



EUCERD Joint Action 2012 - 2015

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What is a Joint Action?

- Co-funded activity between EC and Member States
- Action supporting the work of EUCERD (EJA)
 - Implementation of national plans and strategies
 - Standardisation of RD nomenclature
 - Mapping the provision of specialised social services
 - Mapping of national initiatives across continuum of care with emphasis on quality assurance
 - Integration of RD activities across thematic areas, MS and related activities

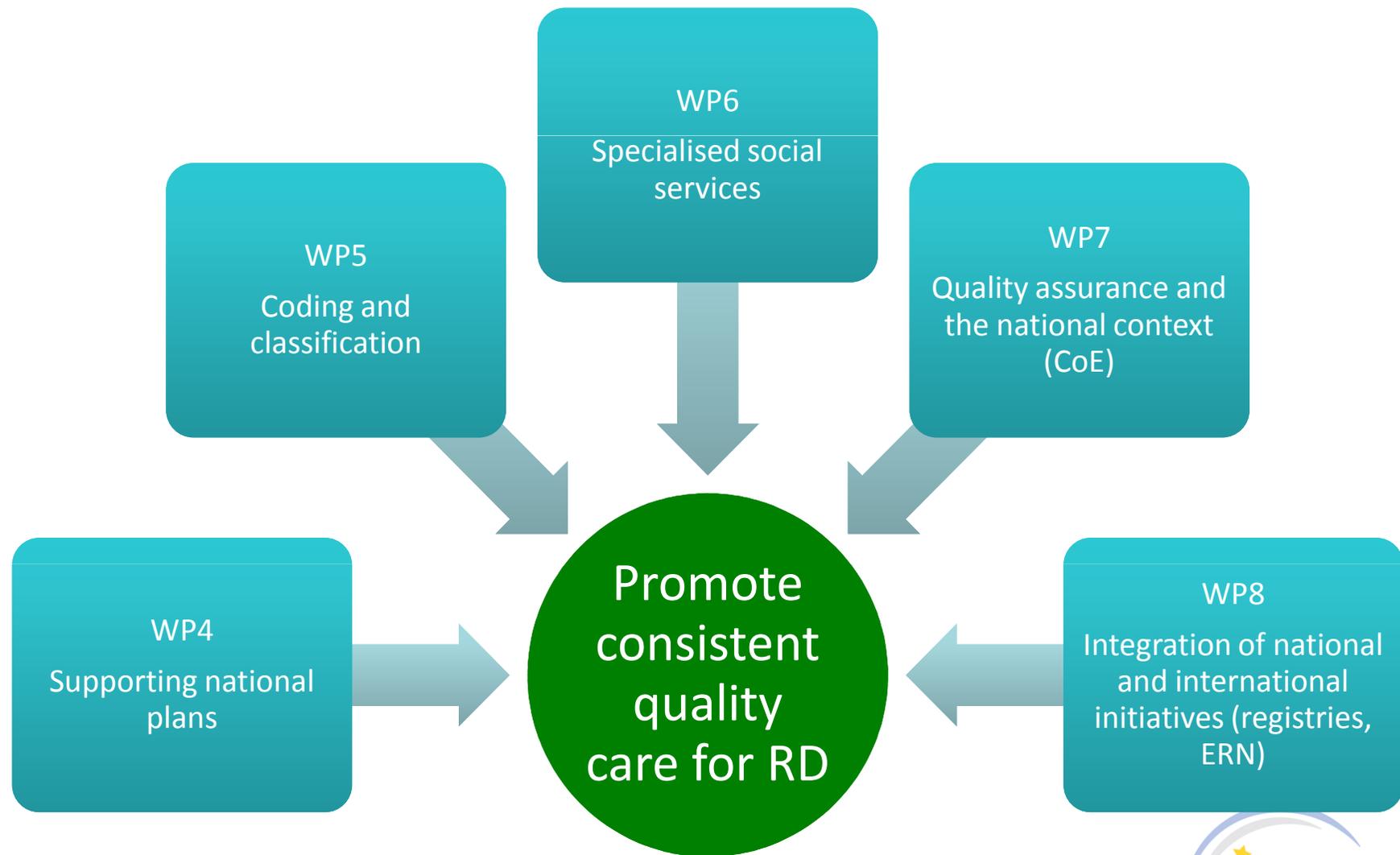
Associated Partners

- Newcastle University (**Kate Bushby**)
- INSERM Paris (**Segolene Ayme**)
- ISS Rome (**Domenica Taruscio**)
- EURORDIS (**Yann Le Cam/Dorica Dan**)
- CIBERER (**Francesc Palau**)*
- Finnish Ministry of Social Affairs and Health (**Helena Kaariainen**)
- Goethe University Hospital Frankfurt (**Thomas Wagner**)
- Portuguese Ministry of Health (**Jose Calheiros**)

Collaborating Partners

- All Member States and other stakeholder representatives via EUCERD membership
 - Collaborating partners can bring great added value
 - EUCERD meetings and associated workshops
 - Contribution to discussion via national planning processes, designation of centres of expertise, ERNs, integration of registry initiatives, etc

EJA Framework



Supporting Workpackages

- WP1 – Management
 - Reporting, communication with EC, etc
- WP2 – Communication
 - EUCERD web site, newsletters, annual state of the art reports
- WP3 – Evaluation
 - Input to project to coordinate process indicators, outputs and outcomes

Building on existing strengths

- National Plans (builds on EUROPLAN project)
 - Technical support for developing and implementing national plans and strategies
 - Capacity building
 - Sharing experience: networking EUCERD MS representatives
 - National conferences as required
- **Domenica Taruscio, EURORDIS**

