ERA-EDTA Registry Report
Kitty Jager & Ziad Massy
London, February 21, 2019
Outline Report to Council

- ERA-EDTA Registry (including EQUAL)
  Achievements in 2018
  Other issues
  Costs 2018 vs Budget 2018

- EDITH
  Progress
  Costs 2018 vs Budget 2018 (for information)

- ESPN/ERA-EDTA Registry
  Achievements during previous contract
  Plans for new contract
  Costs 2018 vs Budget 2018
Registry Staff

- Anneke Kramer, Medical informatician
- Rianne Boenink, Epidemiologist
- Kitty Jager, Epidemiologist / PI
- Vianda Stel, Epidemiologist
- Marlies Noordzij, Epidemiologist
- Nick Chesnaye, Epidemiologist
- Arno Weerstra, Data manager / SE
- Gita Guggenheim, Secretary
- Liesbeth Elbertsen, Quality Officer
- Ronald Cornet, Medical Informatician

5.98 fte

Unpaid advisor
Registry Output
Annual Report

Based on
Individual patient data: 32 registries from 17 countries
Aggregated data: 20 registries from 20 countries

Figure A.7.1
Incidence per million age-related population by age and sex at day 1

Special attention to sex differences
Many figures available for use in one’s own presentation

Registry Output
Annual Report

Slides

Slides

Annual Report CKJ paper

Many figures available for use in one’s own presentation
Registry Output
2018 papers in print and ePup

4. International comparison of trends in patients commencing RRT by PRD. Stel VS. *Nephrology*.
7. Merits and caveats of propensity scores to adjust for confounding. Fu EL. *NDT*.
9. Young deceased donor kidneys show a survival benefit over older donor kidneys in transplant recipients ages 20-50 years. Pippias M. *NDT*.
12. The impact of symptoms on health-related quality of life in elderly pre-dialysis patients: effect and importance in the EQUAL study. Voskamp PWM. *NDT*.
14. Pitfalls of linear regression for estimating slopes over time and how to avoid them by using linear mixed-effects models. Janmaat CJ. *NDT*.
Registry Output

2018 papers in print and ePub

Factors associating with differences in the incidence of renal replacement therapy among elderly: data from the ERA-EDTA Registry


18. The ERA-EDTA Registry Annual Report 2018

19. Access to kidney transplantation

20. Changes in co-morbidity patterns

21. Sex and gender disparities in the epidemiology and outcomes of chronic kidney disease

Different rates of progression and mortality in patients with chronic kidney disease at outpatient nephrology clinics across Europe

Katharina Brück, Kitty J. Jager, Carmine Zoccali, Aminu K. Bello, Roberto Minutolo

Clinical investigation

Merits and caveats of propensity scores to adjust for confounding

Edouard L. Fu, Rolf H.H. Groenwold, Carmine Zoccali, Kitty J. Jager, Merel van Diepen

Maria Pippias’ PhD defense

ERA-EDTA Council Meeting, London, February 21-23, 2019
1) Samar Abd ElHafeez (Egypt)
The effect of living donor source (related versus unrelated) on the survival of kidney transplant recipients

2) Enrico Vidal (Italy)
Demographics of blood pressure in children on RRT

3) Rachel Hellemans (Belgium)
Does kidney transplantation improve patient survival compared to dialysis in the current era in Western Europe? Pilot study with results of the Belgian population.
Registry Output
2018 and 2019 CME courses

2018

• Introductory Course on Epidemiology, Moscow, Russia
• How to become a Reviewer? – European Nephrology Portal (E-learning in collaboration with Reggio Calabria and Leiden)

2019

• Introductory Course on Epidemiology, Innsbruck, Austria
• Critical Appraisal of the Literature (pre-AFRAN course), Mombasa, Kenya
Coding & Definitions Working Group

PRD codes
• 2018 version launched

Cause of Death codes
• Finally ready to start
• Chair retired
• New group to be set up
• Agreements are in progress
• London data have been provided to national registries and Parma and AMC copies have been deleted
## ERA-EDTA Registry costs vs. budget 2018

