

# EDITH

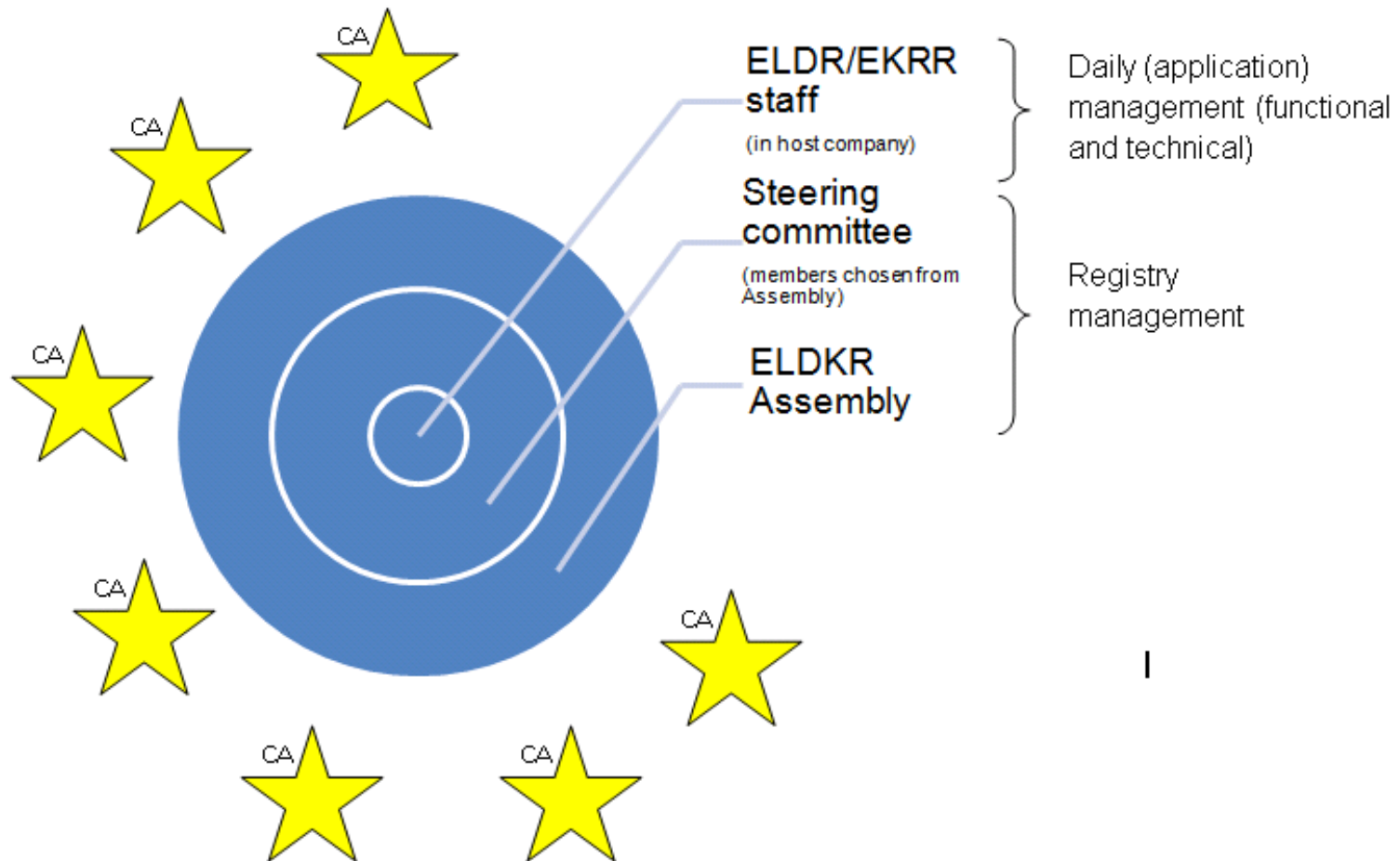
The Effect of Differing Kidney Disease Treatment Modalities and Organ Donation  
and Transplantation Practices on Health Expenditure and Patient Outcomes

