### MORNING SESSION

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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<tbody>
<tr>
<td>09:00 - 09:30</td>
<td>Coffee &amp; Registration</td>
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| 09:30 – 09:40 | Welcome and introduction  
Alberto Pereira and Daria Julkowska                                    |
| 09:40 - 10:00 | Examples of Synergies between both projects (ERICA & EJP RD)             |
| 09:40 - 10:00 | Input to Virtual Platform and its functionalities  
Franz Schäfer, Ana Rath and ERN example                                  |
| 10:00 - 10:15 | Biobanking and Clinical Trials  
Eduardo L. Granados and Luca Sangiorgi                                  |
| 10:15 - 10:30 | ERN Clinical Trials Survey(s)  
Rima Nabbout, Luca Sangiorgi and Dieter Hilgers                          |
| 10:30 - 10:45 | Developed tools for RD researchers (IMT, webinars)  
Adriana Planinic                                                        |
| 10:45 - 11:00 | Communication & Dissemination  
Mari Murel and Yanis Mimouni                                                |
| 11:00 - 11:20 | Coffee Break                                                             |
| 11:20 - 11:40 | Collaboration of ERNs and non-ERNs researchers                          |
| 11:20 - 11:40 | JARDIN-Data Sharing & Integration  
Holm Graessner (TBC)                                                      |
| 11:40 – 12:00 | IHI Call for Clinical Research  
Magda Chlebus (TBC) and Dieter Hilgers                                  |
| 12:00 - 12:20 | Together4RD: position statement on collaboration between ERNs and industry 
Mathieu Boudes                                                            |
| 12:20 - 12:50 | International Collaboration – NIH and IRDiRC and Canadian RD network    
Tiina Urv (NIH), David Pierce (IRDiRC) and Breanne Stewart (MICYRN)     |
| 12:50 - 13:00 | Discussion  
Moderated by Maurizio Scarpa                                              |
| 13:00 – 14:00 | Lunch                                                                    |

**Location:**  
Amsterdam UMC, Conference Room 4, Meibergdreef 9, Amsterdam  
Pre-conference dinner at 19:00. The restaurant (de Waag) is in historical centre!
# AFTERNOON SESSION

## Preparing the path to the European Rare Diseases Research Alliance (ERDERA)

<table>
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<tr>
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| 14:00 - 14:20 | General introduction  
  Daria Julkowska and Yanis Mimouni                                      |
| 14:20 – 14:40 | Updates & Special WP25 Task for ERNs  
  Maurizio Scarpa, Luca Sangiorgi and Alexis Arzimanoglou              |
| 14:40 – 14:50 | Accomplished tasks to be transferred to ERDERA  
  Moderated by Franz Schäfer                                           |
| 14:50 – 15:00 | Data Hub  
  Ronald Cornet                                                       |
| 15:00 – 15:10 | PROMs/PREMgs  
  Ana Rath                                                           |
| 15:10 – 15:20 | Overview of use cases  
  Franz Schäfer and Mar Mañu Pereira                                 |
| 15:20 – 15:40 | Discussions Q&A                                                     |
| 15:40 - 16:00 | Coffee Break                                                         |
| 16:00 – 16:30 | Discussion and next steps  
  Alberto Pereira and Daria Julkowska                                 |
| 16:30 - 17:30 | Borrel & Drinks                                                      |

**Recommended conference hotel**  
Leonardo Royal Hotel Amsterdam  
Booking code: **2011UMC**