

Promoting Implementation of Recommendations on Policy, Information and Data for Rare Diseases: RD-ACTION

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OBJECTIVE

Rare diseases (RD) have been identified as a paradigmatic field in which actions conducted at the European level constitute the adequate response to the specific problems encountered by stakeholders in the RD field. RD-ACTION is a 3-year Joint Action (JA) co-funded by the EU Health Programme (2014-2020). Its aim is to ensure that there is an integrated European approach to the challenges faced by the RD community and at promoting, catalysing and triggering multi-stakeholder debates which are necessary both at European level to build shared strategies and at national level to support the integration of EU policy development across Member States.

METHOD

To gather specific expertise and to build shared strategies to address the specific issues of RD, the governance of the action is organised into three levels:

- a General assembly composed of one member per designated authority* which is the decision-making body of the consortium in charge of review and steer the project.
- An Executive committee composed by the 7 sub-projects leaders in charge of the supervision, communication and cross-talk promotion
- Sub-projects teams in charge of executing, monitoring and cross-talks.
- Workgroups established according to the need identified

*Beneficiaries and European collaborating stakeholders have been designated by the national authorities as competent authorities for Joint Action participation.

RESULTS

Missions and members

MISSIONS

- 1 Support the development and sustainability of Orphanet
- 2 Contribute to solution to ensure codification of RD in health information systems across Europe
- 3 Work on priority issues for people living with RD by implementing the actions identified in the EU Council recommendation on an action in the field of RD. Ensure the sustainability of these actions and support the work of the CEGRD
- 4 Promote, catalyse and trigger multi-stakeholder debates around RD