Building on existing strengths

- Orphanet RD nomenclature and ongoing efforts in ICD11
 - Annotation of RD within ICD11 coding
 - Extend availability of Orphanet nomenclature and its uptake
 - Cross referencing and update of international nomenclatures
- Segolene Ayme

Addressing specific area of need for holistic care

- Specialised social services for RD
 - Map access to specialised social services for RD
 - Therapeutic recreational programmes
 - Respite services
 - Other specialised rehab services (e.g. housing)
 - Guidance to MS and other stakeholders on training for social service providers
 - Integration of RD into social policies and guidelines
- Dorica Dan and EURORDIS team

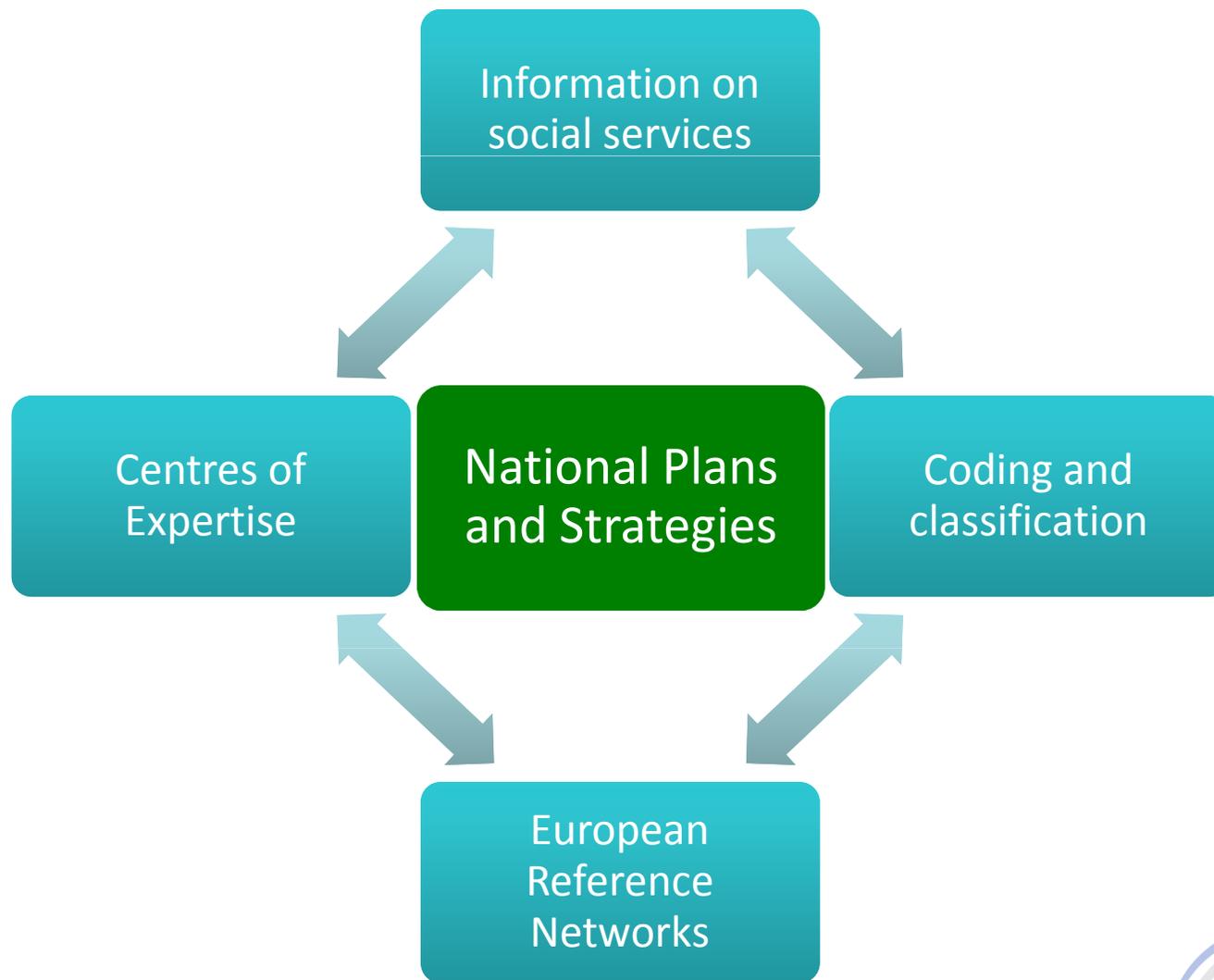
Mapping national initiatives and enhancing quality of RD care

- Designation process for Centres of Expertise
 - Sharing of successful strategies
 - Quality assurance procedures
 - Across continuum of RD care from diagnosis to care delivery
 - Build on existing recommendations and leading to new quality criteria and measures
- CIBERER, Helena Kaariainen

Integration of RD initiatives (disease-specific, national and international)

- Integration of the work of EUCERD and EJA to embed existing resources such as:
 - Patient registries
 - Tissue resources
 - Care guidelines/recommendations
 - RD Networks
 - Into new developments – ERNs
- In the context of ongoing initiatives such as CBHC, ERNs, IRDiRC, PARENT, EPIRARE, etc...
- **Kate Bushby, Thomas Wagner, Helena Kaariainen**

Integrated process utilising all tools and resources to ensure sustainability



EUCERD/MS input and integration

- Feedback sessions at EUCERD meetings
- Specific discussion groups for different workpackages
- Transparency in workshop planning – invitees, programme
- Regular feedback, monitoring of involvement by evaluation team
- Suggestions and feedback welcome – new EUCERD website to be launched later this month!

Thank you!

New website to be launched in September
www.eucerd.eu

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