## Governance WP5 & WP6

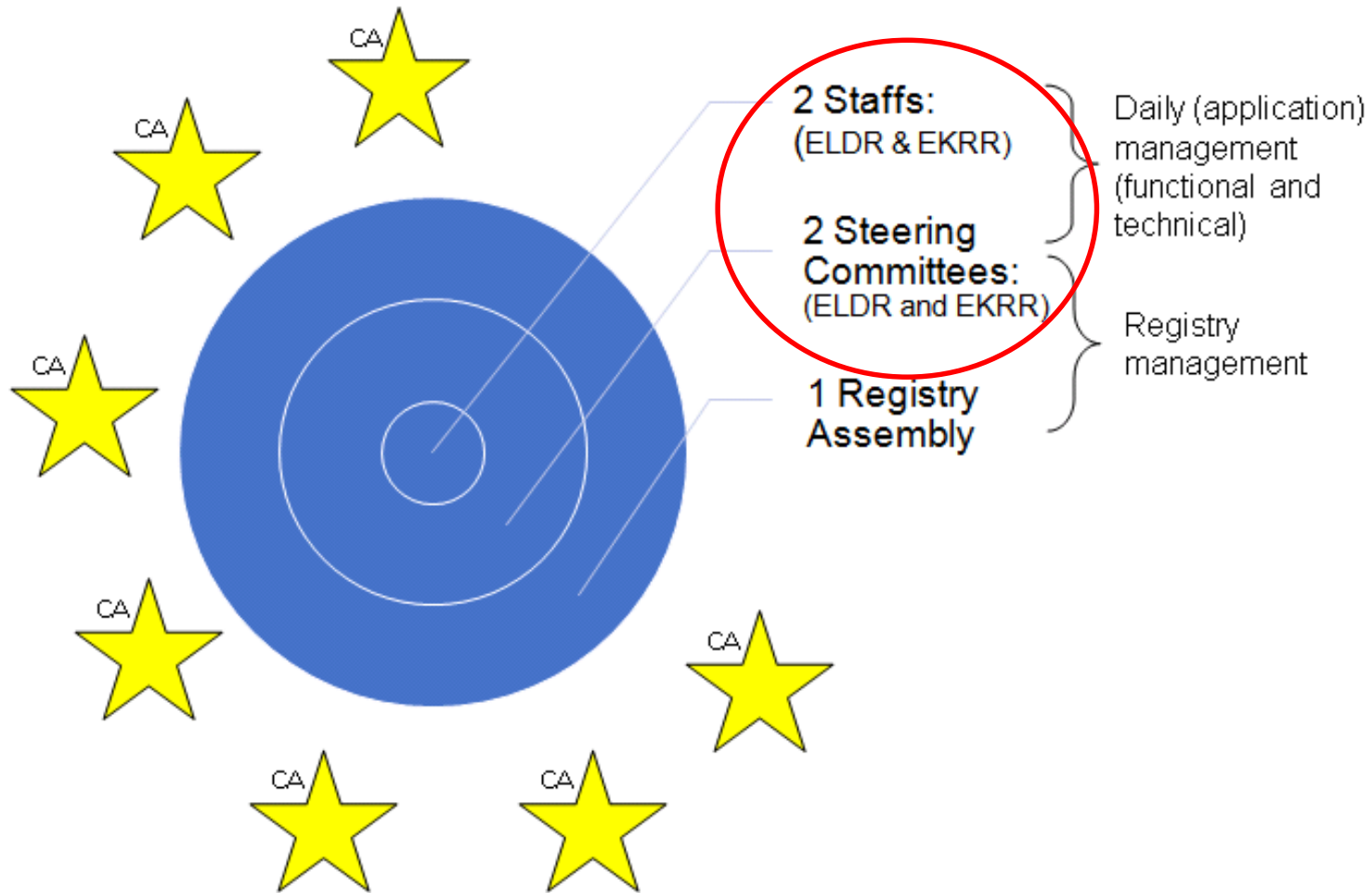
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Jan 30, 2019

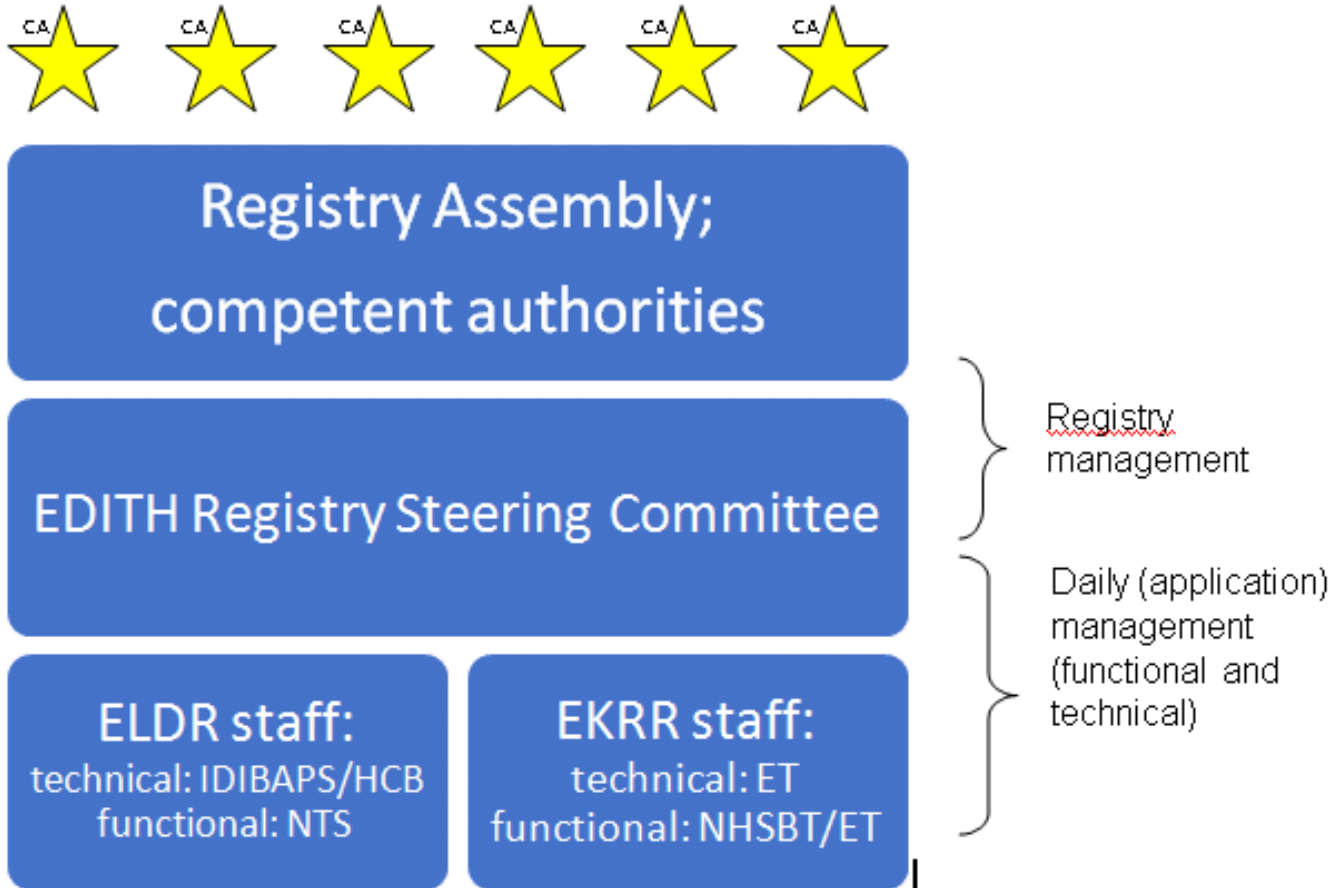
# Proposed governance structure – presented at interim meeting June 2018



