

EUROPLAN

European Project for Rare Diseases National Plans Development

Coordinated by the Italian National Centre for Rare Diseases

Italian National Institute of Health

2012-2015



Co-funded by the



Definition of actions supporting National Plans for Rare Diseases

Group activity - Day 2

INCEPTION WORKSHOP ON NATIONAL PLANNING FOR RARE DISEASES

10-11 September 2012, Rome, Italy



OBJECTIVE OF THE GROUP ACTIVITIES

- To define a action plan to support the development of NP/NS on RD

EXPECTED RESULTS

- A defined action plan for each group

METHOD

- Group discussion



TOPICS AND QUESTIONS

- In the light of the EUROPLAN Recommendations and the strengths and weaknesses identified up to now by EUROPLAN 2012-2015, which activities do you believe feasible in order to develop NP/NS on RD?
- Could we draft a timetable of activities?



TIMETABLE AND ACTIVITIES (1/3)

**Small
group**

PHASE

(45+45 min)

09:00 → 09:45 The **CHAIRPERSON** is responsible for "managing" the meeting: keep time, and moderate discussion.

The **RAPPORTEUR** has to note down the decisions taken by the group, to produce a Powerpoint presentation on the decisions taken by the group, and to present them in plenary.

> In order to define an action plan to support the development of NP/NS on RD, the chairperson will utilize the following questions during the group discussion:

- In the light of the EUROPLAN Recommendations and the strengths and weaknesses identified up to now by EUROPLAN 2012-2015, which activities do you believe feasible in order to develop NP/NS on RD?
- Could we draft a timetable of activities?

> The group will discuss these.



TIMETABLE AND ACTIVITIES (2/3)

**Small
group**

PHASE

(45+45 min)

09:45 → 10:30

- > The group will complete the timetable and will specify the activity, the involved actors, the time allotted and the needed resources.

- > The rapporteur will take note of the group conclusions in order to present them in the plenary.



TIMETABLE AND ACTIVITIES (3/3)

11:00 → 12:00

Plenary

PHASE

(60 min)

- > Each rapporteur will present his/her group conclusions in the plenary (5 min).
- > All participants will share groups conclusions (30 min).



TIMETABLE

ACTIVITY	INVOLVED ACTORS	TIME ALLOTTED	METHODOLOGICAL NEEDED RESOURCE	OBSERVATIONS
<p>1. Stakeholders involvement and communication:</p> <ul style="list-style-type: none"> • Identification of the main stakeholders • Designation of the steering committee • 				
<p>2. Situation analysis:</p> <ul style="list-style-type: none"> • Information gathering • Identification, framing and modeling the problem. • Defining goals, objectives and measures • 				
<p>3. Solution analysis and priority setting:</p> <ul style="list-style-type: none"> • identification of criteria for assessment • selection of criteria inherent to the problem and relevant to the stakeholders • 				
<p>4. Strategic planning:</p> <ul style="list-style-type: none"> • Definition of goals and objectives and measures • Identification and description of alternatives in terms of how they satisfy the policy objectives • Estimation of the expected outcomes, effects, and impacts of each policy alternative • 				



GROUP COMPOSITION

	GROUP A	GROUP B	GROUP C	GROUP D
Chairperson	Rumen STEFANOV (BG)	Dorica DAN (EURORDIS)	Edmund JESSOP (UK)	Christel NOURRISSIER (EURORDIS)
Rapporteur	Stephen NUTT (EURORDIS)	Birgit SCHNIEDERS (DE)	Lene JENSEN (EURORDIS)	Harry SEEVERENS (NL)
Participants	Florian BACHNER (AT)	Katalin BRUNNER (HU)	Michal KONEČNÝ (SK)	Susanne BERGMAN (SE)
	Saskia VAN DEN BOGAERT (BE)	Maria Elena CONGIU (IT)	Ales MAVER (SI)	Tamar CHIGHLADZE (GE)
	Marianne JESPERSEN (DK)	Zane STRAUME (LV)	Pilar SOLER-CRESPO (ES)	Jacek GRALINSKI (PL)
	Inna VABAMÄE (EE)	Odetta VITKUNIENE (LT)	Maria GARDSÄTER (EURORDIS)	Caroline KELLY (IE)
	Katja AKTAN-COLLAN (FI)	Lily CANNON (EURORDIS)	Oleg KVLIVIDZE (EURORDIS)	Katerina KUBACKOVA (CZ)
	Alain GARCIA (FR)	Stein Are AKSNES (NO)	Albert MATEVOSYAN (AM)	Yolande WAGENER (LU)
	Simona BELLAGAMBI (EURORDIS)			Ingeborg BARISIC (HR)
	Svetlana KARIMOVA (RU)			
	Emilia SEVERIN (RO)			

