
EUROPLAN National Conferences

Guidelines for WG Chairs and Rapporteurs

- Workshops or Working Groups (WG) should be composed as much as possible of **representatives of all stakeholders** attending the Conference. Organisers should request participants to specify the WG choice at the moment of registration, in order to monitor the participation and to be able to redress the WG composition, where necessary.
- Working Groups will be guided and supported by **facilitators, Chairs and Rapporteurs**. Each WG of the EUROPLAN Conferences will have at least one Chair, in charge of guiding the group. The **Chair** has the specific responsibility of ensuring that the Theme of the WG is presented in all its components and that outcomes result from the discussion. If deemed necessary, the Chair may be supported by a **Rapporteur**, who will be specifically in charge of taking notes during the discussion in the WG and reporting to the plenary the results of this discussion.
- The identification of WG Chairs should be based on criteria of competence and experience and decided by the organisers, who will assign the most competent facilitators according to the different WG Themes. Chairs should be also skilled in handling and leading a group discussion. The decision should be shared with the members of the Steering Committee.
- Specific tasks of the WG Chair:
 1. Presenting the framework (concise and fact-based) :
 - Council Recommendation, EUROPLAN Recommendations and EUROPLAN Indicators in relation to the WG Theme.
 - Overview of the existing legislation and policy of the country in relation to the WG Theme. This task may be in part or fully entrusted to one or more participants to the WGs, speakers or other invited experts, depending on the situation or what seems more appropriate.
 2. Introducing and guiding the debate – after the opening presentation, a guided discussion will follow, based on the “further guidelines for discussion” (as listed in the Content Outline paper) which will be reported on the slides and will be used as “open questions”. The Chair will encourage the participants to present best practices and examples from the country situation and, most of all, to develop solution-oriented proposals in reply to the open questions of the slides.

3. Leading the final Group's evaluation of the transferability of the EUROPLAN Recommendations in the country and the helpfulness of these Recommendations to the progress of a national strategy or plan on RD in that country. The Group should also come to a conclusion on how the EUROPLAN Indicators can be best used in the specific national context.
 4. With the help of the Rapporteur, if there is one, taking notes of the debate and reporting the results of the WG discussion to the plenary.
- **Presentation slides** (in English) will be provided by the EURORDIS Advisory Group to each WG and will cover the elements of the debate which are common to all countries:
 1. In their first part, the slides will introduce the main concepts of the Council Recommendation on RD, the EUROPLAN Recommendations and the EUROPLAN Indicators as they need to be presented by the WG Chair in the initial part of the WG meeting.
 2. In the second part of the slides, "open questions" for the discussion will be presented: these questions are called "further guidelines for discussion" and are listed in the third column of the main table of the above-mentioned Content Outline document.
 - Additionally, facilitators may look up into the background documents, which will be posted on EURORDIS website, in all existing languages where available. Most of the documents, however, will need to be translated as they are only available in English.
 - In order to prepare the country-focused part of their introduction, it will be up to the facilitators or those who will replace them to collect and assimilate most of the background information on the **country situation** (legislation, policy, best practices, examples, etc.).
 - Altogether, the facilitator needs to familiarise with the content of the main reference documents, the status quo of the country policies affecting rare diseases, the best practices existing in his/her country. 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**.
 - As for the development of **solution-oriented proposals**, it is important to stress that the result of the discussion should be concrete proposals that can be translated into policy actions, rather than generic wishes or descriptions of the status quo.
 - Also, with the help of the slides which will introduce the open questions for each Theme and Sub-Theme, the structure of the Content Outline paper will be followed. It is useful to

recall that this structure is reflected in the structure of the Template of the Conference Report, which in turn mirrors to a large extent the structure of the EUROPLAN Recommendations. This means, in practice, that the concrete proposals stemming from the WG will result from an accurate reflection on the relevant points addressed in the EUROPLAN Recommendations, broken down in the Themes and Sub-Themes as in the Content Outline paper (or in the Template Report).

- Following this structure, and after having considered the country situation, WG participants should be led to propose concrete solutions assess and discuss the transferability of the EUROPLAN Recommendations.
- In preparation to the chairing of WGs, facilitators must be briefed and trained by the EUROPLAN Advisor responsible for the national conference, who will make every effort to visit the concerned country to provide a direct training to the facilitators.
- Moreover, in their preparatory work, facilitators should try 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 they wish to contact.
- It is possible to invite speakers from another country to the WGs 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.