<table>
<thead>
<tr>
<th>Employee / budget item</th>
<th>Average fte Jan-May</th>
<th>Cost Jan-May As per 16-1-19</th>
<th>Budget Jan-May</th>
<th>Average fte Jun-Dec</th>
<th>Cost Jun-Dec As per 16-1-19</th>
<th>Budget Jun-Dec</th>
<th>SURPLUS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtotal staff including overhead</td>
<td>5.16</td>
<td>185.133</td>
<td>211.082</td>
<td>5.67</td>
<td>279.115</td>
<td>318.743</td>
<td>65.577</td>
</tr>
<tr>
<td>Hardware/software (incl SAS)/servers</td>
<td>2.906</td>
<td>2.500</td>
<td>4.697</td>
<td>3.500</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Office</td>
<td>0</td>
<td>500</td>
<td>840</td>
<td>600</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Travel/congress</td>
<td>1.115</td>
<td>6.000</td>
<td>4.826</td>
<td>6.500</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Miscellaneous</td>
<td>11.347</td>
<td>2.500</td>
<td>4.471</td>
<td>4.000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EQUAL webplatform</td>
<td></td>
<td></td>
<td>7.563</td>
<td>10.000</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subtotal other costs</td>
<td>15.368</td>
<td>11.500</td>
<td>22.397</td>
<td>24.600</td>
<td>-1.665</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>200.501</td>
<td>222.582</td>
<td>301.512</td>
<td>343.343</td>
<td>63.912</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Proposal: (1) previous contract surplus € 22.081: AMC will keep €19.385 for ERA-EDTA co-funding of EDITH (last installment) and return €2.696 to ERA-EDTA; and (2) current contract surplus 41.831 euro: AMC will return € 1.831 to ERA-EDTA and € 40.000 to be carried over to 2019.

ERA-EDTA has paid all 2018 installments to AMC (€ 565.925)
## EQUAL costs vs. budget Jan-May 2018

<table>
<thead>
<tr>
<th>Employee / budget item</th>
<th>Fte</th>
<th>Costs made in 2018 as per 16-1-19</th>
<th>Budget as in contract</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtotal central coordination (incl salary overhead)</td>
<td>1.0</td>
<td>27.773</td>
<td>40.000</td>
</tr>
<tr>
<td>Subcontracting webplatform and data management</td>
<td></td>
<td>12.251</td>
<td>17.500</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td><strong>40.024</strong></td>
<td><strong>57.500</strong></td>
</tr>
</tbody>
</table>

Surplus of €17.476. Proposal: €17.476 to be returned to ERA-EDTA. 2018 installments have been paid by ERA-EDTA to AMC = €40.000 for salary and €17.500 for webplatform.
Aim 2 of WP4
Investigate factors influencing the **choice** of treatment modalities by **patients and doctors**
Patient opinion

Survey among dialysis and kidney transplant patients on treatment modality choice

• Information provision (also on conservative management)
• Involvement in decision making
• Factors influencing choice
• Satisfaction with choice

> 30 countries
• Translated in 30 national languages
• 8500 replies (50% transplant /50% dialysis)
• Paper in progress
Nephrologist opinion

- Systematic review on barriers for RRT provision by nephrologists (paper with co-authors)

- Survey on their opinion on treatment modality choice
  - Information provision
  - Decision making
  - Barriers experienced when providing RRT
  - Initiatives to improve the uptake of certain forms of RRT
  - Remote patient management
  - Promotion via National Societies, Registry contact persons, ERA-EDTA, ESOT

Additional work due to GDPR

Ethics approval not needed

Ethics approval in progress
How to increase kidney transplant activity throughout Europe—an advocacy review by the European Kidney Health Alliance

Raymond Vanholder¹, Vianda S. Stel², Kitty J. Jager², Norbert Lameire¹, Fiona Loud³, Rainer Oberbauer⁴, Rianne W. de Jong² and Carmine Zoccali⁵

¹Nephrology Section, Ghent University Hospital, Ghent, Belgium, ²ERA-EDTA Registry, Department of Medical Informatics, Amsterdam Public Health Research Institute, Amsterdam UMC, University of Amsterdam, Amsterdam, The Netherlands, ³Kidney Care UK, London, UK, ⁴Department of Internal Medicine, Medical University of Vienna, Vienna, Austria and ⁵CNR-IIF, Clinical Epidemiology and Pathophysiology of Hypertension and Renal Diseases, Ospedali Riuniti, Reggio Calabria, Italy
### EDITH costs vs. budget 2018 (just for information)

<table>
<thead>
<tr>
<th>Employee / budget item</th>
<th>Costs made in 2018 per 22-01-2018</th>
<th>Funded by EU (as per the budget, but may be lower if hours invested are lower)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtotal staff including overhead</td>
<td>94.785</td>
<td>70.909</td>
</tr>
<tr>
<td>Travel</td>
<td>4.406</td>
<td>3.525</td>
</tr>
<tr>
<td>Hardware/software/miscellaneous</td>
<td>939</td>
<td>0</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>100.130</strong></td>
<td><strong>74.434</strong></td>
</tr>
</tbody>
</table>

- EDITH shortage 2017 was (at least) € 21.509 and shortage 2018 was (at least) € 25.696; this is (at least) € 47.205 in total (with shortage 2019 yet to come);
- As a coverage AMC has already kept € 25,000 (2016 Registry surplus) and € 40,000 (2017 Registry surplus) and has asked to keep €19,385 from Registry 2018 surplus. As a result ERA-EDTA will have paid the total sum as parties agreed upon earlier. After the end of the project – when the calculations by EU will be final (estimated 2021) - the definitive calculation can be made.
ESPN/ERA-EDTA Registry
# Summary of Achievements