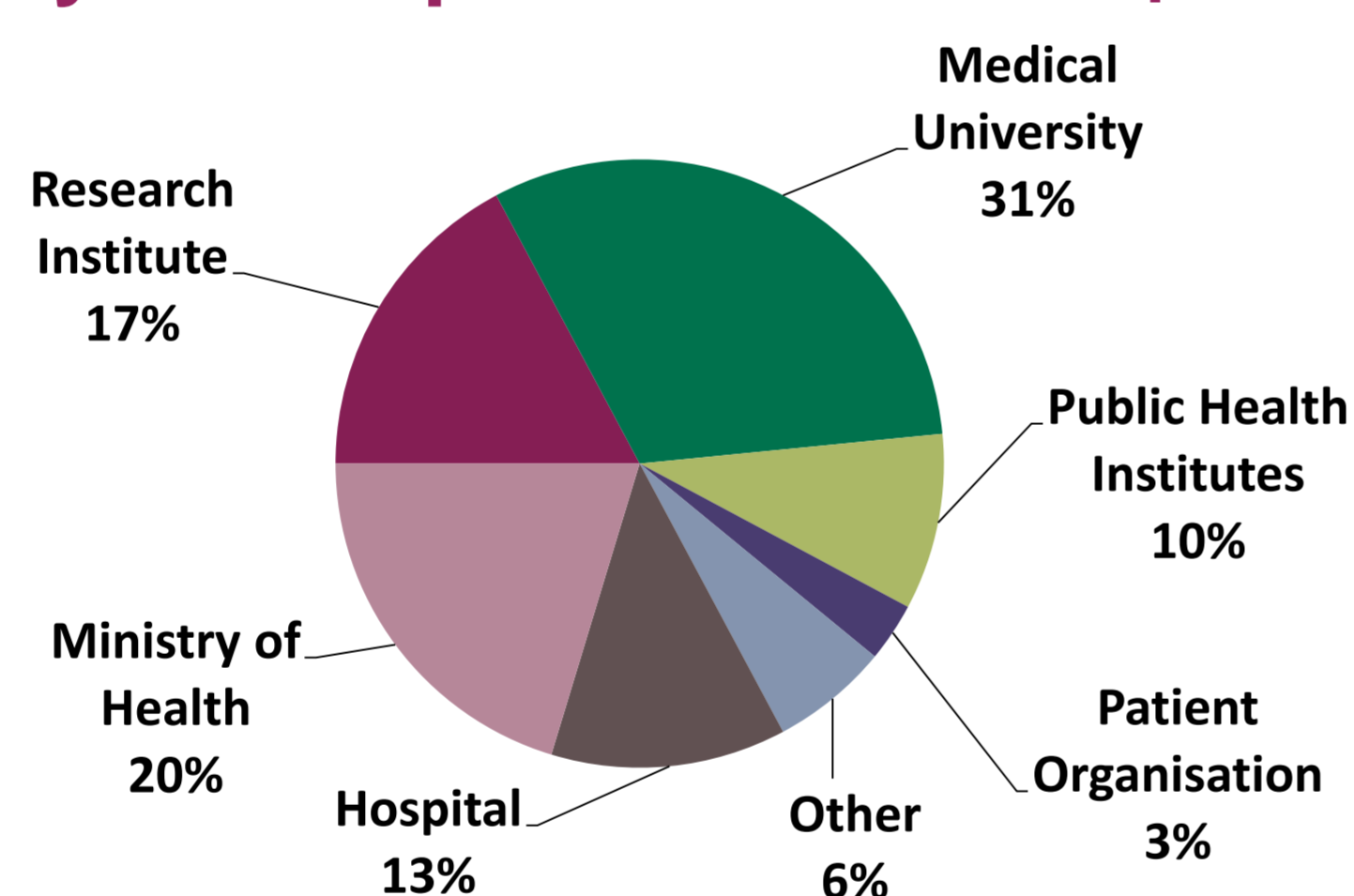
6 Sub-projects



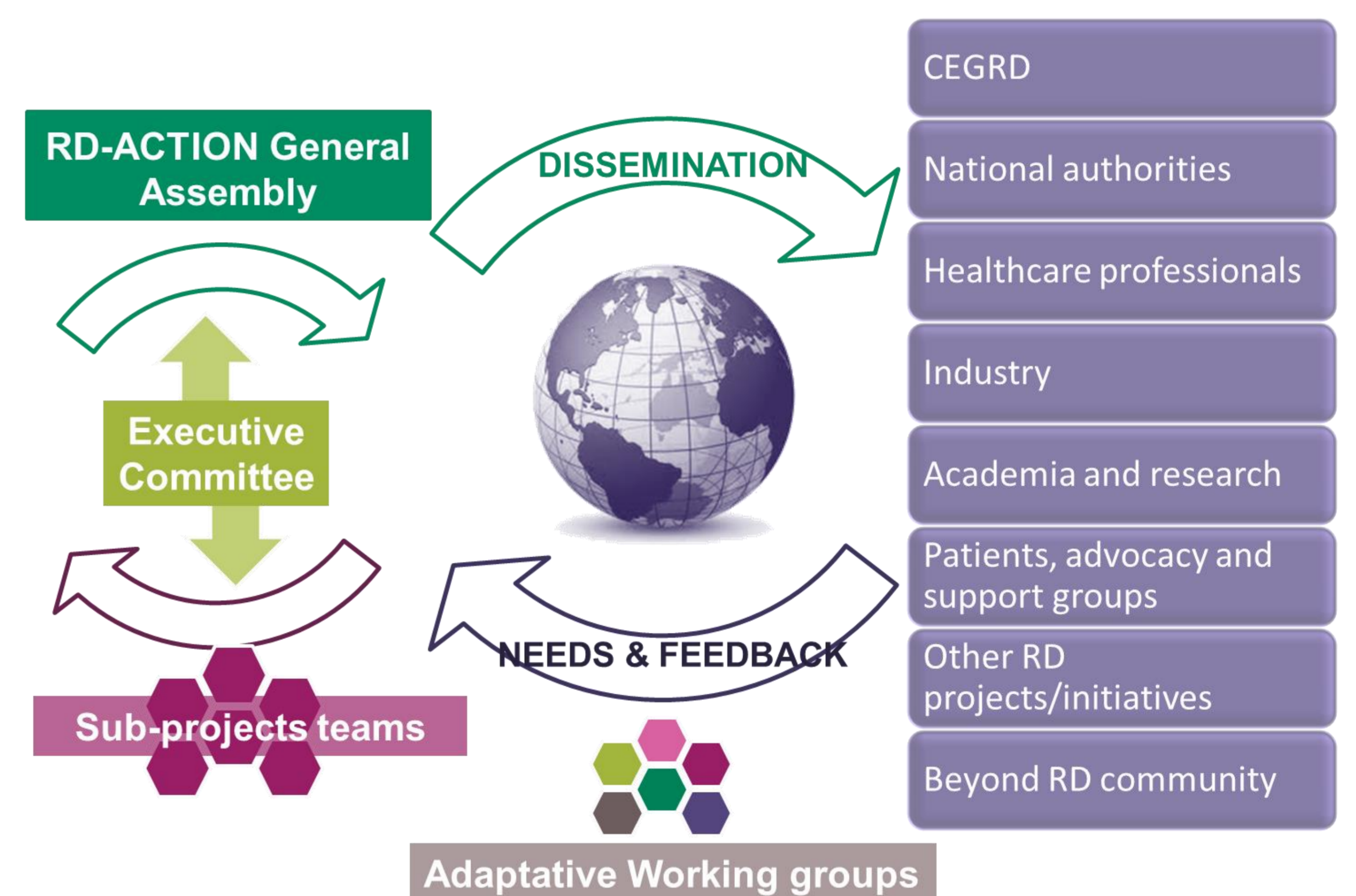
64 partners in 40 countries

34 beneficiaries
30 collaborating stakeholders

Array of competences of the 64 partners



Governance and stakeholders



Achievements

Year 1 Achievements	Outcomes
Evolution of the diagnostic test page in Orphanet	Easier identification of tests for Cross border genetic testing
Establishment of advisory committees and working groups WP5 Working group WP6 Consultative group Task-Force on Interoperable data sharing in the framework of the operation of ERNs Health systems equity working group	Integrated, flexible, multistakeholders approach Convergence and synergy of expertise Concertation of actions Adaptivity to the RD community needs
Review of the technical existing implementation of RD coding	Allows clear overview of specifications strategy of the required resources for coding RD consistently across Member States
European Reference Network matchmaker exercise	Facilitate discussions and collaboration between specialists and possible participants
Orphanet partnerships with other relevant RD initiatives: EURORDIS directory of resources Harmonising phenomics information for a better interoperability in the RD field (HIPBI-RD) Joint Action on Rare Cancers (JARC) RD-CONNECT	Avoid dissipation of work Convergence and synergy of expertise
European Conference on Rare Diseases and Orphan Products 2016 (ECRD)	Opportunity to inform, educate, engage and promote projects in the field of RD

CONCLUSION

RD-ACTION large geographical coverage and the wide array of competences represented gives the project a global, multistakeholder perspective. Moreover the three levels participative governance allows an effective and adaptive response to the RD community needs and allows cross-talks between internal and external projects resulting in a flexible approach which ensures that the products delivered are consistent, non redundant and instrumental to the transfer of European recommendations into national policies.