

Short REPORT ERN-EYE VIRTUAL ANNUAL MEETING

Co-funded by the
European Union



NETWORK COORDINATOR

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This document includes :

- The short report, published on the ERN-EYE website
- The results of the satisfaction survey as annex 1
- The program of the event as annex 2



14th to 15th October 2020 Online event

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ERN-EYE VIRTUAL ANNUAL MEETING

ERN-EYE Project Management Team

Introduction

General Annual Meeting – October 14th- 15th, 2020

Usually October is the month of the ERN-EYE annual workshop. This year, as the General Annual Meeting in March had to be postponed and as it is still not possible to do face-to-face meetings, ERN-EYE organised its meeting in virtual from 14th to 15th October 2020. It brought together close to 150 participants, mainly health care providers members and affiliated partners, ePAG members, as well as prestigious speakers.

The sessions were opened by Hélène Dollfus, coordinator of ERN-EYE. To introduce the meeting, Vytenis Andriukaitis, Former Health Commissioner and WHO Special Envoy for the European region from March 2020, Birute Tumiene, Board of Member States Representative of Lithuania, and Enrique Terol, ERNs Policy officer for the European Commission, gave an overview of the current state of ERNs in Europe.

The first day was dedicated to the state of the art regarding guidelines

and registry. The second day of the Virtual Meeting was dedicated to the affiliated partners. In addition to the initial 29 full members, today ERN-EYE has 15 affiliated partners in 7 new countries (i.e. not covered by full members). It was a great chance for them to introduce their centre and activities.

The meeting ended with a research session during which European calls, including European Joint Program for Rare Diseases (EJP-RD). A specific call on humanities and research in rare diseases and the participation of ERN-EYE were presented. Finally, parallel sessions with the different working groups allowed to discuss key topics such as specific guidelines and e-learning for each of them.

This Virtual Meeting was successful, but we hope that the next workshop will be face-to-face!

ERNs in brief

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European Reference Networks (ERNs) are unique and innovative cross-border cooperation platforms between specialists for the diagnosis and treatment of rare or low prevalence complex diseases.

ERNs are virtual networks bringing together healthcare providers across Europe to tackle complex or rare medical conditions that require highly specialized treatment and a concentration of knowledge and resources. They are being set up under the EU Directive on Patients' Rights in Healthcare (2011/24/EU), which also makes it easier for patients to access information on healthcare and thus increase their treatment options.

The ERNs are supported by European cross-border telemedicine tools, and can benefit from a range of EU funding mechanisms such as the "Health Program", the "Connecting Europe Facility" and the EU research program "Horizon 2020".

This meeting was an opportunity to speak about the upcoming ERN-EYE challenges, and the challenges ahead, especially the registry, the guidelines and the new members.

DAY 1 - OPENING - ERN-EYE WHERE ARE WE NOW?

General objectives of the meeting

Hélène Dollfus, ERN-EYE coordinator, Birute Tumiene, Board of Member States Representative, Vilnius, Lithuania, Vytenis Andriukaitis, Former Health Commissioner, Vilnius, Lithuania, Enrique Terol, DG SANTE, Russell Wheeler, ERN-EYE e-PAG representative.



The workshop was opened by Hélène Dollfus, coordinator of ERN-EYE, Birute Tumiene, Board of Member States Representative, Vytenis Andriukaitis, Former Health Commissioner, Enrique Terol, DG SANTE, and Russell Wheeler, ERN-EYE e-PAG Representative. Hélène Dollfus was happy to welcome all

attendees for this first ERN-EYE virtual meeting, an excellent opportunity to deeply deal with “hottest” topics for Rare Eye Diseases. Enrique Terol highlighted the future challenges of the network: enlargement, monitoring and guidelines, which are also the topics of the meeting.

SESSION 1 GUIDELINES & TRAINING SESSION

The guideline challenge for ERNs

Hélène Dollfus, ERN-EYE coordinator

Hélène Dollfus, as an introduction to the meeting, gave an overview of the planned schedule regarding guidelines based on concrete examples. She mentioned the need of a clear methodology from the provider appointed by the

Commission, a training for involved experts, the endorsement of existing guidelines and the role of a medical writer to organize the work and help experts to write.



