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JARDIN GENERAL ASSEMBLY 2026

Meeting Venue:

Hotel Flemings Wien-Stadthalle
Neubaugürtel 26-28, 1070 Vienna, Austria

13-15 October

Draft Agenda

IMPORTANT: times indicated are local time/CEST

Day 1, 13 October

Plenary Meeting – Session I: 14:00 – 18:30

Chair: JARDIN Coordinator, Till Voigtländer

13:00 – 14:00	Registration/Light lunch/Networking
14:00 – 14:10	Welcome remarks (<i>tbd</i>)
14:10 – 14:20	Opening remarks (<i>Till Voigtländer, JARDIN Coordinator, MUW, Austria</i>)
14:20 – 14:35	Policy Outlook (<i>Philippe Roux, Head of Unit - Health monitoring and cooperation, Health networks - DG SANTE B.3</i>)
14:35 – 15:20	WP2 – Dissemination Update (<i>Luz Yadira Bravo Gallego, FIBHULP, Spain</i>)
15:20 – 15:40	WP3 – Evaluation (<i>Irene Mathijssen, Erasmus MC, Netherlands; Till Voigtländer, JARDIN Coordinator, MUW, Austria</i>)
15:40 – 16:10	Coffee break
16:10 – 16:55	WP4 – Investigation of ERN integration aspects in the national rare disease plans and strategies (<i>Birutė Tumienė, VULSK, Lithuania</i>)

16:55 – 17:55	WP9 • Recommendations on the national and institutional support to ERN clinical centres • Focus on CPMS reimbursement models (<i>Pavla Doležalová, GUH, Czech Republic</i>)
17:55 – 18:30	Open discussion
19:00	<i>Working Dinner at Flemings Wien Stadthalle</i>

Day 2, 14 October

Plenary Meeting – Session II: 09:00 – 13:00

Chair: JARDIN Coordinator, Till Voigtländer

9:00 – 9:10	Setting the stage for day 2 (<i>Till Voigtländer, JARDIN Coordinator, MUW, Austria</i>)
9:10 – 9:55	WP5.1 – National Governance (<i>Luca Sangiorgi, IOR; Silvia Fittipaldi, IOR; Edoardo Gallerani, IOR, Italy</i>)
9:55 – 10:40	WP5.2 – Measuring ERN integration: what the Delphi told us and where we go next (<i>Marta Mosca, AOUP, Italy</i>)
10:40 – 11:10	<i>Coffee break</i>
11:10 – 11:55	WP6 – National care pathways and ERN referral systems: from models to implementation (<i>Birutė Tumienė, VULSK, Lithuania; Geraldine Sweeney, T6.2, HSE, Ireland; Ines Hernando, T6.2, EURORDIS</i>)
11:55 – 12:40	WP7.1 – Shaping national reference networks together: experiences and first outcomes from the pilots projects (<i>Holm Graeßner, UKT; Maximilian Ferencak, UKT, Germany</i>)
12:40 – 13:00	Open discussion
13:00 – 14:00	<i>Lunch break</i>

Plenary Meeting – Session III: 14:00 – 18:00

Chair: JARDIN Coordinator, Till Voigtländer

14:00 – 14:50	WP7.2 • General report • Focus topic: ERN undiagnosed disease programme, Solvathon and CPMS 2.0 (<i>Ursula Unterberger, UKW; Helge Hebestreit, UKW; Holm Graeßner, UKT, Germany</i>)
14:50 – 15:35	WP8 (part I) – Future perspective beyond JARDIN (ERDERA, EHDS, other) (<i>Anne-Sophie Lapointe, DGOS, France; Marco Roos, LUMC, Netherlands</i>)
15:35 – 16:05	<i>Coffee break</i>
16:05 – 16:50	WP8 (part II) – Future perspective beyond JARDIN (ERDERA, EHDS, other) (<i>Anne-Sophie Lapointe, DGOS, France; Marco Roos, LUMC, Netherlands</i>)
16:50 – 17:20	Coordination – summary, conclusions, roadmap to the end of JARDIN (<i>Till Voigtländer, JARDIN Coordinator, MUW, Austria</i>)
17:20 – 18:00	Open discussion

Day 3, 15 October

Workshops: 9:00 – 16:00

9:00 – 9:05	Opening day 3 (<i>Till Voigtländer, JARDIN Coordinator, MUW, Austria</i>)
9:05 – 10:05	WP4 workshop – Towards recommendations for better integration of JA actions and sustainable elements into the National RD Plans/Strategies (<i>Birutė Tumienė, VULSK, Lithuania</i>)
10:05 – 11:05	WP6 workshop – Care coordination in rare disease care pathways: from conceptualization to recommendations for implementation (<i>Birutė Tumienė, VULSK, Lithuania</i>)
11:05 – 11:30	<i>Coffee break</i>
11:30 – 13:00	WP8 workshop – Shaping WP8 recommendations on data management: challenges, controversies, and solutions (<i>Ashray Vohora, Inserm, France; Andy Gibson, LUMC, Netherlands; Annika Jacobsen, LUMC, Netherlands; Helge Hebestreit, UKW, Germany; Lore Van Espen, Sciensano, Belgium; Sylvie Maiella, INSERM, France; Pascal Block, UKFFM, Germany; Sander van Boom, LUMC, Netherlands</i>)
13:00 – 14:00	<i>Lunch break</i>
14:00 – 15:50	WP2 workshop – Shaping the final Communication Blueprint (<i>Luz Yadira Bravo Gallego, FIBHULP, Spain</i>)
15:50 – 16:00	Closing JARDIN General Assembly (<i>Till Voigtländer, JARDIN Coordinator, MUW, Austria</i>)