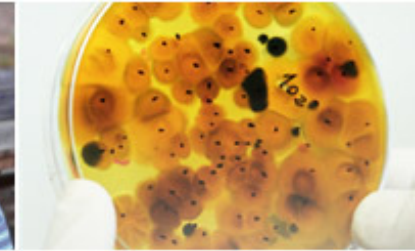


Instituto Nacional de Saúde
Doutor Ricardo Jorge



INSA, I.P.
Instituto Nacional de Saúde Dr. Ricardo Jorge

EJA: EUCERD Joint Action: working for rare diseases
Glória Isidro

24 de Março de 2014



Introduction

- **Joint Action is a co-funded activity between European Commission (EC) and Member States (MS)**

Total of **5.504.258€** (five million, five hundred and four thousand and two hundred and fifty-eight Euros) = **EC 54.4%** (2.994.162€)+ **45.6 % MS (2.510.096€)**

- **Project duration: 42 months from March 1st, 2012**
- **Action supporting the mandate of **EUCERD**/ expert group**

EUCERD

The **European Union Committee of Experts on Rare Diseases** was formally established by the [European Commission Decision of 30 November 2009 \(2009/872/EC\)](#) and its first mandate took place between 2010 and 2013.

Since 2014 EUCERD was substituted by the **European Commission Expert Group on Rare Diseases**, established by [Decision 2013/C 219/04](#) with its first meeting in Feb in Luxembourg.

- assisting the Commission in the monitoring, evaluating and disseminating the results of measures taken at Community and national level in the field of rare diseases;
- contributing to the implementation of Community actions in the field, in particular by analyzing the results and suggesting improvements to the measures taken;
- contributing to the preparation of Commission reports on the implementation of the Commission Communication and the Council Recommendation;
- delivering opinions, recommendations or reports to the Commission either at the latter's request or on its own initiative;
- assisting the Commission in international cooperation on matters relating to rare diseases;
- assisting the Commission in drawing up guidelines, recommendations and any other action defined in the Commission Communication and in the Council Recommendation;
- providing an annual report of its activities to the Commission.

Areas of Recommendation (aims):

- i) Improve the visibility and recognition of RD;
- ii) Contribute to the development of the dissemination of knowledge about RD, from specialized research through supporting health care professionals and patient empowerment;
- iii) Contribute to improving accessibility to quality services in providing care, from diagnosis through the social support to innovative therapies