Presentation of the timeline and work packages of the CPG Programme to the ERNs

Maria Redondo Berdugo, Fundación Progreso y Salud, Sevilla, Spain



Maria Redondo Berdugo presented the timeline and work packages of the CPG Programme. She insisted on the fact that there is a need for a structural framework to facilitate collaborative research among ERNs. There are two principal strategies:

- 1) Central engagement of Members of all ERNs in all project activities.
- 2) Seeking strategic partnerships with all major European and international RD research stakeholders

Training & e-Learning in ERNs, ERN-EYE strategy

Dorothee Leroux, ERN-EYE project manager



Dorothee Leroux presented the progress of the ERN-EYE e-learning programme as well as the webinar, educational videos and training projects. Last year, ERN-EYE diffused two educational videos:

- 1) How to welcome visually impaired people in the

hospital (mostly for non-specialists professionals)

- 2) Covid-19: Protective measures at your fingertips (mostly for patients)

The ERN-EYE knowledge generation work is a key part of the network's activities.

A good start and many projects for the next year!

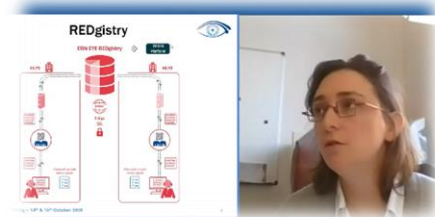
SESSION 2 REDGISTRY SESSION

The ERN-EYE basic registry: REDgistry

Dorothee Leroux, ERN-EYE project manager

Dorothee Leroux spoke about the ERN-EYE registry. She reminded that a basic registry is urgently needed in Europe for all Patients with Rare Eye Diseases for epidemiology and Clinical Trials recruitment. This registry is our major goal from the

beginning of the network. The ERN-EYE registry, now granted, is called REDgistry and will integrate the ontology work done in Sainte-Odile. Based on the work done for the Clinical Patient management System, ERN-EYE defined a minimum dataset with

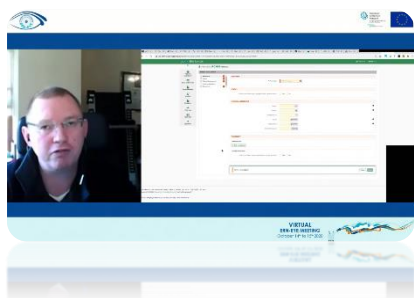


few items but shared across all ERN-EYE centers.



REDgistry technical solution driven by open app

Con Hennessy, Open App, Dublin, Ireland



Con Hennessy presented the open app solution for clinical and

patient registries. To fit ERN-EYE needs, he focussed his speech on the functionalities of his technical solution. He presented the Virtual Collaboration Platform, the patient consultation workflow, medical image viewers possibilities, records assess, full time-line of events. He also presented the

possible future upgrade, links with other registries (National registries for example) or CPMS, and HL7 hospital integration.

It was a good opportunity for all ERN-EYE members to have a demonstration of the platform and to ask their questions.

The EU RD Platform: an EU hub for RD registries

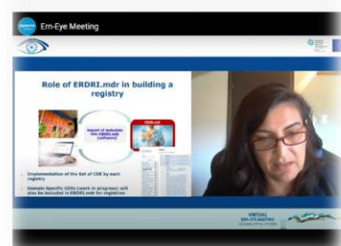
Andri Papadopoulou, Joint Research Center, Ispra, Italy

Andri Papadopoulou spoke about the European Rare Disease Registries Infrastructure (ERDRI) platform and its tools for ERNs registries. Noticeably she presented the EUPID service, a pseudonymisation tool. She insisted on the fact that EUPID offered to all registries joining the EU RD Platform to prevent duplicate registration of patients. It

offers a provision of distinct pseudonyms for patients in different contexts and a preservation of the possibility for reidentification by a trusted third party. The pseudonymisation process is essential to have a reliable registry.

The presentation of the European Directory of registries and the metadata repository as the two

Live – General Session



major components of the FAIRification of ERNs registries was highly important to ERN-EYE members, futures daily users of REDgistry.

