Rare Disease Registry

Where do we go from here

Success so far

- More than 30 conditions
- >17.000 participants
- New consent form allows linking with other databases and simplifies communication with patients

Deficiencies

- Most patients not covered under new consent
- Data entry incomplete for many patients (especially from paediatric centres)
- Little activity from many RDG
- Many, many conditions not yet covered
- Especially for very rare disease, supranational registries are needed

Most patients not covered by new consent

- Plan to employ person by renal registry
- To obtain research passport for all contributing units
- To contact patients for new consent document

Data entry incomplete for many patients

- Units without a direct electronic link still have to enter data by hand
- For many patients, only name, d.o.b. and diagnosis have been entered
- => time will help

Little activity from many RDG

- Many RDG have not had organized a patient day, nor done any research
- Many cannot even provide an annual report (in time)

- Given the lack of completeness of registry data, research activity may pick up
- Is the current structure right for all conditions?
- Do we really need RDG for all conditions?
- Could research proposal be submitted ad hoc by interested researchers to RDC?

Many, many conditions not yet covered

- The current structure makes a short research project difficult
- Could there be a lower level of RaDaR: patients are entered, data collected and are available to interested researchers?
- Could there be data collection on ALL patients with rare kidney diseases under section 251, similar to the ESKD registry?

Especially for very rare disease, supranational registries are needed

- We will always be bound by national information governance regulations
- Within these, international collaboration should be encouraged as much as possible (e.g. ERKNet)

You’re thoughts?