

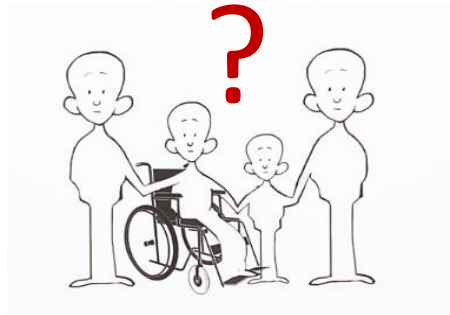


INNOVCare – Innovation in social care provision to complex diseases

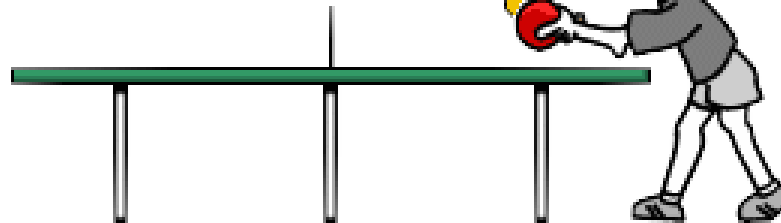
Raquel Castro, Social Policy Manager



The dilemma



Health



Social
Local



INNOVCare

Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions



INNOVCare - Background

EurordisCare Survey (2002-2008)

RAPSODY - Rare Disease Solidarity Project (2006-2008)

EUCERD Joint Action WP6 - Specialised Social Services and Integration of RDs into Social Policies (2012-2015)

National Plans & EUROPLAN Conferences - good practices (2012-2015)

Preparation of the CEGRD recommendations on social care (ongoing)



- Mapping social services for RDs in Europe
- Preparing case studies and good practices
- Developing of definition for resource centres for RDs – “one stop shop” services and starting to collect information on case management and integrated care
- Identifying main issues and hurdles regarding social care for RDs

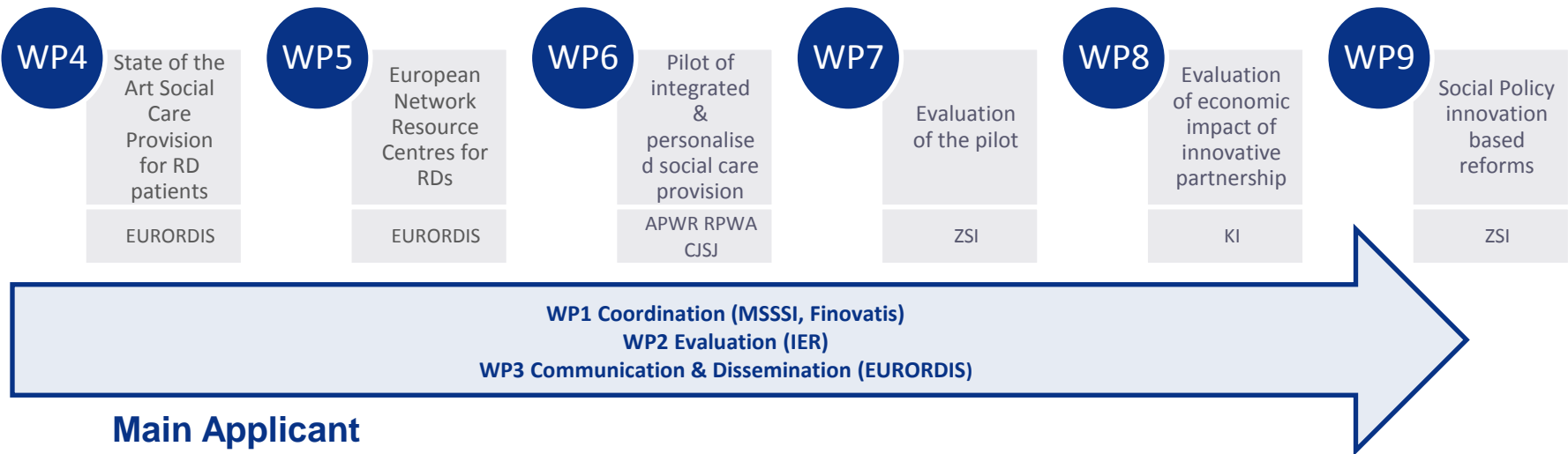
INNOVCare - Call for proposals

- Call for proposals from EC-DG Employment (2014)
- Call “social policy innovation supporting reforms in social services” - specific focus on “one stop shop services” and “case handlers”
- Not specific to health/disability – open to all vulnerable populations
- Over 200 projects submitted
- 7 selected – led by public bodies in Spain (3), Italy (2), Netherlands (1) and Latvia (1)
- INNOVCare is the only project on health/disability and with European scope