The data protection challenge

Petra Wilson, Healthcare Practice Brussels, Belgium



Petra Wilson presented the challenge of data protection in registries. Key questions are the recognition of disease registries national law to provide a legal base for care and research, specific guidance for research ethics committees, support to hospital DPO from national DPA,

development of a suitable function for disease registries in the EHDS and specialist law or code of conduct at EU level. These questions are crucial for all the clinicians involved in our REDgistry development.

The next steps for HCPs and Working Groups

Hélène Dollfus, ERN-EYE coordinator



Hélène Dollfus reminded that the registry is obligatory for all ERNs. All have to keep in mind the objectives as a benefit for all patients. Registry generates epidemiology data and information for trials, it is an open

platform to «plug in» other registries: specific syndromes, groups of diseases, etc. Each ERN-EYE HCP will have to nominate one representative for REDgistry governance Board.

SESSION 3 CPMS SESSION

CPMS activity report for 2019

Dorothee Leroux, ERN-EYE project manager

Dorothee Leroux reminded what CPMS is: a complete system with secure access, with secure storage, pseudonymized data, used for data collection and panel members review, with a complete online meeting system and outcome document generation. This system is supported by the European

Commission. With a regular increase of users (except during the spring 2020 COVID crisis), in September 2020, ERN-EYE had a little more than 50 active users upon 66 registered users.



Helpdesk activity report

Francesco Rotolo, ERN-EYE CPMS IT specialist



Francesco Rotolo presented the activities of the helpdesk team based in Strasbourg. The Helpdesk provided the CPMS members several tools for a better and easier use of the CPMS, especially tutorials, user guide, webinars. Members can

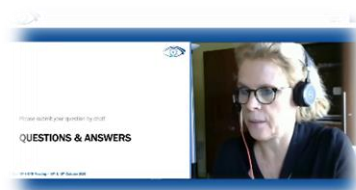
find the documents and procedures in a dedicated section named “CPMS-Virtual Clinic” at <https://www.ern-eye.eu/ern-eye>. In October 2020 there are 66 registered users, 17 more than in 2019.

A new start for the CPMS: The need to boost, (with affiliated partners, trainees, ex conferences, ...)

Hélène Dollfus, ERN-EYE coordinator

The Clinical patient management System is now online for 2 years already. ERN-EYE developed an EYE-Specific dataset and a helpdesk and guidance to help users. But the number of panels is still very low. Hélène Dollfus insisted

on the fact that it needs urgently a way to improve the use of CPMS. She proposes to have a grand round meeting every two months for each WG called GREET online meeting with cases and seniors experts engaged in the meeting.



PLENARY SESSION: REPORT OF WG LEADERS

Michael Larsen, Chair of WG1, Axel Petzold, Chair of WG2, Markus Preising, Chair of WG3 Daniel Böhlinger, Chair of WG4

Michael Larsen, Axel Petzold, Markus Preising and Daniel Böhlinger gave feedbacks about what they talked about in their respective working groups. In brief,

main points were the CPMS, guidelines and the e-learning. They all want to participate in the meeting GREET to improve the CPMS.



DAY 2 - SESSION 4 WELCOME TO THE AFFILIATED PARTNERS!

What is an AP and what is expected from them?

Hélène Dollfus, ERN-EYE coordinator



This year, in addition to historical full members, each ERNs welcomed

new so-called Affiliated partners. This status is dedicated to countries who don't have any full member in a given ERN. We can distinguish 2 types of Affiliated partners : associated national centres who participate in one network only or national Coordination Hubs, who

establish a link with more than one Network at once. They are not full members but they ensure a good geographic coverage and each AP have the opportunity to take part in all ERN-EYE activities such as knowledge generation and CPMS.

