

[illegible]

European Reference Networks

Impact on access to IT tools

On 31 October 2019, Brexit implementation date:

In case of hard Brexit – no transitional measures – loss of ERN membership means loss of access to the ERN IT tools (CPMS, ECP, ...)

Task Force 50:

Agrees that action should be taken to ensure the continuity of panels in CPMS and minimise the Brexit impact on the patients whose cases are under discussion in consultation panels in the CPMS

Impact on access to CPMS (1)

Possible scenario's:

1. UK panel member, patient not enrolled by UK HCP: panel member loses access.
2. UK panel member, patient enrolled by UK HCP: access rights exceptionally transformed into guest user access.
3. UK panel lead: panel lead needs to be replaced by EU27 panel lead.

Impact on access to CPMS (2)

Definition of guest user according to the Implementing Decision, Article 1a (d):

(d) "Guest user" means a healthcare provider who is not a member or Affiliated Partner and who has the right, following the approval of the competent European Reference Network Coordinator, for a limited period of time, to enrol patients in CPMS and participate in the panel related to that patient or to participate in a specific panel as an expert.

The access period is limited to 90 days

Impact on access to CPMS (3)

Actions to be taken in case of panel lead change:

1. Commission to identify the concerned panels
2. Contribution from the ERNs Coordinator.
3. Actions depend on the panel stage

Impact on access to CPMS (4)

Actions to be taken depend on the panel stage:

- Open' stage: Panel lead can be changed only to user from the same centre. So, the panel should be moved to next stage.
- 'Panel selection' stage: Panel lead can be changed by the current panel lead, another HP from the enrolling centre or an assigned panel manager.
- 'Data Completion' – 'Assessment' – 'Outcome' stage: The workflow needs to be moved back to panel selection and lead can be changed by the current panel lead, another HP from the enrolling centre or an assigned panel manager.
- 'Sign Off' – 'Outcome' stage, still in draft: The workflow needs to be moved back to panel selection and lead can be changed by the current panel lead, another HP from the enrolling centre or an assigned panel manager
- 'Sign Off' – 'Outcome' has been signed off: The panel lead cannot be changed. The panel lead should move the panel to "Closed" stage and archive the panel if necessary.

Impact on data protection

Following the amendment of Implementing Decision 2014/287/EU:

Defines the allocation of the responsibilities of the joint-controllers, HCP and Commission (Annex III)

When UK HCPs will lose ERN membership and access to the CPMS after 31 October, they will be no longer in the position to fulfil their obligations as data controller;

As a consequence, the patient data of their cases should be wiped from the system, unless the patient signs an additional consent agreeing to share their personal and clinical data with the ERN Coordinator, and the Coordinator accepts to act as joint controller for that data.

In case the patient does not consent or ERN Coordinator refuses, the concerned patient data will be wiped from the CPMS database.



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