INNOVCare - Overview

- *Innovative patient-centred approach for social care provision to complex conditions*
- Time frame:
 - 36 months
 - 01/10/2015 to 30/09/2018
 - Kick off meeting 1-2/12/2015, Madrid (tbc)
- Consortium:
 - 8 partners
 - 6 countries – Spain, France, Slovenia, Romania, Austria, Sweden

INNOVCare - Structure & partners



Main Applicant

MSSSI Ministry of Health and Social Affairs – Spain

Co-Applicants

Finovatis – France

IER Inštitut za Ekonomska Raziskovanja – Slovenia

EURORDIS – France

APWR RPWA Asociatia Prader Willi din Romania (NoRo Resource Centre) – Romania

CJSJ Regional County Sălaj – Romania

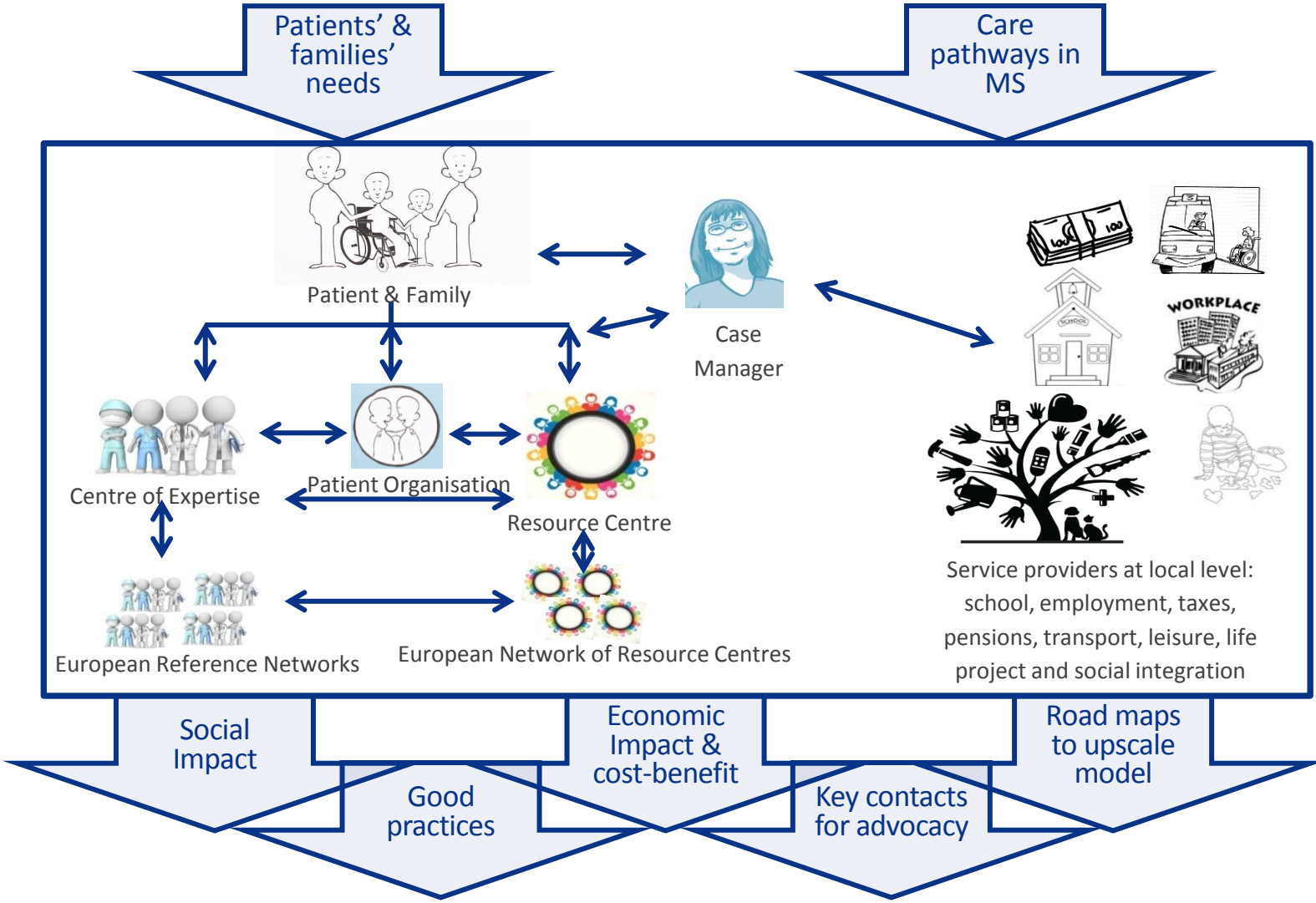
ZSI Zentrum für Soziale Innovation – Austria