Presentation of the new affiliated partners

- Marko Hawlina, Eye Hospital, University Medical Centre Ljubljana, Slovenia;
- Jaime Etxebarria Ecenarro, Hospital Universitario Cruces, Barakaldo (Bizkaia), Spain;
- Markus Ritter, Center for Inherited Retinal Disorders and Neuroophthalmology / Dpt. of Ophthalmology, Medical University of Vienna, Vienna, Austria;
- Beata Busanyova, National Institute of Children's Diseases, Department of Paediatric Ophthalmology of Medical Faculty Comenius University, Bratislava, Slovakia;
- Benedict Vella Briffa, Mater Dei Hospital, Msida, Malta;
- María Nieves Moreno, Hospital Universitario Clínico San Carlos, Madrid, Spain;
- Bernardo Sanchez, Hospital Clínic I Provincial de Barcelona, Barcelona, Spain;
- Jaume Catala Mora, Hospital Universitari de Bellvige, Barcelona, Spain;
- Rupert Wolfgang Strauß, Dpt. of Ophthalmology and Optometry, Kepler Universitaetsklinikum Linz, Linz, Austria;
- José Carlos Pastor, Hospital Clínico Universitario de Valladolid, Valladolid, Spain;
- Estefanía Cobos Martín, Hospital Universitari de Bellvige, Barcelona, Spain;
- Mona Schneider, Graz Hospital, Austria

A representative of each Affiliated partner had the opportunity to introduce their centre and activities.

SESSION 5 RESEARCH SESSION

EJP general contours and interactions with ERN-EYE

Daria Julkowska, European Joint Program for Rare Diseases, Paris, France



Daria Julkowska highlighted the main objective of EJP-RD: create a research and innovation

pipeline "from bench to bedside" ensuring rapid translation of research results into clinical applications and uptake in healthcare for the benefit of patients. The mode of action is a large programme that integrates existing infrastructures, trainings, funding programmes and tools, expands them and develops new essential ones to

offer harmonized (and centralized) RD research ecosystem that is easy to use for scientists and produces benefits for patients in the most efficient way. She also presented the Joint Transnational Call 2021 that supports transnational, innovative, and interdisciplinary Social Sciences and Humanities research projects.

Humanities & research in rare diseases: examples

Laura Benkemoun, Fondation Maladies Rares, Strasbourg, France

Laura Benkemoun presented the state of the art in the field of humanities and research in terms of calls for projects related to rare diseases in France and Europe. The

French Rare Diseases Foundation supports this aspect in order to improve the journey of patients with rare diseases.



Closing session

Hélène Dollfus, ERN-EYE coordinator

Hélène Dollfus concluded the virtual meeting with a summary of the main points that were mentioned. ERN-EYE needs to develop guidelines and improve the CPMS. There will be also big changes with the Brexit issue and the new members' integration. It will certainly be financially more complicated for

meetings with around 150 to 200 people per meeting but nevertheless we hope that the next workshop will be face-to-face! She thanked all the speaker and participants, hoping the virtual platform was a great virtual solution to work together during the pandemic.







VIRTUAL ERN-EYE MEETING



Live – General Session



Annex 1

ERN-EYE VIRTUAL ANNUAL MEETING

SATISFACTION SURVEY RESULTS

Satisfaction Survey- Results

Usually October is the month of the ERN-EYE annual workshop. This year, as the General Annual Meeting in March had to be postponed and as it is still not possible to do face-to-face meetings, ERN-EYE organised its meeting in virtual from 14th to 15th October 2020. It brought together close to 150 participants, mainly health care providers members and affiliated partners, ePAG members, as well as prestigious speakers.

The first day was dedicated to the state of the art regarding guidelines and registry. The second day of the Virtual Meeting was dedicated to the affiliated partners.

Finally, parallel sessions with the different working groups allowed to discuss key topics such as specific guidelines and e-learning.

After the meeting, the ERN-EYE management team spread out a satisfaction survey to collect the opinion of the participants.

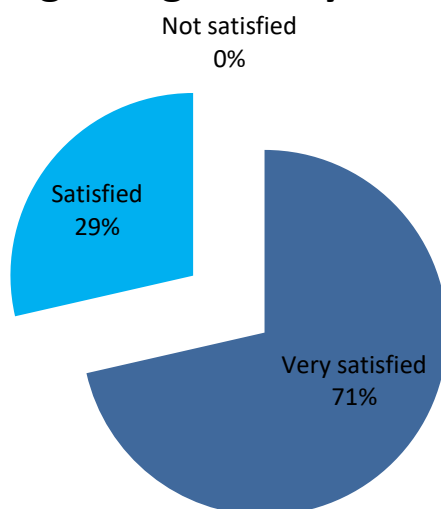
49 people answered the survey, representing one third of the participants at the meeting.

