



Achieving Comprehensive Coordination in Organ Donation



Accord
Achieving Comprehensive
Coordination in Organ Donation



A look into the future of Living Donor Registries in the European Union

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Kirsten Ooms-de Vries

On behalf of the ACCORD consortium

Agenda

- Back to the beginning...
- Future...
- How to achieve this...
- Feasibility of these solutions...
- Plea...

Agenda



Back to the beginning

Why do we want living donor follow-up?

- Increase in number of living donors
- Responsibility to take care of a living donor (individual)
- Responsibility to take care of living donors (in general)
 - Which donors are eligible?
 - Is the operation procedure safe?
 - How about the safety on the long run?
 - Informed consent

Back to the beginning

EU Directive 2010/53/EU on standards of Quality and Safety of human organs intended for transplantation

“Member States shall ensure that a register or record of the living donors is kept and shall endeavor to carry out the follow-up of living donors.”

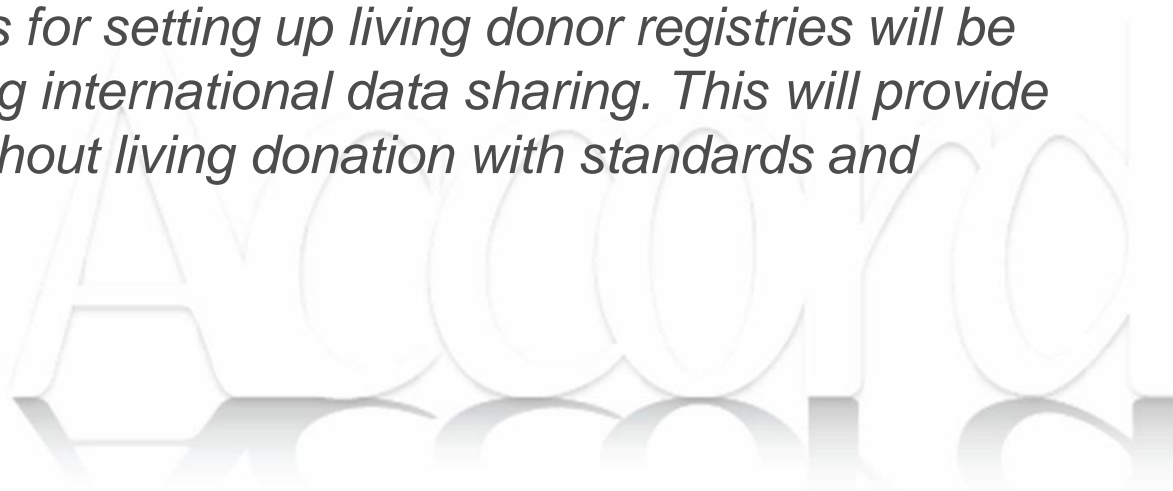
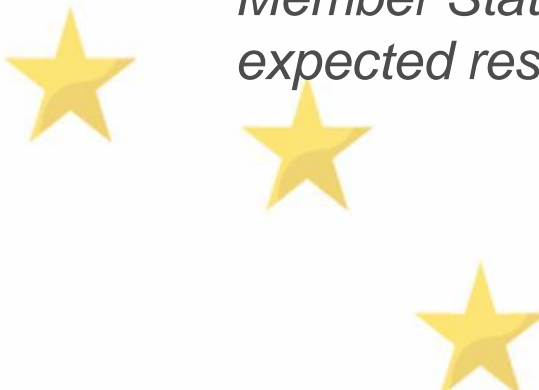
ACCORD Work Package 4

Objective:

- *‘Developing live donor registries and fostering international data sharing on live donation’*

Expected outcomes:

- *‘Recommendations for setting up living donor registries will be provided, facilitating international data sharing. This will provide Member States without living donation with standards and expected results’.*



Future



Future

Follow-up of every living donor



Future

International data sharing



How to achieve this

- Incidental data collection with data from existing (national) registries
- Periodic data collection with data from existing (national) registries
- Incidental / periodic collection of aggregated data
- A European Registry of Registries

Feasibility

Lessons learned from the ACCORD project:

- Collecting different items
- ‘Comparing apples with oranges’
- Variation in governance / policies
- Very time consuming
- No structural system

Feasibility

Possible solutions:

- One common data set
- One common data dictionary
- According to recommended database structure



Feasibility

But....

- Still very time consuming
- Still no structural system
- Danger of variation because of decentralized decision making



Solution

**A European registry of
registries according to
ACCORD recommendations!**

ACCORD



ACCORD WP4 was a great success

**‘The living donor registry
can start tomorrow!’**

ACCORD



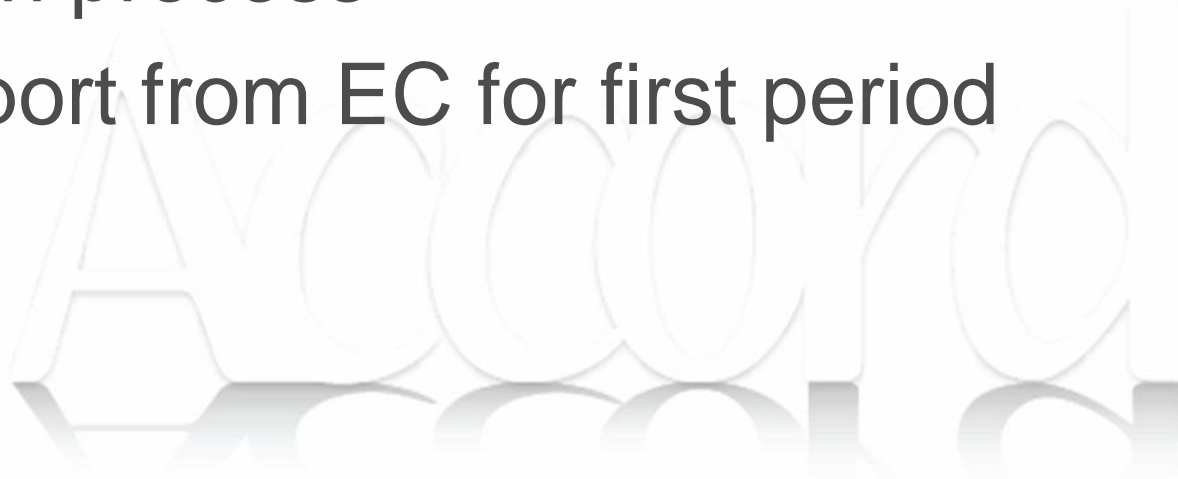
What do we need?

- Implementation of data set and data dictionary
- A solid application
- Installment of the governance organisation
- Specified policies
- Sustainable financial structure



Pathway

- Enthusiastic countries to participate
- Competent partners to facilitate a European RoR
- Experienced partner to guide this implementation process
- Financial support from EC for first period



Future

100% completeness



WORLD



DWW

Plea

- Follow-up of every living donor in the EU
- Data collection in a digital registry
- International data sharing in a RoR
 - established a.s.a.p.
 - using the experience, knowledge and enthusiasm from the ACCORD project
 - according to ACCORD recommendations
 - with support from the EC

Thank you! WP 4 partners



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France
Germany
Ireland
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Poland
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