KI Karolinska Institutet – Sweden

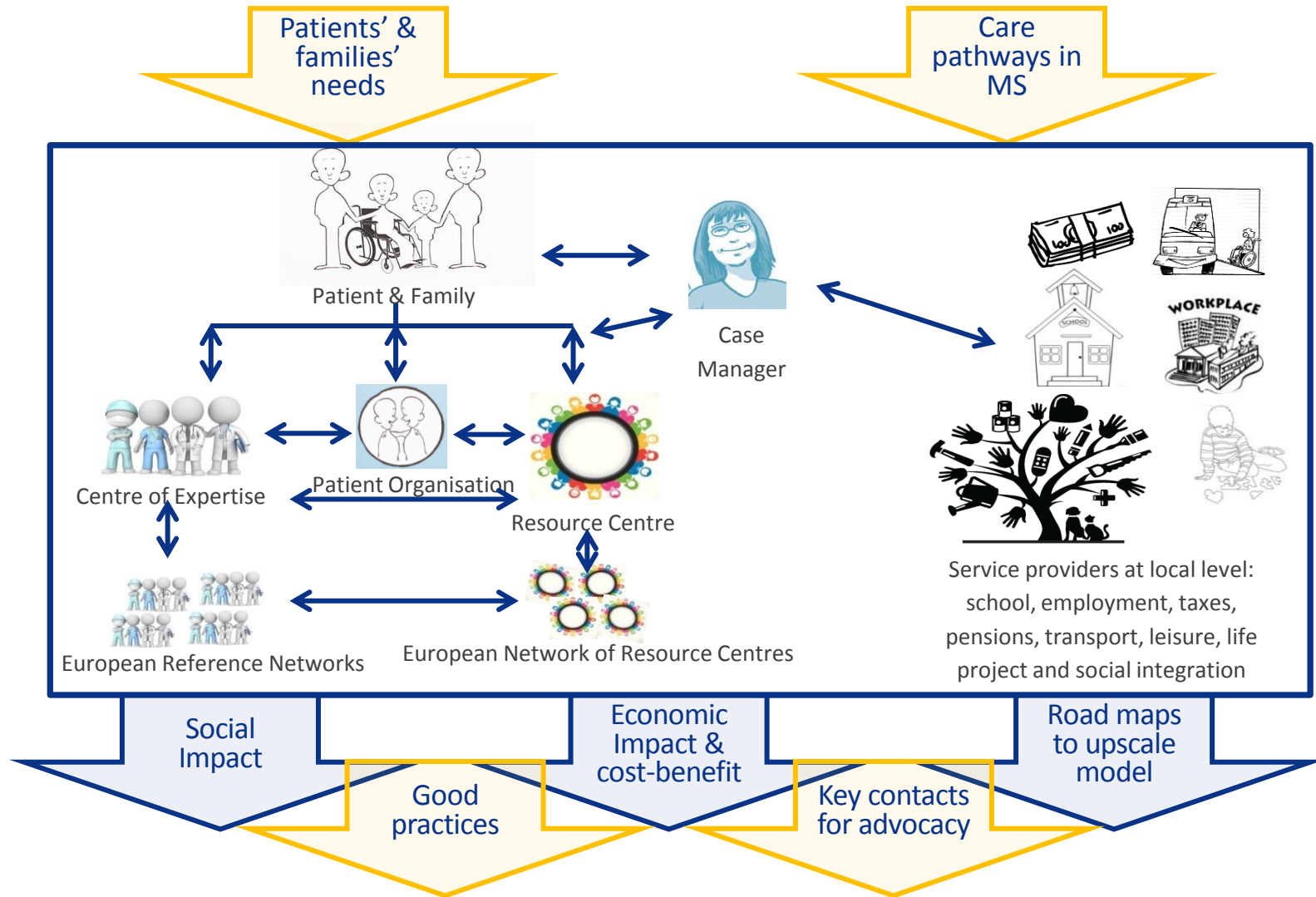
INNOVCare - Objectives

- Assessment **social unmet needs of people with a RD and their family**
- Analysis of **existing social care models in MS**
- **Exchange of expertise/good practices** between national one-stop-shop services (resource centres)
- Proposition of a **model of optimised patient social care pathway**, integrating the national one-stop-shop service with regional case managers:
 - Implementation and evaluation of a **pilot** (Romania)
 - Analysis of **scaling opportunities** - beyond RDs (to other diseases, disabilities) and to other MS
 - Assessment of the **economic impact and cost-benefit** of the care model
- Strengthening partnerships between public, private and civil society organisations providing social services to RD patients/families

INNOVCare - Concept



INNOVCare – EURORDIS role



INNOVCare – EURORDIS' role

- Leader of WP3 Communication; WP4 State of the Art of Social Care Provision and Patients/Families' needs; WP5 European Network of Resource Centres for Rare Diseases
- Collect data on patients'/families' needs (via Patient Voices) and on care pathways in MS
