EUROPLAN National Conferences 2012-2015

Guidelines for Workshop Chairs

The EUROPLAN National Conferences 2012-2015 are structured in plenary sessions and thematic Workshops. Each Workshop will address one main theme in the field of rare disease policy. The Workshops of EUROPLAN National Conferences should be composed as much as possible of representatives of all stakeholders attending the Conference. Conferences’ organisers should request participants to specify their Workshops of choice at the moment of registration, in order to monitor the participation and to be able to adjust the Workshops composition, where necessary.

1. Workshops will be guided and supported by Chairs. Each Workshop of the EUROPLAN Conference will have at least one Chair, in charge of guiding the group. The Chair has the specific responsibility of ensuring that the policy area (“theme”) of the Workshop is presented in all its components and that concrete outcomes emerge from the discussion.

2. The Workshop Chair may be supported by a Rapporteur, who is specifically in charge of taking notes during the discussion and reporting to the plenary the results of this discussion.

Appointment of Chairs of the Workshops

The appointment of the Workshops’ Chairs is decided by the conference organisers and shared with the members of the Steering Committee. Workshops’ Chairs are appointed on the basis of competence and experience in the Workshop thematic area. Chairs should be skilled also in handling and leading a group discussion.

Specific tasks of the Workshop Chair are:

1. Presenting the framework (concise and fact-based):
   - Overview of the EU policy/legislative framework: Council Recommendation, EUROPLAN Indicators, EUCERD Recommendations and relevant legislation, in relation to the theme of the Workshop. The presentations prepared by

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1 The format of the EUROPLAN National Conference is described in details in the “Common Format for EUROPLAN National Conferences 2012-2015” and in the Content Guidelines for EUROPLAN National Conferences 2012-2015”: http://www.eurordis.org/content/documents-organise-national-conference
EURORDIS (available on EURORDIS website²) provide support for this overview that is common to all National Conferences.

- Overview of the existing legislation and policy of the country in relation to the theme of the Workshop. This task may be in part or fully entrusted to one or more participants to the Workshop, speakers or other invited experts.

2. **Introducing and guiding the debate.** After the opening presentation, a guided discussion will follow, based on the “topics for discussion” as laid down in the “Content Guidelines”³ and reported in the slides of the Workshop presentation. The Chair will encourage the participants to present best practices and examples from the country and, most of all, to develop solution-oriented proposals in reply to the open questions of the presentations/Content Guidelines.

3. **Leading the Workshop’s to come up with concrete proposals** to advance, improve national policies for people living with rare diseases in the respective thematic area discussed. The Workshop should also come to a conclusion on how EUROPLAN Indicators can be best used in the specific national context. It is important to stress that the result of the discussion should be solution-oriented proposals, i.e. concrete proposals that can be translated into policy actions, rather than generic wishes or descriptions of the status quo.

4. **Reporting the results of the Workshop discussion to the plenary.** The Chair should take note of the debate and key elements put forward during the Workshop, with the help of the Rapporteur (if one is appointed).

**Presentations by Theme / Workshop**

Presentation slides by Theme / Workshop (in English) are provided by EURORDIS and uploaded on EURORDIS website. They cover the elements of the debate which are common to all countries:

- In the first part, the slides introduce the Recommendations of the Council on RDs to Member States and the EUROPLAN Indicators. They need to be presented by the Chairs in the initial part of the Workshop.

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² [http://www.eurordis.org/content/documents-organise-national-conference](http://www.eurordis.org/content/documents-organise-national-conference): please see Power Point template presentations from 1 to 6.

³ [http://www.eurordis.org/content/documents-organise-national-conference](http://www.eurordis.org/content/documents-organise-national-conference): please see Content Guidelines (CG) from 1 to 6.
In the second part of the slides, “open questions” for the discussion are presented. These questions are called “Topics for discussion” and are listed in the Content Guidelines. Not all of the questions have to be addressed. The Conference organiser, the Steering Committee and the Workshops’ Chairs, together with their EURORDIS Advisor are in charge of selecting the questions which are the most relevant to the national situation.

The PowerPoint presentations that introduce the topics for discussion for each Theme and Sub-Theme, follow the structure of the Content Guidelines. It is useful to recall that this structure is also reflected in the Template for the Final Report to which the organisers shall adhere when drafting the Final Report of the Conference.

Presentations by Theme / Workshop

The Workshops’ Chairs (and Rapporteurs, where applicable) need to familiarise with both the main EU reference documents and the status quo of the country policies affecting rare diseases. This requires a significant amount of preparatory work. It is essential for the good success of the Conference that this preparatory work is done ahead of the Conference and in a collegial way:

- Most of the background documents that are relevant to the EU policy/legislative framework can be found in the Content Guidelines, left column “Resources”.

- In order to prepare the country-focused part of their introduction, it will be up to the Chairs and conference organisers to collect and assimilate most of the background information on the country situation (legislation, policy, best practices, examples, etc.). The EUCERD State of the Art Annual Reports⁴ are useful documents for this purpose.

- Chairs may be briefed and trained by the EUROPLAN-EURORDIS Advisor responsible for the national conference, who will make every effort to visit the concerned country to provide a direct training.

- Chairs are kindly requested to coordinate their efforts with the members of the Steering Committee. They are of course warmly invited to ask for the support of experts, patients or other stakeholders in the sector they may know or wish to contact.

⁴ [http://www.eucerd.eu/?page_id=163](http://www.eucerd.eu/?page_id=163)
Additional
It is possible to invite speakers from another country to the Workshops to introduce a given theme if there is not enough expertise in the country to cover that theme, or just to provide an external contribution or a fresh input to the discussion. It is important, however, that the presentation of the national situation is not neglected and is presented by local stakeholders.