

ERN Support and Training programme- WP17- EJP RD
Report Workshop “Bone impairment in rare diseases”

Date/Venue/Format

June 9th and 10th 2022, Lyon, virtual and in person

Numbers (speakers, ERNs represented, patient representatives)

30 participants in person + 16 participants in virtual

Actual number of participants: 29 in person + 10 in virtual

Please provide breakdown (in %) of international participation:

European participants	90 %
American participants	0 %
Canadian participants	0 %
Other: please specify	10 % : Thailand, Pakistan, Myanmar, UK

Number of evaluation forms submitted: 18

Number of EACCME® certificates distributed: 0

Analysis of the workshop satisfaction survey

Summary of the survey completed by the participants:

Your feedback as a provider must include at least the information listed below. Please refer to the EACCME® participants’ satisfaction survey for the information to be provided below:

<i>Category</i>	<i>Number of respondents</i>	<i>Mean score</i>
Quality of the event	<u>18</u>	<u>Excellent</u>
Relevance of the event	<u>18</u>	<u>Extremely useful</u>
Suitability of formats used during the event	<u>18</u>	<u>Extremely useful</u>
Ways the event affected the participant’s practice	<u>18</u>	<u>-choosing better outcomes for patients with rare diseases</u> <u>-be more aware of human phenotypes when using animal models (mouse, zebra fish)</u>



		<u>-consideration of clinical aspect in basic research activity</u>
Commercial bias	<u>18</u>	<u>none</u>

Most of the participants found that the content of the workshop was of great scientific quality. Scientific program seemed to be well balanced between scientific talks and time for discussion. Basic research scientists learned a lot about outcomes for patients with rare diseases and clinicians improved their knowledge on fundamental research and animal models.

If applicable a main result of the workshop

Interactions between participants led to useful discussions and several future collaborations between research teams to create new research projects. All researchers and physicians asked whether it would be possible to organize another meeting on the topic every 2 years so as to maintain the network in the field.

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

The workshop seemed to be extremely useful for most of participants. We learned that participants would have appreciated a talk given by patients' association or patients themselves. It would have been of great interest to complete the scheme: basic research, clinical research and patients' feedback. We recorded the sessions with Teams but there were very few interactions with people attending the event online. The format with few participants (about 30 in person) was ideal since everyone could really discuss together during the two days.