**March 2016 – September 2018**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>A further increase in coverage of countries contributing data from 38 to 40</td>
</tr>
<tr>
<td>2</td>
<td>Continuous improvement of national benchmarking reports</td>
</tr>
<tr>
<td>3</td>
<td>Publication of 14 papers in high-ranking medical journals + 1</td>
</tr>
<tr>
<td>4</td>
<td>Internships of four nephrologists/researchers from Austria, Greece and the Netherlands. + Italy</td>
</tr>
<tr>
<td>5</td>
<td>Contribution to several ESPN Working groups</td>
</tr>
<tr>
<td>6</td>
<td>Finalisation of the second full PhD project on disparities in incidence and outcomes</td>
</tr>
<tr>
<td>7</td>
<td>(Invited) presentations at ERA-EDTA and ESPN congresses, as well as at various (inter)national conferences</td>
</tr>
<tr>
<td>8</td>
<td>Contribution to the IPNA global RRT Registry</td>
</tr>
<tr>
<td>9</td>
<td>Two ESPN/ERA-EDTA Registry Annual Reports and newsletters</td>
</tr>
<tr>
<td>10</td>
<td>Contribution to the paediatric chapter of the ERA-EDTA Registry annual reports</td>
</tr>
</tbody>
</table>

### Table 1. Summary of achievements of the Registry between March 2016 and September 2018

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Mortality risk disparities in children receiving chronic renal replacement therapy for the treatment of end-stage renal disease across Europe: an ESPN-ERA/EDTA registry analysis</td>
</tr>
</tbody>
</table>

**Articles**

*Mortality risk disparities in children receiving chronic renal replacement therapy for the treatment of end-stage renal disease across Europe: an ESPN-ERA/EDTA registry analysis*
**Summary of Plans 2019 – 2020**

(Contract ESPN/ ERA-EDTA/ AMC signed December 2018)

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**Table 2. Summary of plans of the Registry for the period of January 2019 to December 2020**

<table>
<thead>
<tr>
<th>Data collection</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Further expand the data collection and feedback, including the implementation</td>
<td>Further expand the data collection and feedback, including the implementation of new benchmarking features in national reports</td>
</tr>
<tr>
<td>2. Collect additional data for specific research projects</td>
<td>Collect additional data for specific research projects</td>
</tr>
<tr>
<td>3. Continue the production of Annual Reports</td>
<td>Continue the production of Annual Reports</td>
</tr>
<tr>
<td>4. Continue the contribution of a paediatric section to the ERA-EDTA Registry</td>
<td>Continue the contribution of a paediatric section to the ERA-EDTA Registry report</td>
</tr>
</tbody>
</table>

**Research**

| 5. Continue the production of scientific papers on innovative topics              | Continue the production of scientific papers on innovative topics |
| 6. Continue the ESPN/ERA-EDTA internship programme                               | Continue the ESPN/ERA-EDTA internship programme                  |
| 7. Continue our contribution to the IPNA global RRT Registry                      | Continue our contribution to the IPNA global RRT Registry         |
| 8. Increase our collaboration with and contribution to the various ESPN Working | Increase our collaboration with and contribution to the various ESPN Working groups |
| 9. Seeking collaboration with other networks and registries                        | Seeking collaboration with other networks and registries           |
| 10. Apply for additional funding from other sources like the European Commission  | Apply for additional funding from other sources like the European Commission |
### ESPN/ERA-EDTA Registry costs vs. budget 2018

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<th>Cost made in 2018 (as per 16-1-2019)</th>
<th>Budget as in contract</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtotal staff including overhead (incl. reimbursement for maternity leave)</td>
<td>1.0</td>
<td>66,990</td>
<td>87,967</td>
</tr>
<tr>
<td>Hardware/software</td>
<td></td>
<td>2,580</td>
<td>1,955</td>
</tr>
<tr>
<td>Office</td>
<td></td>
<td>-</td>
<td>360</td>
</tr>
<tr>
<td>Travel</td>
<td></td>
<td>2,210</td>
<td>1,800</td>
</tr>
<tr>
<td>Miscellaneous</td>
<td></td>
<td>2,173</td>
<td>3,120</td>
</tr>
<tr>
<td><strong>Subtotal other costs</strong></td>
<td></td>
<td><strong>6,963</strong></td>
<td><strong>7,235</strong></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td><strong>73,953</strong></td>
<td><strong>95,202</strong>*</td>
</tr>
</tbody>
</table>

* Contributions from different parties: 47.480 % AMC/ 17.506 % ESPN / 35.014 % ERA-EDTA
Surplus €21,249, including € 3,719,67 for ESPN and € 7,440,22 for ERA-EDTA. AMC will re-imburse € 11,159,89 to ERA-EDTA. All 2018 installments have been paid by ERA-EDTA to AMC = € 50,000.