

ERN-EYE Kick-Off Meeting

ERN-EYE Project Management Team

The first meeting of the European Reference Network ERN-EYE was held in Tübingen (Germany) from April, 3rd to April, 5th, 2017 and officially launched the work of the 29 health care providers from 13 European member states.

Rare Eye Diseases (RED) are the leading cause of visual impairment and blindness for children and young adults in Europe. More than 900 REDs are listed in the portal for rare diseases and orphan drugs (ORPHANET). These include more prevalent diseases such as retinitis pigmentosa which has an estimated prevalence of 1 in 5 000, as well as some very rare entities described only once or twice in medical literature. ERN EYE addresses these conditions

During the meeting, the participants discussed about the network's main aim: the development of a virtual clinic — known as EyeClin — to guarantee the best coverage of REDs and facilitate cross-border dissemination of expertise. They also work with their working groups. There are four thematic working groups: rare diseases of the retina, neuro-ophthalmology rare diseases, paediatric ophthalmology rare diseases, and rare anterior segment conditions. In addition, six transversal working groups are addressing issues common to the four main themes. Additional working groups focus on specific areas, including genetic testing, registries, research, education, communication and patients.

Many participants responded to the satisfaction survey following the meeting. The results showed that the participants were overall rather very satisfied with the meeting.

In the following graphs, you find all the answers of the survey in the detail.

In general, the meeting lived up to my expectations



Documentation was made available in a timely manner

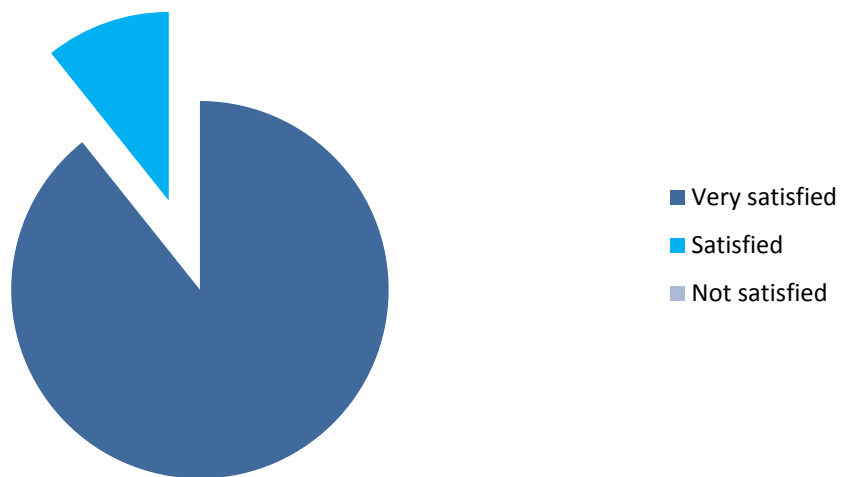


We noted that the participants were generally satisfied with the progress and organization of the Tübingen meeting. However, it seems that for some of them, the documentation was provided a little late. This has been corrected for the meeting at Mont Ste-Odile.

Meeting registration was efficient and straightforward



Meeting staff/officials were generally helpful



The participants of the meeting in Tübingen were generally satisfied of the work of the staff of the ERN-EYE team for the registration and on site.

The venue and its location met my expectations



Internet access was good and reliable



The locations for ERN-EYE meetings are decided according to the people available to host a meeting, varying the member countries and hospitals. It will of course never be perfect for everyone, but we try to make it accessible to all. We also try to offer the best technical conditions to work.

The meeting sessions offered valuable insights for ERN-EYE



The meeting outputs will be useful to my work and my work related to ERN-EYE



The meeting in Tübingen allowed the different members of the network to meet and put in place the first works of the ERN-EYE. In view of the results of the satisfaction survey, it seems that the meeting in Tübingen allowed most of them to fulfill the desired objectives.