



European
Reference
Network



EpiCARE

GUIDELINES

EpiCARE Case Discussion Guidelines (Surgical and Non-Surgical)

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EUROPEAN REFERENCE NETWORKS
FOR RARE, LOW PREVALENCE AND COMPLEX DISEASES

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INTRODUCTION

Case discussions are an integral role of European Reference Networks (ERN) and are in line with the European Commission's directive.

The Clinical Patient Management System (CPMS) is utilised to perform these case discussions. This is an online secure, encrypted platform to gather the information of these cases and allow for free-flowing discussion amongst the experts within the ERN. The use of this platform by the ERNs is used by the EU as a key performance indicator and therefore it is imperative that this platform is appropriately used by all members.

EpiCARE uses CPMS for discussions involving both surgical and non-surgical cases and these must be submitted to the platform by ERN members. If the referring physician is not a member of EpiCARE then they must liaise with a member in order for their case to be discussed.

However, due to the functionalities within CPMS being unable to display EEG and video-EEG, EpiCARE also uses a different, secure platform to hold these discussions and the cases must then be added retrospectively to CPMS.

GUIDELINES

Arrange a case

- Consent the patient to be discussed by EpiCARE (if needed consent forms are available in all EU languages) – This is mandatory and must be consented to a minimum of consent for care
- Contact Nicola OL to book the next available date (Nicola.openshaw-lawrence@epi-care.eu)
 - Surgical case discussion 2nd and 4th Wednesday of the Month from 16H00 to 17H30 CET
 - Non-Surgical case discussion 3rd Wednesday of the Month from 16H00 to 17H30 CET
- Send a short summary of case to Nicola:
 - Title - max 5 words (indicating nature of the case and whether paediatric or adult case)
 - Summary
 - Experts needed when appropriate (specialty)
 - Main questions asked to the panel
 - Degree of emergency (In less than 4 weeks; In less than 8 weeks)

Pre-case preparation

- Download the presentation template (surgical/non-surgical) from the website
- Enrol patient details onto the CPMS platform (minimum 48 hours before the meeting and independently of the platform to be used¹), see below for directions
- Inform Nicola that the patient is enrolled and share the panel number and nickname
- If this is first time of using TEAMS platform, ensure that settings are correct on your computer to share the screen (contact Nicola if you would like to check this)

¹ If the case is not placed on CPMS at least 48 hours prior to the meeting, then you will unfortunately not be able to present your case. This is above all due to General Data Protection Regulations (GPRD)

How to enrol a patient on CPMS

- Sign into CPMS <https://cpms.ern-net.eu/login/> (if this is the first time you will have to create an account please contact Nicola for the guidelines)
- Select Centre on the left of the dashboard
- Select enrol patient
- Complete information
 - Date enrolled (date entered into CPMS)
 - Detail the HCP that advice has already been sought from
 - Complete consent details (mandatory to have “consent for care” to discuss the patient)
 - Identifying data (this data is not shared with panel members outside of your HCP)
- Select Enrol Patient
- Confirm that you will follow relevant data protection regulations
- Select “open new panel”
- Complete consultation request and select create panel

Case discussion on the TEAMS Platform

- Sign in 5 minutes minimum before start
- Be prepared to present, with all relevant applications ready/open to show data
- Always show presentation in presentation mode
- Make notes of recommendations by the experts

Within 24 hours of the meeting

- Send the presentation (PDF of the PowerPoint) and a summary of the panel recommendations to Nicola
- We do not need transfer of the EEG recordings and videos
- 1 week following the case discussion you will be able to download the outcome document from CPMS for the patient files or referring clinician
- Ensure that if the case was presented on behalf of another clinician/HCP that the full outcome is explained to them so patient care can continue

In case you wish your patient to be discussed again please contact Nicola and she will support you with this.

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