It was the first time that an ERN-EYE meeting was organised online. In view of the 49 answers of the satisfaction survey, it seems that, generally speaking, this meeting met the expectations of the participants. Many praised the quality of the speakers and their intervention.

The only weakness in the organisation of this meeting was perhaps the quality of the images on the platform. Otherwise, the organization in general suited the participants.

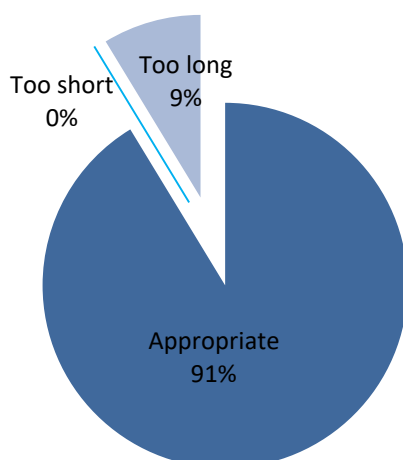
The results are presented below, question by question, with the percentages of responses.

The meeting was generally well organised



Total votes : 49

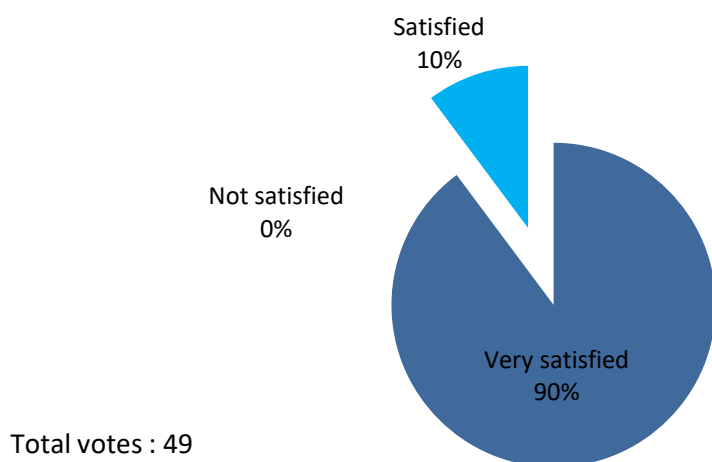
The duration of the meeting was



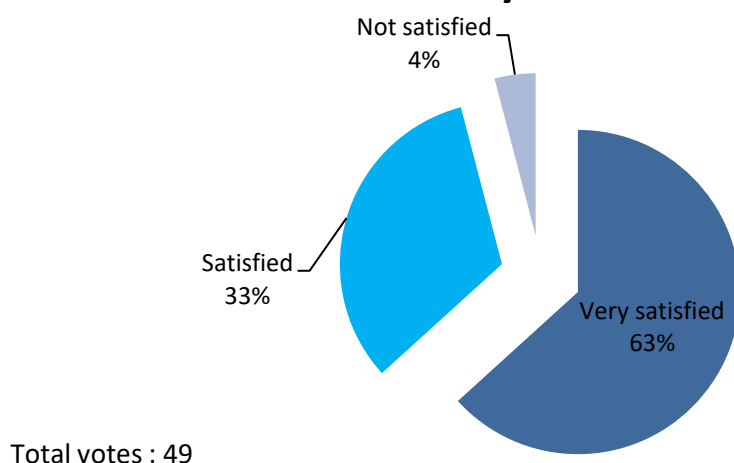
Total votes : 49

We noted that the participants were generally satisfied with the progress and organization of the meeting. This time, the duration of one day and a half seemed to be good, a little too long for some of them.

