



LESSONS LEARNT FROM SUCCESSES AND FAILURES IN DEVELOPING NATIONAL PLANS

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INCEPTION WORKSHOP ON NATIONAL PLANNING FOR RARE DISEASES

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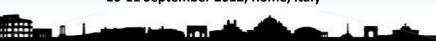


JOINING PAST AND FUTURE

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





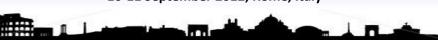
OBJECTIVES OF THE GROUP ACTIVITIES

- 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?

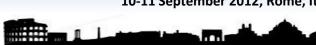
As for OPPORTUNITIES:

- 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)

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.

Home group

PHASE

(30 min)



TIMETABLE AND ACTIVITIES (2/4)

15:50 \rightarrow 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)

- $16:20 \rightarrow 16:50$ > 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) | Odeta 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) | | | |

