[insert ERN Logo]

Supporting Partner (patients) Collaboration Agreement

**Between the European Reference Network (ERN) for [insert name of ERN] and [Insert name of Supporting partner] [ROLE]**

**12/03/2024**

[insert name of ERN] mission statement

“ insert ERN mission statement”

Text and sections highlighted in yellow are optional or need to be tailored to the governance terminology, please read the comments to adjust the template.

## what are supporting partners?

In addition to Full Members and Affiliated Partners[[1]](#footnote-2) of the ERN networks, there is another term used to describe organisations or individuals that officially collaborate with ERNs, namely, Supporting Partners. According to the European Commission’s document on terminology issued on 20 June 2018, “it is proposed to use the term Supporting Partner as a generic term to define healthcare providers, medical societies, and any other entity or individual experts which, without having a commercial relation with the ERNs and their Full Members or Affiliated Partners, or with the European Commission, contribute in different ways to the work of the networks. When using the term Supporting Partner it shall be clear that it refers to a collaboration with entities, and individual experts which are neither Full Members nor Affiliated Partners”.

[INSERT NAME OF ERN] has added the possibility for **individual patients, family members with specific expertise, international patient organisations registered outside Europe, patient organisations registered in Europe but that do not have a designated ePAG advocate in the ERN (the wider patient community) and social media-based patient support groups** who are all willing to contribute to the activities of the network in various ways. Such individuals are not represented by a patient organisation and therefore are not considered as ePAG advocates. These experts may apply and will be invited by the [INSERT NAME OF ERN] in agreement with the ePAG and will sign a collaboration agreement based on this template with [INSERT NAME OF ERN].

Supporting Partners may express their interest in collaborating with [INSERT NAME OF ERN] by sending a motivation letter to the ERN Coordinating team and ePAG Chair explaining how they would like to collaborate with the ERN and CV of the contact person who will act as a liaison with the Network or the individual patient or family member.

The application will be considered by an Evaluation team for [INSERT NAME OF ERN] Workstream [INSERT] (the workstream leader, the Clinical lead, Research Lead, Educational Lead and the ePAG representative) who will provide advice/approval regarding the collaboration with the Supporting Partner (patient).

*Therefore, this collaboration agreement recognises the important contribution of [INSERT] in supporting [INSERT NAME OF ERN].*

The evaluation team reviewed the application and agreed to invite [INSERT] to join as a Supporting Partner.

[INSERT] is therefore officially recognised by [INSERT NAME OF ERN] as a Supporting Partner and [INSERT NAME OF ERN] affirms its commitment to continue to work in collaboration with [INSERT] for the benefit of patients with rare uro-recto-genital diseases and complex conditions under the leadership of Prof [INSERT NAME OF ERN COORDINATOR] and [INSERT NAME OF ERN COORDINATING CENTRE].

## Terms of [INSERT NAME OF ERN] and [INSERT]’s collaboration:

* [INSERT] agrees to work in collaboration with [INSERT NAME OF ERN] where possible on areas of common strategic interest so that [INSERT] will bring additional expertise to the [INSERT NAME OF ERN] network. Specifically, as recommended by the Evaluation team, [INSERT] will be involved in [add here the activities or project in which they will be involved.
* The agreement will be for a [1-, 3- or 5-year period] and will be then re-evaluated in relation to the tasks outlined in this collaboration agreement.
* [INSERT] will be respectful to the viewpoints and opinions of others in conveying their opinions and input to [INSERT NAME OF ERN] and ensure criticism is constructive, to ensure that we can maintain the very high standards of professionalism that [INSERT NAME OF ERN] adheres to; an open and collaborative debate where all individuals can feel respected and valued is a core principle.
* At the request of the ERN coordinator, [INSERT] will consider attending the [insert name of ERN] annual meetings with no voting rights but an advisory status and informative role. Reimbursement of travel expenses will be agreed by [insert name of ERN] on a case by case basis and be subject to budget availability.
* At request of the [insert name of ERN] Coordinator, [INSERT] will consider participating in the development of specific collaborative activities, such as disease area clinical practice guidelines or other clinical decision support tools; ERN registry-related activities; training and education, awareness raising and communication or ERN research activities.
* At the request of [insert name of ERN] ePAG, [INSERT] will consider collaborating on specific tasks and projects to support the day-to-day work of the ePAG.
* [INSERT] will be invited to participate in relevant meetings.
* [INSERT] will help raise awareness about [INSERT NAME OF ERN].
* [INSERT] will receive regular information from [INSERT NAME OF ERN] and will contribute to disseminate information/surveys etc about [INSERT NAME OF ERN].
* [INSERT] agrees that [INSERT NAME OF ERN] includes the personal information and email provided in the application in the ERN contact database and distribution lists and use this personal data for the activities related to this agreement.
* [INSERT] and [INSERT NAME OF ERN] should meet at least once a year concerning collaboration, expectations, and future directions.
* If [INSERT] wishes to terminate their collaboration with [INSERT NAME OF ERN], in case of Conflict of Interest (COI) difference in direction, or other reasons, they should write to the ERN Coordinator explaining the reasons for the termination. The termination will be reviewed by the [INSERT NAME OF ERN] Coordinating Team and then a letter will be sent to [INSERT] to end the collaboration.
* If [INSERT NAME OF ERN] wishes to terminate the collaboration with [INSERT] due to COI, difference in direction, or other reasons, after an additional consultation has been offered to exchange views, discuss the change in collaboration and future options, a letter will be sent by the [INSERT NAME OF ERN] Coordinating Team to end the termination.

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| **Signature (Supporting Partner):**  [NAME]  [ROLE]  Date: | **Signature [INSERT NAME OF ERN] :**  [NAME]  [INSERT NAME OF ERN] Coordinator  Date: |

Delegated Decision's Annex I: Criteria and Conditions to be Fulfilled by the Networks:

[https://ec.europa.eu/health/sites/health/files/ern/docs/ern\_delegateddecision\_20140310\_en.pdf](about:blank)

Please see the excerpt below on international collaboration:

Delegated Decision's Annex I: Criteria and Conditions to be Fulfilled by the Networks

(7) To comply with the requirement set out in point (vi) of Article 12(4)(a) of Directive 2011/24/EU (‘**collaborate closely with other centres of expertise and networks at national and international level**’), the Networks must:

1.     (a)  **exchange and disseminate knowledge and best practices,** in particular by supporting national centres and networks;

2.     (b)  **set up networking elements**, such as communication tools, and methodologies **to develop clinical guidelines and protocols; exchange clinical information** in accordance with EU data protection provisions and national imple­menting measures, in particular Directive 95/46/EC, and Article 3 of this Delegated Decision; **develop training** alternatives and models and operation and coordination practices, etc.;

1. Definitions of Affiliated Partners and the process of their designation by the Member States to work with ERNs can be found here: [https://ec.europa.eu/health/ern/board\_member\_states\_en](about:blank) [↑](#footnote-ref-2)