Meeting registration was efficient and straightforward

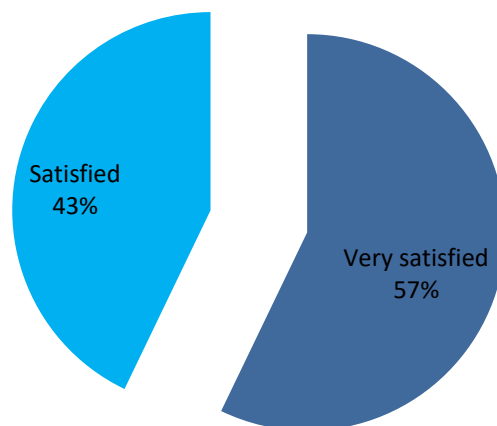


Documentation was made available in a timely manner



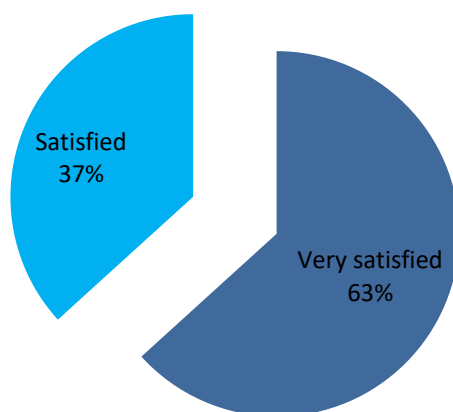
The registration was efficient for the participants but some of them would receive the documentation earlier.

The virtual platform met my expectations



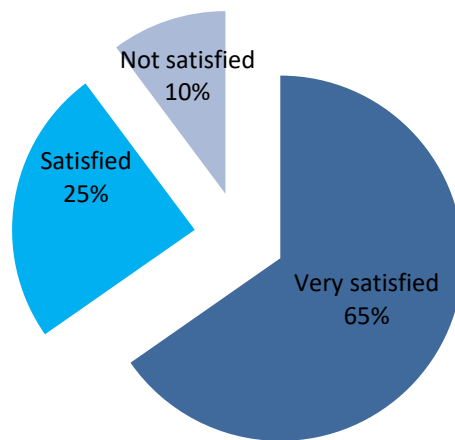
Total votes : 49

The quality of the sound



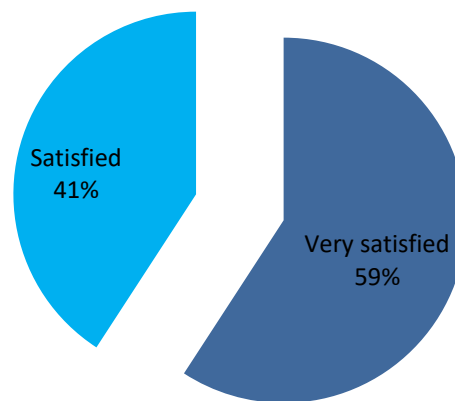
Total votes : 49

The quality of the image



Total votes : 49

The chat solution

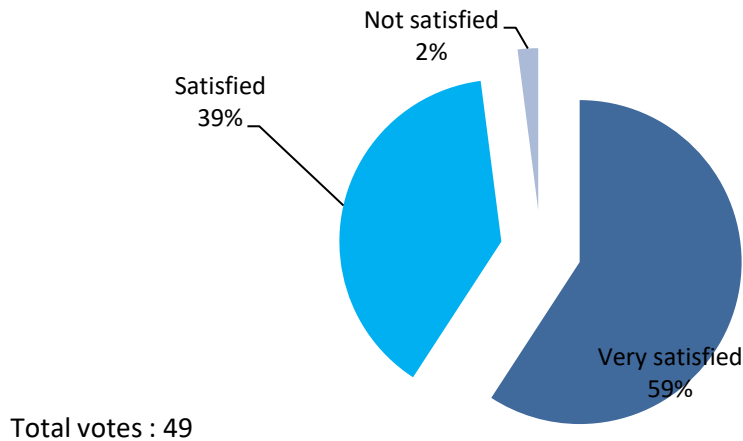


Total votes : 49

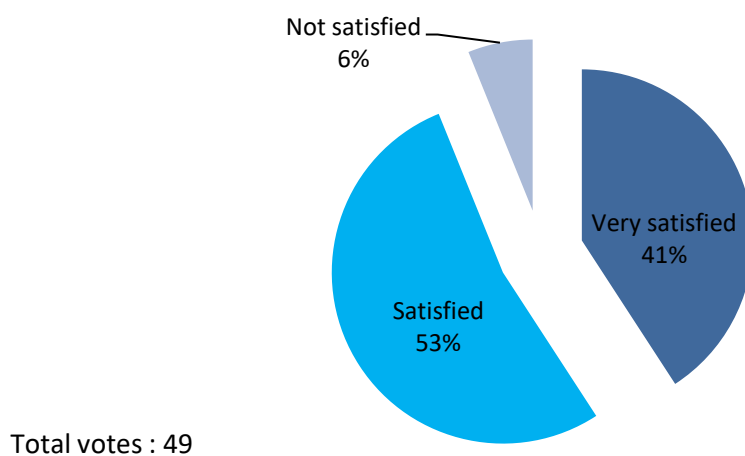
The virtual platform made it possible to satisfy almost all the participants.