# Proposed governance structure – structural phase, after project



# Proposed governance structure – project phase



# Assembly – structural phase

<b>Members:</b>	Countries participating in ELDR and/or EKRR (1 per MS), patient/donor rep.
<b>Role:</b>	governing body
<b>Responsibility:</b>	framework of policies for functioning of registry
<b>Tasks:</b>	appointment of steering committee members governance of steering committee
<b>Meeting frequency:</b>	yearly

# Differences project / structural Assembly

	PROJECT PHASE	STRUCTURAL PHASE
Responsibility / tasks	Advice on sustainable registry governance and financing	Registry functioning, content, policies and financing; installing /governing a steering committee for “daily” management
Members	All competent authorities	all countries participating in ELDR and/or EKRR (1 member for each MS, and a substitute member can be appointed), and a patient/donor representative
Meeting frequency	Competent authority meeting (2 times a year)	yearly



# 2 Steering Committees – structural phase

**Members:** 5 members per CS, chosen from Assembly

**Role:** End responsible for (daily) registry management

**Responsibility:** data request procedure

**Tasks:**

- reviewing (and granting) requests for data or standardized reports
- daily application management (major financial investments only with approval of the Assembly)

**Meeting frequency:** at least 1 or 2 times a year, frequent mail contact

# Differences project / structural Steering Committee(s)

	PROJECT PHASE	STRUCTURAL PHASE
Responsibility / tasks	Registry functioning, content, policies and financing;	Responsible for “daily” registry management and data request handling (carried out by staff)
Members	EDITH Steering Group	2 SC’s, each with 5 members chosen by Assembly
Meeting frequency		1-2 times a year



# ELDR /EKRR Staff – structural phase

**Members:** functional application manager, statistician, administrative employee

**Role:** daily application management

**Responsibility:** functional application management and data request procedure

**Tasks:**

- user management
- daily application management (new developments with approval of Steering Committee)

**Meeting frequency:** daily

# Differences project / structural Staff

	PROJECT PHASE	STRUCTURAL PHASE
Responsibility / tasks	Development, implementation and management during project	daily application management and data request handling
Members	ELDR: IDIBAPS & NTS EKRR: ET & NHSBT	ELDR hosting organisation EKRR hosting organisation
Meeting frequency	Frequent (as deemed necessary, either physical or by telco)	daily

# Sustainability aspects EDITH registries

- Prerequisite: embedded in existing organization
- Personnel / Staff
  - Administrative support (1 fte)
  - Technical support (1-2 fte)
  - Data management (1 fte)
- Software licenses
- Infrastructure, connectivity
- Services: Privacy, security, legal issues
- Office space

# Sustainability aspects EDITH registries

- Preferably existing organization with:
  - Experience with registry maintenance (EU level)
  - Donation, Transplantation, Allocation expertise
  - Experience with outsourcing and SLA mgt
  - Administrative organization
  - Technical support function
  - Data management available
  - Security officer
  - Data Privacy officer
  - Legal support

# Sustainability aspects EDITH registries

- National registries are a national issue
- Estimated total yearly budget (EDITH): 500K
- Merging of the two registries to one platform
- Shortlist of candidate organisations:
  - Eurotransplant
  - ESOT
  - ERA-EDTA
  - .....?





*Thank you!*