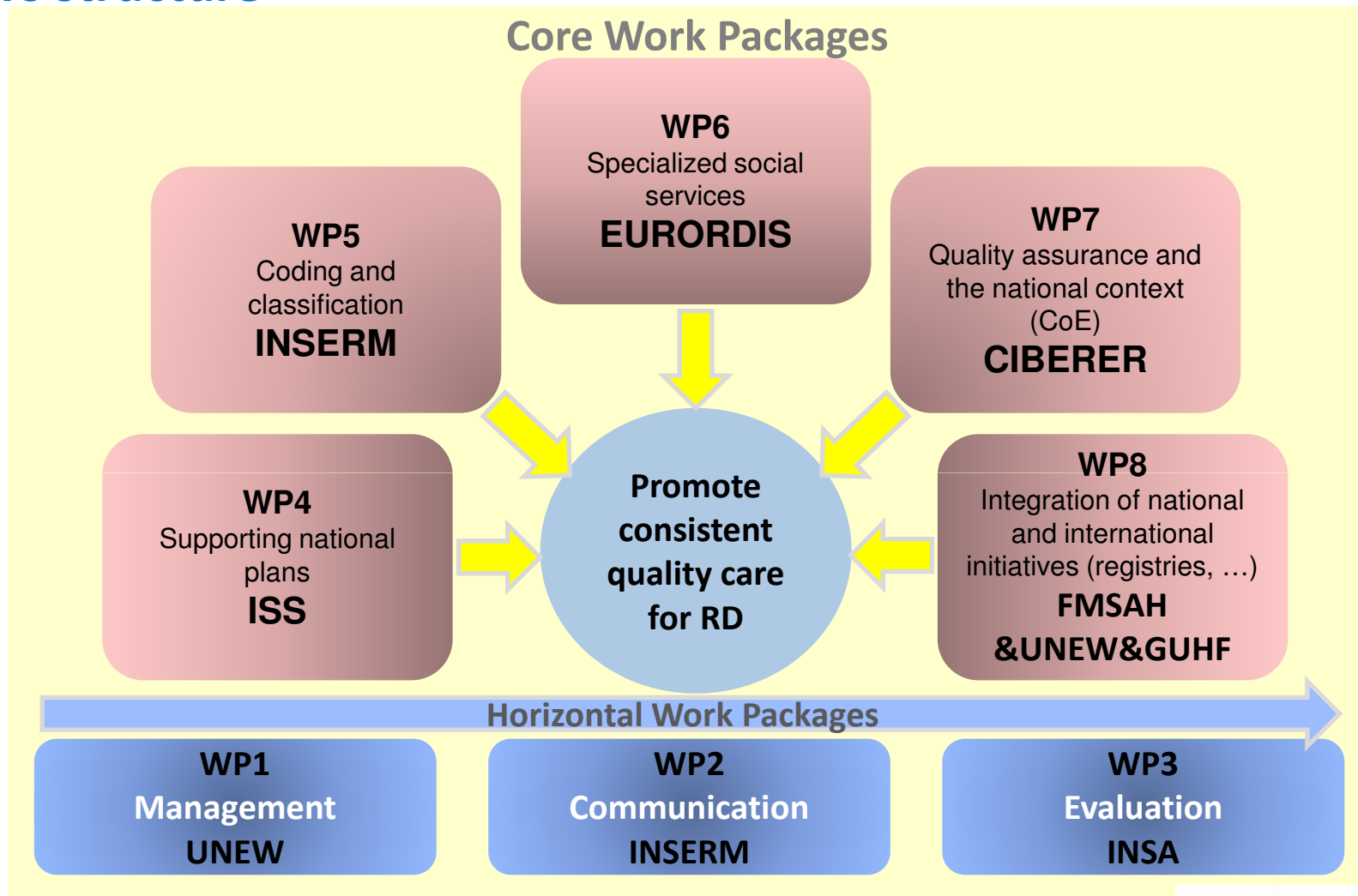
Associated Partners

- Newcastle University (Kate Bushby)
- INSERM Paris (Ségolène Aymé)
- ISS Rome (Domenica Taruscio)
- EURORDIS (Yann Le Cam/Dorica Dan)
- CIBERER (Francesc Palau)
- Finnish Ministry of Social Affairs and Health (FMSAH)(Helena Kääriäinen)
- Goethe University Hospital Frankfurt (GUHF)(Thomas Wagner)
- Portuguese Ministry of Health → INSA (Gloria Isidro)

