



Organisation of the data in the dataset



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ERN-EYE CONSULTATION FORM

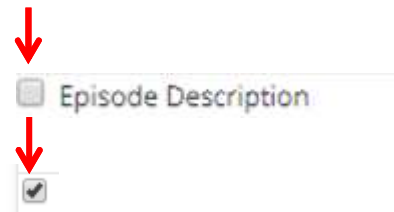
- Consultation Request
- ERN-EYE Subspecialty
- Common Data
 - Patient Information
 - Episode Description
 - Rare Disease Diagnosis
 - Comorbidities
 - Phenotype/Genetic Features and Biobanks
 - Family History
 - Health Behaviours
 - Allergies and Other Adverse Reactions
 - History of Past Illness and Disorders
 - Special Treatment Intervention
 - Surgical Procedures
 - Transplantation History
 - Medication Summary
 - Others
- Eye Data
 - Ophthalmological History
 - Exam - Eye External
 - Exam - Refractive Measurements
 - Exam - Best Visual Acuity
 - Exam - Intraocular Pressure (IOP)
 - Exam - Oculomotor Neuro-Ophthalmology
 - Exam - Slit-Lamp Examination
 - Exam - Fundoscopy / Fundus Images
 - Exam - Cornea Pachymetry & Corneal Topography
 - Exam - Functional Ophthalmic Testing
- More Eye Data
 - Imaging Tests
 - Histology/Pathology
 - Ophthalmological Therapies
 - Rehabilitation Low Vision Aid
 - Participation in clinical trials
 - Additional Medical History
 - Medical Documents

- The dataset is divided into 4 main sections:

1. Consultation Request
2. Common Data
3. Eye Data
4. More Eye Data

- These sections are divided into many subsections.

- To fill in the desired sections, click on the checkbox before the item.



- Click on the item to go there directly.





1. Fill in the «Consultation request»: it is mandatory for all panels.

ER-N-EYE CONSULTATION FORM

Consultation Request

It comprises the urgency of the panel, the reason for the consultation, the name of the leader and thematic area. All fields with an * are mandatory.

ER-N-EYE CONSULTATION FORM

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Do not use any nicknames liable to identify the patient, including his/her first name or last name.

Is urgency required for this panel?

* Nickname:

* Is this a repeat of a previous panel for the same patient but a different episode?
 Yes No Don't know

* Consultation request description short:

* Consultation request reason: Diagnosis Treatment Other

* Consultation request reason description:

* Healthcare provider:

* Point of care specialist:

* ERN:

* Panel lead:

* Primary thematic area:
 Anterior Segment Rare Eye Diseases
 Neuro Ophthalmology rare diseases
 Pediatric Ophthalmology Rare Diseases
 Retina Rare Eye Diseases



2. Fill in the sections and subsections you want.

E. g. Functional Ophthalmic Testing

Enter psycho-physical testing results (visual fields, microperimetry, colour vision tests) and also insert the results of objective tests (electrophysiology: VEP, ERG and EOG).

Eye Data

- Ophthalmological History
- Exam - Eye External
- Exam - Refractive Measurements
- Exam - Best Visual Acuity
- Exam - Intraocular Pressure (IOP)
- Exam - Oculomotor Neuro-Ophthalmology
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- Exam - Functional Ophthalmic Testing**

OPHTHALMOLOGICAL EXAM FUNCTIONAL OPHTHALMIC TESTING

Psycho-physical testing

Date:

Visual fields performed:

- Kinetic visual fields, manual Goldmann (Classic) or automated Goldmann (Octopus)
- Static visual fields, Humphrey or Octopus
- Microperimetry, Centervue Maia or Nidek
- Colour Vision
- Other

Objective tests

Electrophysiology

Tests performed:

- Visual evoked potentials, Flash (VEP)
- Pattern VEP
- Ganzfeld-ERG (ffERG)
- Multifocal ERG (mfERG)
- Electro-oculogram (EOG)

ISCEV standards: Yes No



Some remarkable sections



➤ Rare disease diagnosis

ERN-EYE CONSULTATION FORM Current Diagnosis

Consultation Request ERN-EYE Subspecialty

Common Data

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Search All Coding Systems:

Diagnosis Coding System: ICD-10 ICC3-3 Orphanet Other

ICD-10 classification:

ICC3-3 Diagnostic Group:

ICC3-3 Histology/Morphology:

ICC3-3 Topography:

Orphanet nomenclature:

Date of first symptoms onset:

Date of current Diagnosis:

Status of current Diagnosis: Active In Remission Resolved Relapse Other

* Diagnosis Provider: ERN member Affiliated ERN Member Non-ERN member

* Treatment Healthcare Provider: ERN member Affiliated ERN Member Non-ERN member

Diagnostic Test: LOINC Text

Date of observation:

Result:

Diagnosis coding systems available: ICD-10, ICC3-3, Orphanet or free text.
Additionally, many items use **HPO terms** for description.



Some remarkable sections



➤ Phenotypes/Genetic Features and Biobanks

Click on **+ Add genetic/phenotype/biobank** to add an genetic information according to HGNC or free text.

Common Data

- Patient Information *
- Episode Description
- Rare Disease Diagnosis** *
- Comorbidities
- Phenotype/Genetic Features and Biobanks

PHENOTYPE/GENETIC FEATURES AND BIOBANKS

+ Add genetic/phenotype/biobank

PHENOTYPE/GENETIC FEATURES AND BIOBANKS

Genetic study performed: LOINC Text

Gene Affected: HGNC Symbols Text

DNA Variant:

DNA Nucleotide reference sequence (RefSeq Id/LRG Id):

DNA Nucleotide variant description:

RNA Variant:

RNA Nucleotide reference sequence (LRG Id):

RNA Nucleotide variant description:

Protein Variant:

Protein sequence (RefSeq Id/LRG Id):

Protein variant description:

Phenotypic Abnormality (HPD):

Other changes:

Allelic State:

Somatic Mutation as included in COSMIC (RefSeq Id/LRG Id):

Specimens stored at biobank:

Biobank details:



Some remarkable sections

➤ Family history

Draw or attach a pedigree.

- Common Data**
- Patient Information
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- Family History

FAMILY HISTORY

Consanguineous Parents? Yes No Unknown

Healthy carriers in the family? Yes No Unknown

Other cases in the family? Yes No Unknown

PEDIGREE

Affected Add text here...

Carrier Add text here...

Use this section to upload and display Pedigree images into CPMS. Please note that only permitted formats can be displayed (i.e. PNG, and JPEG)

Image: [Click here to attach file](#)

➤ Imaging test and Medical documents

Drag and drop the files directly to the CPMS to upload files (.jpeg, .pdf or DICOM).
Note that you can upload files in many sections in the CPMS.

- More Eye Data**
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File Picker: Attach images and files

Add Files

Drop DICOM files, zip files or documents here or click to upload

You can attach DICOM studies or other files to this Form. Drag the files or directories to be copied into the box above.



Close



Image viewer tool



- CPMS has an integrated image viewer tool (supported imaging techniques: CT scans MRIs; PET scans; Tomography; Echographs; RXs; Dicomized Static Images; Endoscopies).
- Edit the images (**but not during a meeting**): change the viewport layout; invert colour; zoom; panning; flip image to make use of this tool



ERN-EYE Helpdesk