

EDITH

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

Opening

2nd Technical Meeting

30. January 2019 in Leiden, The Netherlands

Disclaimer

This presentation is part of the project EDITH (Grant Agreement No. PP-01-2016) which is receiving funding from the European Union

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Agenda

Welcome and organisational aspects – DSO

WP 4 Treatment modality choices, outcomes and costs for end-stage kidney disease WP4 – AMC and CNT

- Update on patient and nephrologists' surveys, presentation of preliminary results and next steps
- Update on cost study, presentation of preliminary results and next steps

WP 5 Living Donor Registry – NTS and IDIBAPS

- Presentation of the living donor registry and its functionalities (e.g. data entry, donor entry, reporting, handling of helpdesk)

WP 6 Transplant Recipient Registry – ET and NHSBT

- Presentation of the kidney transplantation registry and its functionalities (e.g. data entry, reporting, handling of assistance)

Lunch break

Joint session WP 5 & WP 6

- Presentation of the time schedule as well as the technical and logistical aspects of data collection (→ involvement of countries)
- Update on WP5 & WP6's document on the governance structure / link between both registries
- Involvement of ESOT / EDITH presentation at congress (EKITA)

Summary and Conclusion – DSO

EDITH Reporting

- Interim report was forwarded to the Commission in October 2018
- The report was approved in November 2018 and the second pre-financing payments were executed in December 2018
- The final financial report has to be submitted in January 2020

→ Any delay will undermine the closure of the project

IMPORTANT: Any expenses incurred after 31/12/2019 will be considered non-eligible.

Organisational aspects

- **NCA Meeting**

- EDITH will be presented during the next NCA-Meeting in February.
Please organise within your WP and/or with us.

→ 5-10 minutes per technical WP,
no EDITH introduction needed.
Slides to be submitted to DSO
before 08.02.2019!

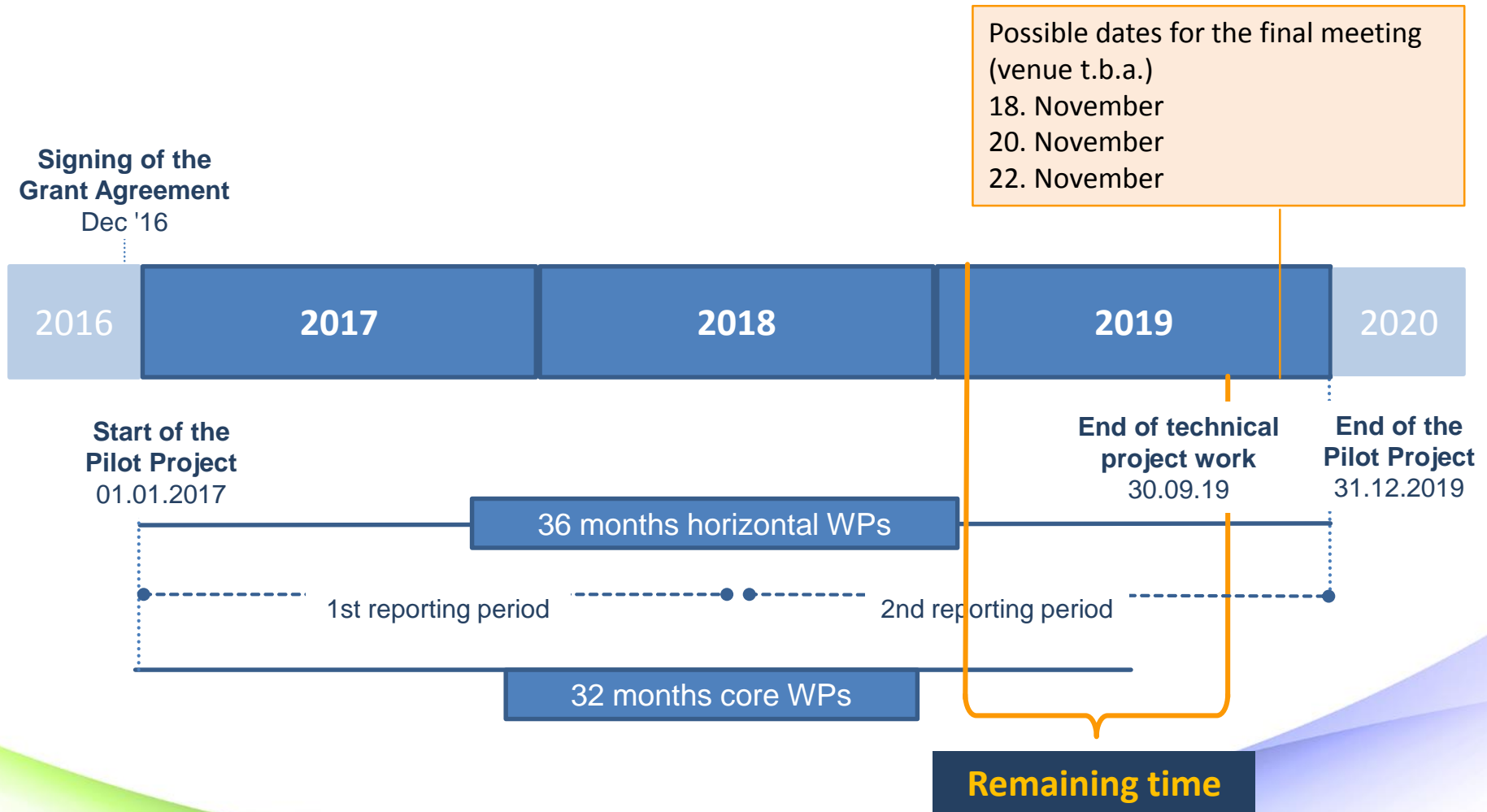
- **Commission's registries' meeting**

- Follow-up event in Brussels on 20 February.
- Representatives of WP 4, WP 5 and WP 6 should be present
- ECCTR will attend the meeting. ECCTR is a registry, which was build
 - within the framework of a European project, and
 - under the terms of the GDPR

→ prepare your questions!

- As last time, we could take the opportunity to meet afterwards

EDITH overview



To Do's WP4

- D4.1 Report on the frequency of end-stage kidney disease treatment modalities in MS and associated countries **June 2019**
- D4.2 Report on impact of treatment modality choice on health outcomes **June 2019**
- D4.3 Report on factors influencing the choice of treatment modalities by patients and doctors **August 2019**
- D4.4 Report on the current practices in CKD – financial impact **August 2019**

To Do's WP5

- D5.2 Report on the ELDR specifications (dataset, functional and technical requirements) **March 2018**
- *D5.3 Report on governance organisation for the ELDR (and data request handling)* **January 2019**
- D5.4 Report on the support given **April 2019**
- D5.5 Report of ELDR implementation **June 2019**
- D5.6 Recommendation for a sustainable ELDR **August 2019**

To Do's WP6

- D6.3 Report on technical needs, reporting requirements and IT **September 2017**
- D6.5 Establishment of a web-based registry for collecting follow-up data on a European level **June 2019**
- *D6.6 Report on governance, organisation, publication policies and data sharing policy for European Registry* **June 2019**
- D6.7 Report on the design and implementation of a Quality of Life tool for kidney transplant recipients **June 2019**
- D6.8 Report on plans for the sustainability of National and European transplant registries **August 2019**

To a successful

EDITH meeting