- Facilitate the establishment of the network of resource centres and the collection of good practices via network meetings
- Represent patients/users in coordination with our members
- Keep coherency between work packages
- Connect stakeholders
- Ensure the two way communication between INNOVCare and the rare disease community and advocacy actions

INNOVCare – WP4 State of the Art

Time frame: Oct 2015-Sept 2016

Patients' and families' needs – Study via Patient Voices

- Quantitative study on social needs (Europe) - identification & dimension
- Qualitative study (8 selected countries) - care pathways
- Please send us any surveys you've conducted on these matters

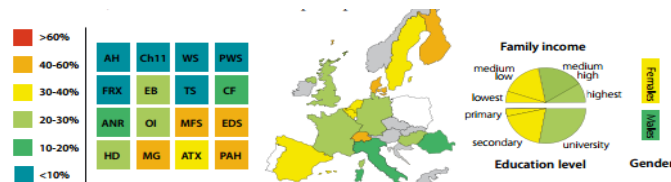


Figure 33 Percentage of patients who reduced or stopped professional activities due to their disease, across disease and country groups

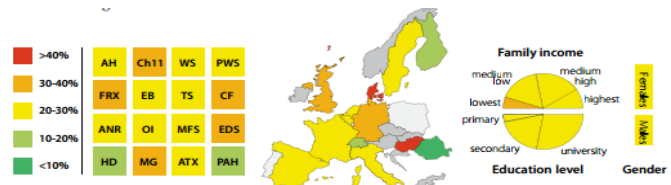


Figure 9 Difficult access to social services across disease and country groups

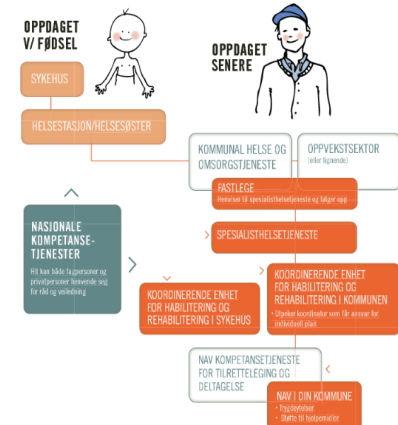


INNOVCare – WP4 State of the Art

Time frame: Oct 2015-Sept 2016

Study of care pathways in Member States

- Selection of 8 countries with consortium (based on diversity, feasibility & policy criteria)
- Care pathways & authorities/services involved
- Good practices

