

# Guideline : choose among the following questions to set up your 2 Day Workshop

I think it would be useful to distinguish between questions related to :

- organizational development
- and questions related to implementation of the orphan medicinal act.

## A) Organizational development:

1. How do you perceive the strengths and weaknesses of your National Alliance?
2. How do you see the role of your alliance in the process of improving access to diagnosis and care?
3. How would your alliance benefit from increased European contact and collaboration, and what kind of support would be needed to optimize this?

## B) Orphan medicinal products:

1. Has your alliance developed a policy regarding the orphan medicinal act?
2. Do you think collaboration between patient organizations and pharmaceutical laboratories/companies can stimulate these to develop new medicinal products?
3. Has your alliance a strategy as to raising awareness on issues like best practices, safety issues, clinical trials and reporting of side effects among member organizations?
4. What barriers do you know of with regard to development and testing of orphan medicinal products in your country?
5. What do you know about clinical trials on orphan medicinal products in your country and what will your alliance do to keep updated on this issue?
6. Do your member organizations experience lack of information on / limited access to clinical trials?
7. Has your alliance or member organizations made inquiries into the availability of orphan medicinal products in your country?
8. Do general practitioners or other treating doctors have access to knowledge about such products?
9. Have you identified any barriers or significant delays in the availability of new orphan medicinal products for patients?

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