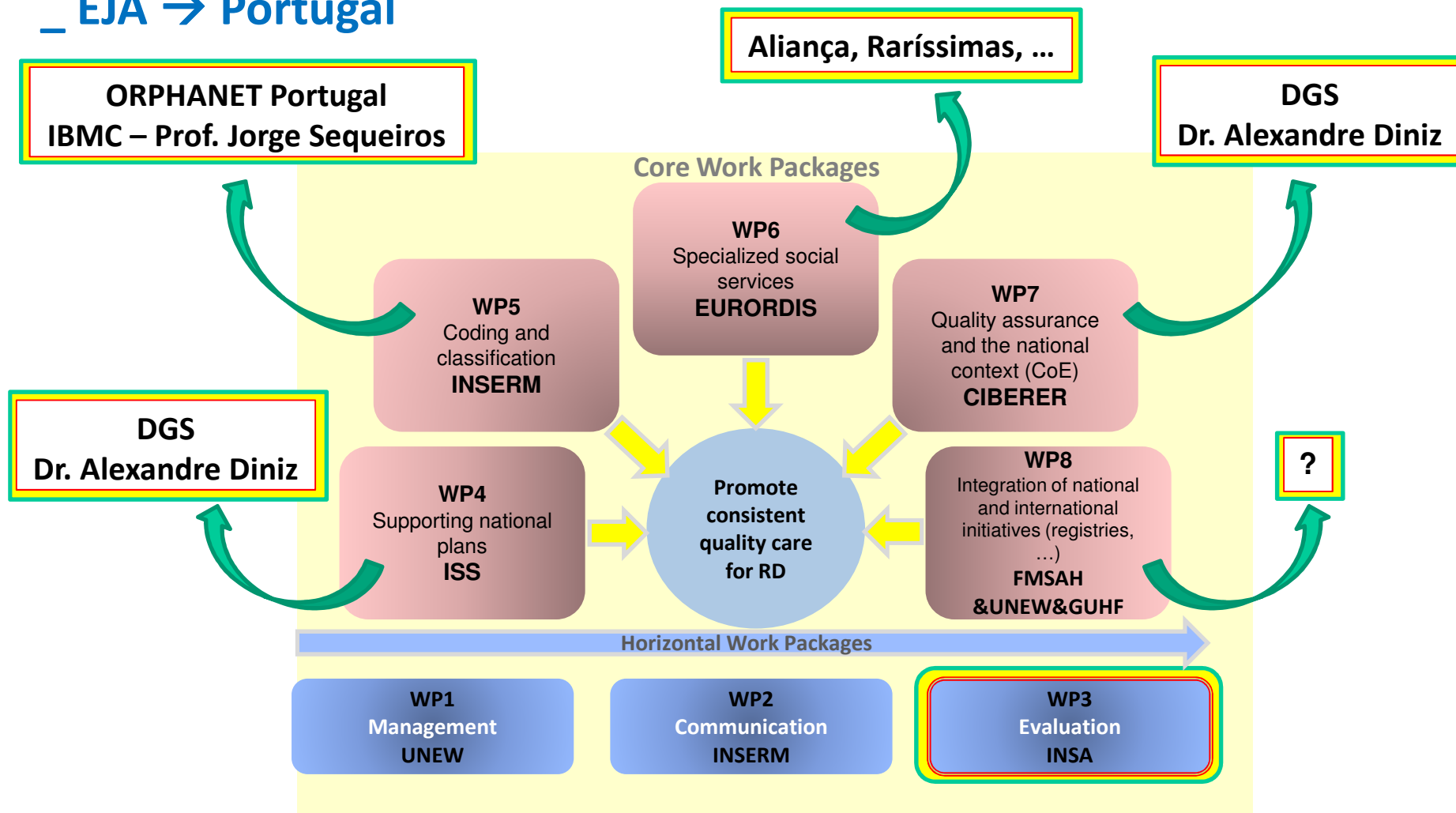
Collaborating Partners

- All MS and other stakeholder representatives, via EUCERD/ expert group membership
- Collaborating partners are the link between National and EU level activities
- The Expert Group on RD is therefore a key player in EJA activities
 - Needs and opinions of MS (EUCERD meetings, workshops, national conferences, other activities)
 - Dissemination of outputs
- The hope is to retain and cement this two-way relationship

EJA's structure



_ EJA → Portugal





WP	Final objective
WP1	To manage the joint action and to make sure that it is implemented as planned.
WP2	To ensure that the results and deliverables of the joint action will be made available to the target groups.
WP3	To verify if the joint action is being implemented as planned and reaches the objectives.
WP4	Support the process of elaboration and implementation of national plans and strategies for RD. (Continuation of Europlan)
WP5	Contribute to the ICD11 preparation to ensure an exhaustive coding of RD and an appropriate classification; promote the codes addition for RD in other nomenclatures; promote and facilitate the Orphanet nomenclatures use in health information systems and especially data national repositories on RD patients.
WP6	Publish recommendations on social services and integration of RD into social policies and services.
WP7	Identify effective approaches of health care services towards efficient improvement of RD patients quality of life.
WP8	Develop a model of sustainability for RD initiatives.