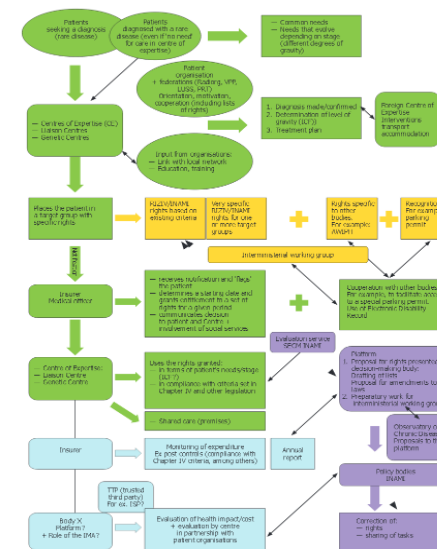


INNOVCare – WP4 State of the Art

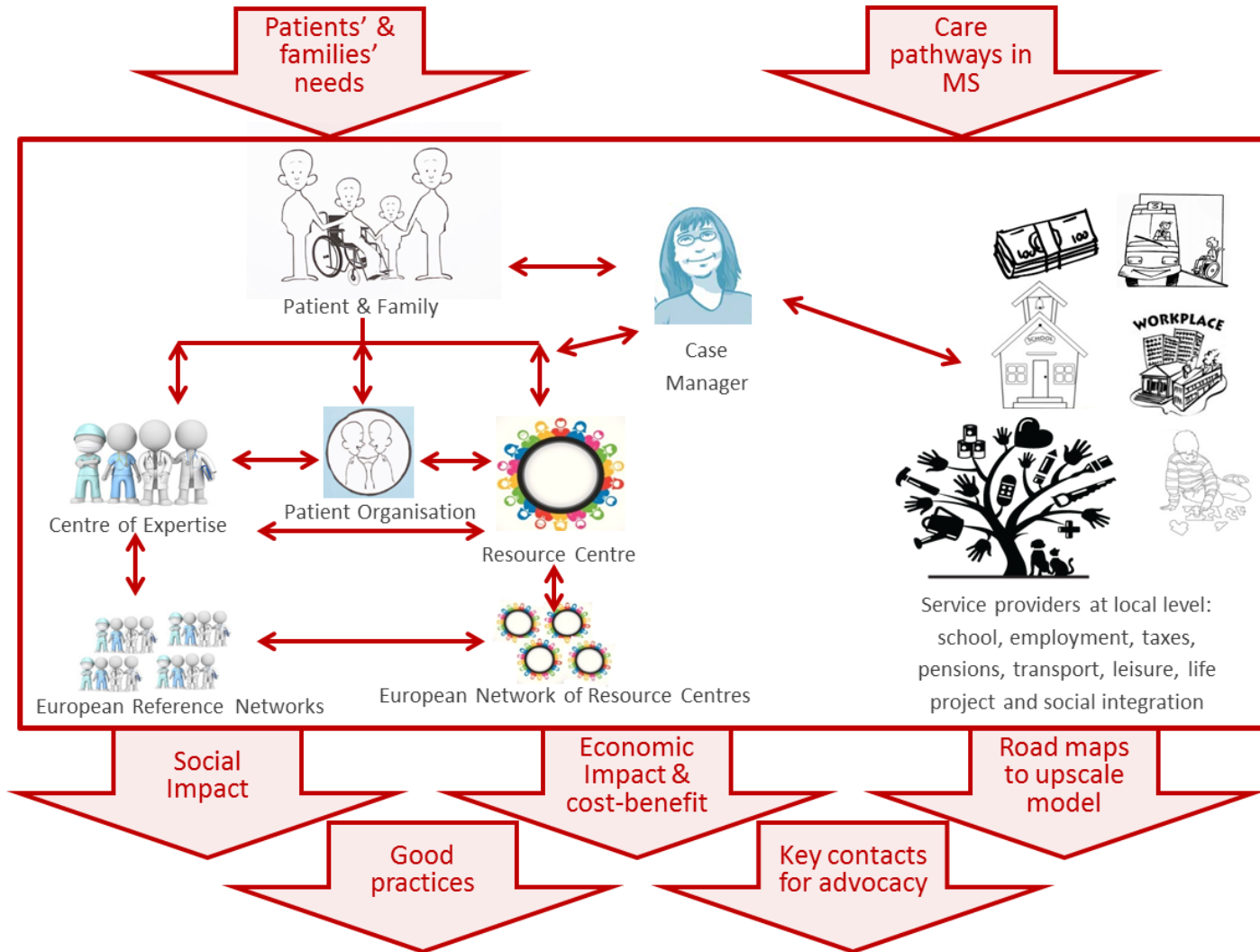
Time frame: Sept-Oct 2016

Comparative study

Analysis of gaps between patients'/families' needs and the current care pathways



INNOVCare = Opportunities





EURODIS
Rare Diseases Europe

October 2015

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