



EUCERD Joint Action 2012 - 2015

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Zalau, Romania – 6th Dec 2012

Background

- Nov 2008 – EC Communication ‘Rare Diseases: Europe’s Challenges’
- June 2009 – Council Recommendation
- Nov 2009 – European Union Committee of Experts on Rare Diseases (EUCERD)
 - To assist the EC in formulating and implementing policies
 - To encourage and foster cross-talk between stakeholders in the field
 - Composition, methods, Recommendations
- EUCERD Joint Action

Nature of the Joint Action

- Co-funded activity between the EC and the MS
- Practical support
- Month 10 of 42
- Overall Goals:
 - Enhancing visibility and recognition of rare diseases;
 - Contributing to the development and dissemination of knowledge on rare diseases
 - Contributing to improvements in access to quality services and care, from diagnosis, through to care and social support and innovative therapies.



EJA Partners

- Coordinator = 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

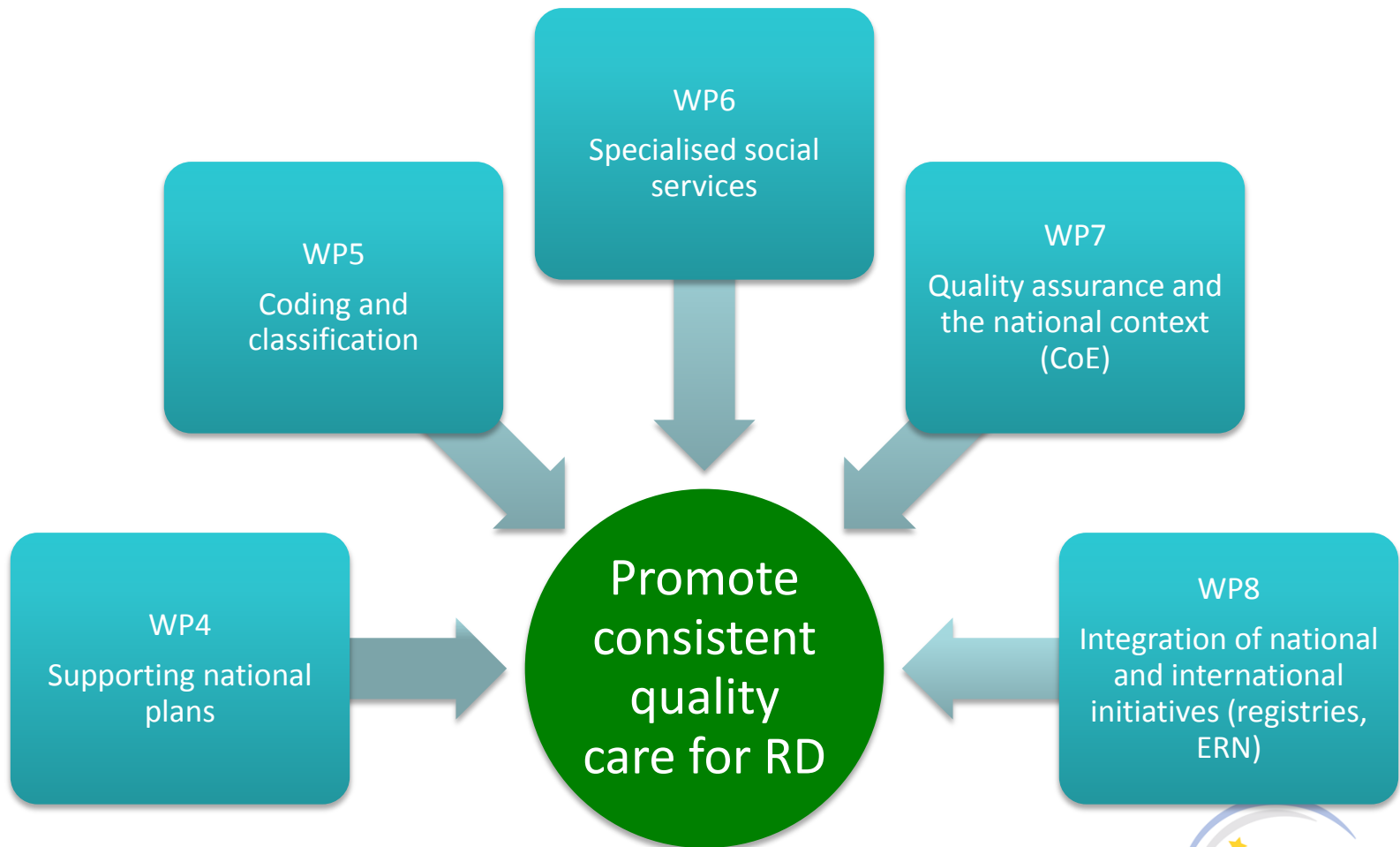
Scope of Activities

- Horizontal work packages
 - WP1 – Management (Reporting, communication with EC, etc)
 - WP2 – Communication (EUCERD web site – www.eucerd.eu - newsletters, annual state of the art reports
 - WP3 – Evaluation (Input to project to coordinate process indicators, outputs and outcomes)

Core work packages

- Wp 4: Implementation of national plans and strategies
- Wp5: Standardisation of RD nomenclature
- Wp6: Mapping the provision of specialised social services and integrating RD into social policies
- Wp 7: Mapping of national initiatives across continuum of care with emphasis on QA
- Wp8: Integration of RD activities across thematic areas

