability Plan

Achieving the Aims

Review national arrangements for collection of kidney transplant recipient data

- Devise and circulate short survey

Identify support needed by each MS for establishment of registry

- Devise and circulate short survey
- Subsequently provide support for sustainability measures where needed

Deliverable 6.1 due September 2017

NHSBT to lead

Achieving the Aims

Define data set to be used as basis for the registry

- Circulate final data set from EFRETOS project (Tier 1 and 2 variables), with modifications, for comment
- Discuss and agree additions/deletions to list
- Produce data dictionary for national follow-up registries

Deliverable 6.2 due September 2017

ET to lead

Achieving the Aims

Specify technical needs of database

Detailed consideration needed to establish needs for data input, management and validation, reporting, consent

- Undertake preparatory work leading to draft report
- Agree which MS will be included at early stage and which will follow on later
- Revised report circulated July 2017

Deliverable 6.3 due September 2017

Achieving the Aims

Specify functional design of European web based registry

- Preparatory work leading to draft report and discussion on functional design
- Circulate revised report in November 2017

Deliverable 6.4 due December 2017

Technical Design of Registry

Led by Eurotransplant