INSA's Team

Glória Isidro (DGH) – gloria.isidro@insa.min-saude.pt

José Calheiros (CD) – jose.calheiros@insa.min-saude.pt

Dezso David (DGH) – dezso.david@insa.min-saude.pt

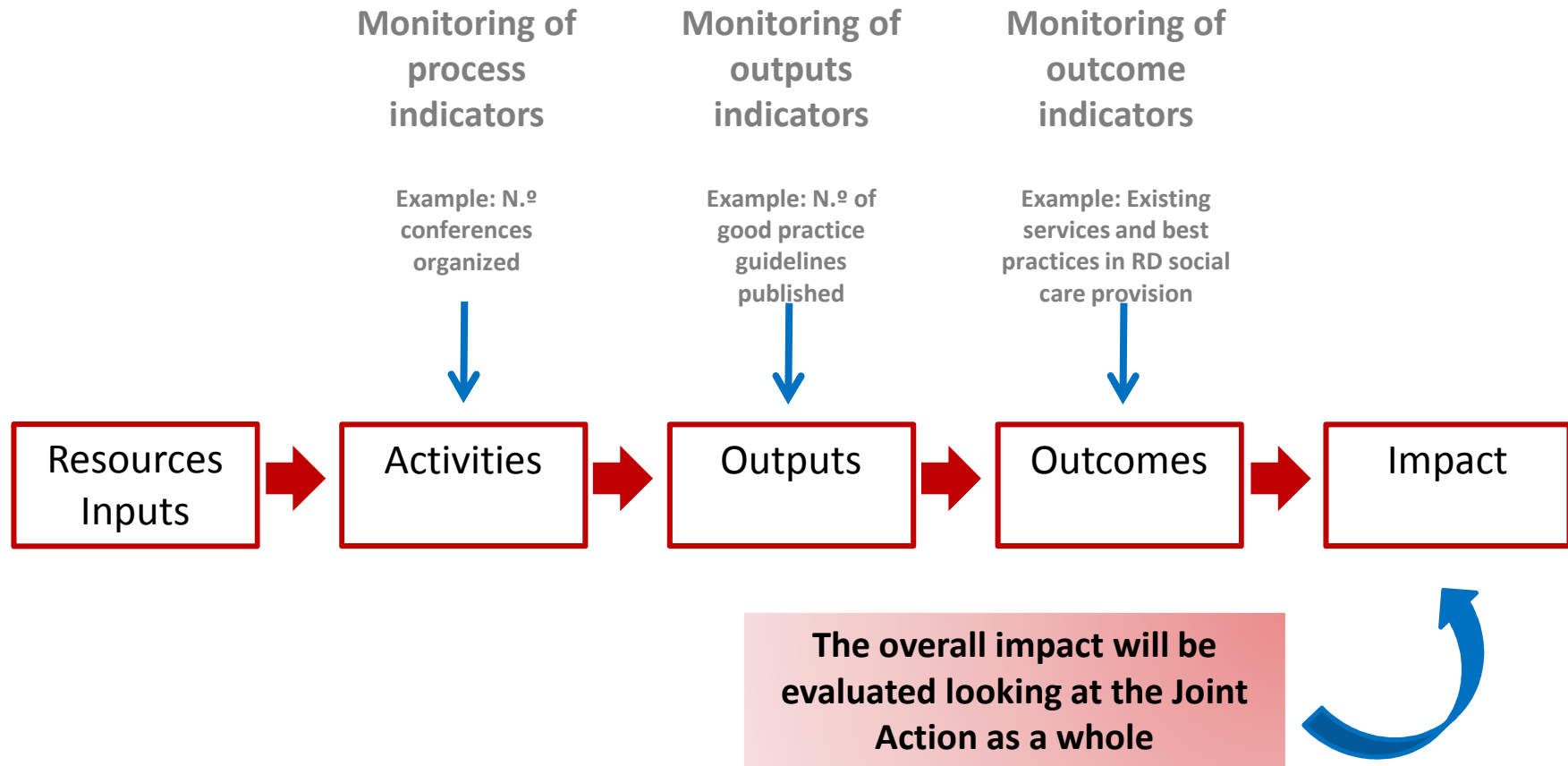
Cristina Furtado (DDI) – cristina.furtado@insa.min-saude.pt

Ausenda Machado (DEP) – ausenda.machado@insa.min-saude.pt

Verónica Gomez (DGH) – veronica.gomez@insa.min-saude.pt

_Evaluation's strategy

WP3
Evaluation
INSA



Future actions

- ✓ May 2014: ECRD workshop: ISS National plans
- ✓ 4th Quarter 2014: Eurordis Integration of Social Care for RD
- ✓ 2014/15: Cross-Border Genetic Testing – sharing best practices (UNEW/MSAH)

In planning:

- ✓ Phase 3 workshop on Indicators/DS (ISS)
- ✓ Final conference on NP/NS (ISS)
- ✓ Evaluation of EJA with Expert Group (INSA)
- ✓ INSA will organize one workshop in **November** where all partners will present their WP

Thanks to:

_ Kate Busby and Stephan Lynn from UNEW

_ All Project Partners

_ WP3 Team: Cristina Furtado, Dezso David, Ausenda Machado, José Calheiros and Verónica Gomez