EJA Framework



Building on existing strengths

- USE WHAT IS THERE – partner selection
- National Plans (builds on EUROPLAN 1 project)
 - Technical support for developing and implementing np/ns
 - Capacity building
 - EURORDIS - National conferences
- 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

Updates – wp 4 (national plans)

- EUROPLAN 2 – website (www.euoplanproject.eu)
- First inception workshop held September 2012
 - Establish working groups to define key indicators for evaluating RD initiatives using a Delphi methodology
 - First conferences have just taken place (organised by EURORDIS)

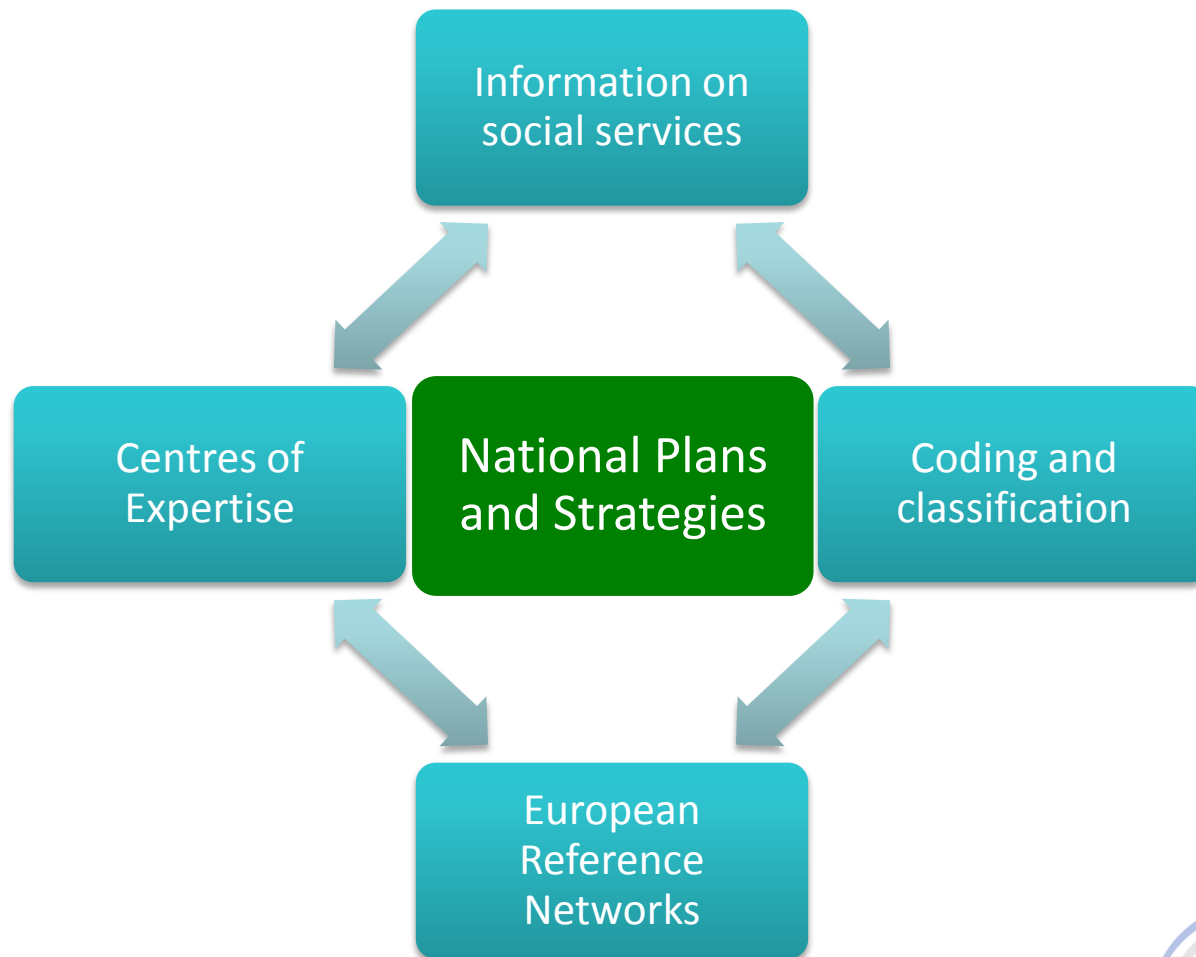
Updates – wp 5 & 7

- Wp 5: Codification of RD
 - ICD11 alpha draft completed, beta draft in progress
 - Adoption of the Orphanet nomenclature in the ICD11 framework is in progress
 - Workshop held (Sept) on cross-referencing with other terminologies.
- Wp 7 Quality Assurance in RD healthcare
 - Developing a qualitative research strategy, tools and methodologies for collection and validation of relevant information

Updates - wp 8: Integration

- Scope – work with initiatives and MS (impact)
- Registries - workshop held in Nov to provide information on current initiatives and EC vision
- ERN Recommendations – two workshops organised and final draft document with EUCERD members
- Developing links with other relevant initiatives
 - EPAAC (harmonising RD/cancer national plans – Rare Cancers Europe and RARECAREnet)
 - EUnetHTA (enhancing collaboration between MS)
 - PARENT Joint Action
 - RD-Connect
 - IRDiRC

Integrated process utilising all tools and resources to ensure sustainability



Thank you!

www.eucerd.eu

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