The quality of the image was not optimal and it was sometimes difficult to read the presentations. We will manage to improve it for the next virtual meeting.

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 goals of the workshop were to draw the situation of the ERN-EYE projects, as well as the next issues for ERN-EYE in the coming months. It was also a good opportunity to welcome the new affiliated partners. In view of the results mentioned above, it seems that the objective has been achieved.

Annex 2



PROGRAM

ANNUAL ERN-EYE GENERAL MEETING (virtual event)

October 14th - 15th 2020

WEDNESDAY – 14th OCTOBER 2020

8.50 – 9.05	Opening - ERN-EYE where are we now? General objectives of the meeting <i>Hélène Dollfus, ERN-EYE Coordinator, HUS, Strasbourg, France</i>
9.05 – 9.15	Welcome address from Board of Member States <i>Birute Tumiene, Board of Member States Representative, Vilnius, Lithuania</i> <i>Vytenis Andriukaitis, Former Health Commissioner, Vilnius, Lithuania (pre-recorded video)</i>
9.15 – 9.25	State of the art for ERN's in 2020 <i>Enrique Terol, Policy officer for ERNs, Brussels, Belgium</i>
9.25 – 9.40	Advances in European cooperation for Rare Diseases <i>Russell Wheeler, ERN-EYE e-PAG Representative</i>
9.40 – 9.45	Q&A

GUIDELINES & TRAINING SESSION - GENERAL SESSION

9.45 – 9.50	The guideline challenge for ERNs <i>Hélène Dollfus, ERN-EYE Coordinator, HUS, Strasbourg, France</i>
9.50 – 10.05	The commission view and recommendations for ERNs concerning guidelines <i>Enrique Terol, Policy officer for ERNs, Brussels, Belgium</i>
10.05 - 10.20	Presentation of the timeline and work packages of the CPG Programme to the ERNs <i>Manuel Herrera, Fundación Progreso y Salud, Sevilla, Spain</i>
10.20 – 10.30	Training & e-Learning in ERNs <i>Dorothee Leroux, ERN-EYE Project manager, HUS, Strasbourg, France</i>
10.30 – 10.40	Missions for the working groups & Open discussion in Live session <i>Hélène Dollfus, ERN-EYE Coordinator, HUS, Strasbourg, France</i> Q&A

10.40-11.00 COFFEE BREAK

REDGISTRY SESSION - GENERAL SESSION

11.00 – 11.10	The ERN-EYE basic registry: REDgistry <i>Dorothee Leroux, ERN-EYE Project manager, HUS, Strasbourg, France</i>
11.10 – 11.30	REDgistry technical solution driven by open app <i>Con Hennessy, Open App, Dublin, Ireland</i>



- 11.30 – 11.45 The EU RD Platform: an EU hub for RD registries
Andri Papadopoulou, Joint Research Center, Ispra, Italy
- 11.45 - 12.05 The data protection challenge
Petra Wilson, Healthcare Practice Brussels, Belgium
- 12.05 – 12.10 The next steps for HCPs and Working Groups
Hélène Dollfus, ERN-EYE Coordinator, HUS, Strasbourg, France
- 12.10 – 12.30 Q&A Live session with all for questions

12.30 – 13.30 LUNCH PAUSE

CPMS SESSION - GENERAL SESSION

- 13.30 – 13.40 CPMS activity report for 2019
Dorothee Leroux, ERN-EYE Project manager, HUS, Strasbourg, France
- 13.40 – 13.50 Helpdesk activity report
Francesco Rotolo, ERN-EYE CPMS IT specialist, HUS, Strasbourg, France
- 13.50 – 14.00 A new start for the CPMS: The need to boost, (with affiliated partners, trainees, ex conferences, ...), *Hélène Dollfus, ERN-EYE Coordinator, HUS, Strasbourg, France*
- 14.00 – 14.10 Q&A

