

ERN Support and Training programme- WP17- EJP RD

Report Workshop “Genetics and Precision Medicine in Rare Diseases”

Date/Venue/Format

18-19 May 2023/DoubleTree by Hilton Hotel Lisbon - Fontana Park/In- person

Numbers (participants, speakers, ERNs represented, patient representatives)

17 attendees

5 speakers

17 ERNs represented

3 patient representatives

Analysis of the workshop satisfaction survey

The results from satisfaction survey have demonstrated a very positive evaluation of the workshop:

Overall, the quality of this workshop was classified as **excellent** by most attendees (11) and the remaining as **very good**. It was considered **very useful** for their future (14) and **just right** appropriate for their level of knowledge (just 3 exceptions). The majority were **very satisfied** (9,13,10 and 10) or **satisfied** (6, 2, 6, and 6) with the date and time, location, connection process and speakers of the workshop. The organization and structure of the programme have also been well classified (13 and 9 **very satisfied**, respectively).

Most importantly, the attendees considered the workshop have allowed them to gain better understanding in the topic (12 **strongly agree** and 5 **agree**), which was one of its the main purposes, and for most of them the learning objectives set were appropriate (11 **strongly agree** and 4 **agree**) and have been met (11 **strongly agree** and 5 **agree**).

Regarding what was **most appreciated** we mention some comments the attendees left that demonstrate our main goals for the event were achieved:

“Practical content about genetics”;



"...it truly was a "workshop" since there was a session for group work and presentation, not just a theoretical part. The relatively "light" schedule: everyone was generally with energy and interested in all sessions.";

"The speakers were precise and their talk easily understandable. The presentations from the participants were interesting and tied together what was in the conversations throughout the workshop.";

"Interacting with people from different backgrounds";

"The sympathy of everyone in the organization and speakers.";

" Discussion and opportunity for interaction";

"The program covered all aspects involved in the "Genetics and Precision Medicine in a Rare Disease" and it was clearly exemplified for monogenic diabetes. Moreover, we were able to work in groups in a research project where the concepts learnt about genetics and precision medicine were applied to a Rare Disease...).":

"Very good and scientific.

From the **negative aspects** we highlight 1 comment that mentions that some sessions were too general, while there is another comment describing the difficulty of understanding the topics. Since our attendees were from different expertise fields it is natural to exist some differences in the expectation and knowledge of the topic, therefore we presented the topics from general to specific. We consider a success the fact that most of them have felt the content was appropriate.

The **suggestions of improvement** include better timetable management, preparation of cases in advance, more practical exercises and including online option to attend the workshop.

2-3 participants' testimonials

We send attached 2 testimonials that were published in LinkedIn.

If applicable a main result of the workshop (e.g. working group created to do xxxx)

Although there is no current working group, during the workshop there was group work and presentations of their projects as well as discussion with everyone. The attendees have shared contacts and have demonstrated interest in participating in future projects together.



Conclusions, lessons learned, best practice to keep in mind.

We are proud to have met our goals and we consider it was very rewarding to organize this event after all the feedback we have received from the participants.

We learned that practical exercises and working groups as well as time for interaction is very important and this should always be planned in advance.

This was an excellent opportunity for knowledge sharing in the topic and connection from different roles in the scientific world: clinical, genetic and research.

