

EUROPLAN

European Project for Rare Diseases National Plans Development

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LESSONS LEARNT FROM SUCSESSES AND FAILURES IN DEVELOPING NATIONAL PLANS

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INCEPTION WORKSHOP ON NATIONAL PLANNING FOR RARE DISEASES

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JOINING PAST AND FUTURE

The findings of the survey can be used for supporting the planning process by:

- Identifying how the strengths can be utilised to further support the planning process
- Identifying ways to overcome the weaknesses
- Developing a plan to detail the activities to carry out



OBJECTIVES OF THE GROUP ACTIVITIES

- To identify actions that would support the development of NP/NS on RD
- To identify targets and stakeholders of communication for NP/NS on RD

EXPECTED RESULTS

- A list of initiatives aimed at making the best use of the strengths identified for developing NP/NS



METHOD

- Group discussion
- Jigsaw technique
 - a cooperative learning technique that is structured in three phases:
 1. creating heterogeneous groups (Home groups)
 2. diving them into new groups to become expert on a topic (Expert groups)
 3. returning to their Home groups



TOPICS AND QUESTIONS

- As for **WEAKNESSES**:
 - How can we mitigate the effects of the weaknesses?
 - How can the identified strengths help reduce weaknesses?
- As for **OPPORTUNITIES**:
 - Which strategy could be adopted to counterface weaknesses?
 - How can we turn weaknesses into opportunities?
 - How can we share strengths?
- As for **COMMUNICATION**:
 - Which strategy could be adopted to promote more effective communication among all stakeholders?



TIMETABLE AND ACTIVITIES (1/4)

Home group

PHASE

(30 min)

15:20 → 15:50 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 identify actions that would support the development of NP, the chairperson will utilize the following questions during the group discussion:

- As for **WEAKNESSES**: How can we mitigate the effects of the weaknesses? How can the identified strengths help reduce weaknesses?
- As for **OPPORTUNITIES**: Which strategy could be adopted to counterface weaknesses? How can we turn weaknesses into opportunities? How can we share strengths?
- As for **COMMUNICATION**: Which strategy could be adopted to promote more effective communication among all stakeholders?

> Each Home Group allocates members to the Expert Group in a balanced way to bring back to the Home Group.



TIMETABLE AND ACTIVITIES (2/4)

15:50 → 16:20 Each topic will be discussed in the respective Expert Group:

**Expert
group**

PHASE

(30 min.)

- Expert Group on **WEAKNESSES** : they will discuss the topic starting from the above-mentioned questions on weaknesses
- Expert Group on **OPPORTUNITIES** (who answers question 2)
- Expert Group on **COMMUNICATION** (who answers question 3)



TIMETABLE AND ACTIVITIES (3/4)

Home group

PHASE

(30 min)

- 16:20 → 16:50**
- > The participants of each Expert Group will return to their own Home Group and will present the results of the discussion held in the Expert Group.
 - > The Home Group will discuss and agree the answers to the 3 questions; then they will choose a name.
 - > The rapporteur will take note of the group conclusions in order to present them in the plenary



TIMETABLE AND ACTIVITIES (4/4)

Plenary

PHASE
(50 min)

- 16:50 → 17:40** > Each rapporteur will present his/her group conclusions in the plenary (5 min).
- > All participants will share groups conclusions (30 min).



GROUP COMPOSITION

	GROUP A	GROUP B	GROUP C	GROUP D
Chairperson	Rumen STEFANOV (BG)	Avril DALY (EURORDIS)	Edmund JESSOP (UK)	Christel NOURRISSIER (EURORDIS)
Rapporteur	Stephen NUTT (EURORDIS)	Birgit SCHNIEDERS (DE)	Lene JENSEN (EURORDIS)	Harry SEEVERENS (NL)
Participants	Florian BACHNER (AT)	Lia TZALA (EL)	Michal KONEČNÝ (SK)	Susanne BERGMAN (SE)
	Saskia VAN DEN BOGAERT (BE)	Katalin BRUNNER (HU)	Ales MAVER (SI)	Tamar CHIGHLADZE (GE)
	Marianne JESPERSEN (DK)	Zane STRAUME (LV)	Pilar SOLER-CRESPO (ES)	Jacek GRALINSKI (PL)
	Inna VABAMÄE (EE)	Odetā 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)			Dorica DAN (EURORDIS)
	Svetlana KARIMOVA (RU)			Ingeborg BARISIC (HR)
	Emilia SEVERIN (RO)			