14.10 – 16.00 INTERACTIVE PARALLEL SESSIONS

WG parallel sessions

Each Work group leader will be sent a road map and a report will have to be produced to the management team

Retinal Rare Eye Diseases - WG 1

Leaders: Bart Leroy & Michael Larsen

Neuro-Ophthalmology Rare Diseases - WG 2

Leaders: Axel Petzold & Steffen Hamann

Pediatric Ophthalmology Rare Diseases - WG 3

Leaders: Birgit Lorenz & Jane Ashworth

Anterior Segment Rare Eye Diseases - WG 4

Leaders: Daniel Böhringer & Petra Liskova

15.45-16.00 COFFEE BREAK

- 16.00 – 17.00 **General session** Conclusions for WGs and wrap up
WG1 - Retinal Rare Eye Diseases : Michael Larsen
WG2 - Neuro-Ophthalmology Rare Diseases : Axel Petzold
WG3 - Pediatric Ophthalmology Rare Diseases : Birgit Lorenz
WG4 - Anterior Segment Rare Eye Diseases : Daniel Böhringer
- 17.00 – 17.20 General conclusion of the day, *Hélène Dollfus*

WELCOME TO THE AFFILIATED PARTNERS!

- 8.45 – 8.50 What is an AP and what is expected from them?
Hélène Dollfus, ERN-EYE Coordinator, HUS, Strasbourg, France
- 8.50 – 10.30 Presentation of each AP, 7 min each:
- Hospital Universitari de Bellvige, *Barcelona, Spain*
 - Hospital de sant Joan de Déu, *Barcelona, Spain*
 - Hospital Clínic I Provincial de Barcelona, *Barcelona, Spain*
 - Hospital Universitario Cruces, *Barakaldo (Bizkaia), Spain*
 - Hospital Universitario Clínico San Carlos, *Madrid, Spain*
 - Hospital Universitario La Paz, *Madrid, Spain*
 - Hospital Clínico Universitario de Valladolid, *Valladolid, Spain*
 - Styrian KAGes University Hospital Graz, *Graz, Austria*
 - Dpt. of Ophthalmology and Optometry, Kepler Universitaetsklinikum Linz, *Linz, Austria*
 - Center for Inherited Retinal Disorders and Neuroophthalmology / Dpt. of Ophthalmology, Medical University of Vienna, *Vienna, Austria*
 - Eye Hospital, University Medical Centre Ljubljana, *Ljubljana, Slovenia*
 - National Institute of Children's Diseases, Department of Paediatric Ophthalmology of Medical Faculty Comenius University, *Bratislava, Slovakia*
 - Mater Dei Hospital, *Misida, Malta*
 - University Hospital Centre Zagreb - University Department of Ophthalmology, *Zagreb, Croatia*
 - Hopital de Luxembourg, *Luxembourg*

10.30-11.00 COFFEE BREAK

RESEARCH SESSION - GENERAL SESSION

- 11.00 – 11.45 EJP general contours and interactions with ERN-EYE
Daria Julkowska, European Joint Program for Rare Diseases, Paris, France
- 11.45 – 12.00 Humanities & research in rare diseases: examples
Laura Benkemoun, Fondation Maladies Rares, Strasbourg, France
- 12.00 – 12.15 ERICA, *Alberto Pereira, Leiden, The Netherlands* (pre-recorded video)
- 12.15 – 12: 35 How ERN-EYE could participate to EJP various EU calls & Live session with all for questions, *Hélène Dollfus, ERN-EYE Coordinator, HUS, Strasbourg, France*
- 12.35 – 12.55 Brainstorming session on the future of ERN-EYE; Brexit and how to welcome and integrate all the new members in 2021
- 12.55 – 13.00 Closing session, *Hélène Dollfus, ERN-EYE Coordinator, HUS, Strasbourg, France*

14.30 – 17.00 PARALLEL SESSIONS

Genetic Testing - TWG 6
Leader: Elfride De Baere

Latvia internal meeting

15.45: ePAG internal meeting