

NEWSLETTER

MAY 2022

The ERN Exchange Programme is designed to share knowledge and stimulate collaboration between professionals in the European Reference Networks (ERNs). After four months of suspension the programme has now reopened. Professionals are again able to plan exchanges and share their knowledge and experiences on the specific expertise and objectives of their ERN. In this newsletter, we will give you an update on the current state of affairs.

Do you have any updates to share? Please send your contribution to ERNexchange@ecorys.com.

We are happy to announce that the ERN Exchange Programme has been resumed per 1 April 2022! Since the restart of the programme, already 77 exchanges are being prepared and two exchanges even took place last month! These numbers show that the ERN Programme is still relevant, the need for exchanges is high and the enthusiasm and motivation to organise exchanges are still there! So now is the time to submit your proposal for exchange!



Reopening of the ERN Exchange Programme: plan your exchange!

Now that the programme has been resumed, it is good to realise that the end date of the programme also comes closer. Exchange visits under this Programme can be made until 31 December 2022, so there are 8 months left to organise them. We encourage all networks to make use of this opportunity. If you need any advice or help to elaborate exchanges, don't hesitate to contact your ERN coordinator/manager, or the Ecorys support team (ERNexchange@ecorys.com).

ERN	Planned/used as % of total available
PaedCan	100%
EUROBLOODNET	100%
RND	89%
RARE-LIVER	64%
ERKNet	57%
eUROGEN	47%
VASCERN	41%
RITA	38%
GUARD HEART	29%
EpiCARE	25%
ERN Euro-NMD	24%
CRANIO	24%
ITHACA	23%
TRANSPLANT CHILD	21%
ENDO ERN	18%
SKIN	15%
EURACAN	9%
RECONNET	7%
EYE	7%
GENTURIS	6%
METAB ERN	5%
LUNG	0%
BOND	0%
ERNICA	0%

Figure 1: overview of planned/used packages per ERN (per end of April 2022)



Changes in the utilisation of packages

The experiences of the organisation of exchanges before the suspension, have been evaluated and demonstrated opportunities to further improve the programme. In consultation with HaDEA, we agreed on the following adjustments:

- Besides individual exchanges, we still encourage group meetings/visits as long as the proposed exchanges are focused on sharing expertise, experiences and, highly specialised knowledge under the scope and frame of the 24 European Reference Networks.
- Last-minute visits are easier to arrange now; if the signed Mobility Agreement cannot be shared 2 months before the visit, visitors can arrange the travel themselves and be reimbursed for the costs (up to a maximum of 300 euro for flights and 200 for train tickets). If the Mobility Agreement is shared 2 months in advance, Ecorys can arrange the travel.
- The maximum duration of an exchange visit has increased from 3 to 6 weeks, in order to better meet the varying needs of the ERNs.
- Daily allowance (DSA) is now also applicable for weekend days for exchanges with a duration of multiple weeks. The weekends in between will be covered with DSA.



Participant of an exchange of Endo-ERN:

"My experience of the exchange is great! As psychologists working in medical / pediatric psychology we hardly have such opportunities to meet and make plans for future collaboration and research. I expect the exchange will be the start for future fruitful collaborations."



Savi Shishkov, participant of an exchange from Endo-ERN

"Now after my visit is over I can confidently say that my stay in Leiden was very useful for me because it helped me expand my knowledge on rare pituitary disorders. It was really interesting to see how in different institutions work is done and problems are solved in a completely different way. Apart from that mobilities such as this one represent a valuable opportunity for an international collaboration."



Various modalities to organise exchanges

To inspire and motivate you to start preparing exchanges, we would like to recall the various modalities that can be used.

Clinical exchanges

Individuals or teams of health care professionals go on an exchange visit to enhance their clinical skills. The evaluations of these visitors are very positive. They mostly value the following results:

- Gaining more specialised knowledge on rare diseases;
- Seeing considerably more patients with a rare disease than would have been possible in their own hospital;
- The opportunity to contribute to the treatment of complex cases;
- Meeting in person with colleagues in the ERN.

The visitors consider that the exchange visit strengthens their ERN in the following ways:

- Increased compliance to medical guidelines for the disease(s) treated;
- Better diagnosis and patient care;
- Increased incorporation of patients' perspectives in treatment decisions;
- Diminishing disparities in knowledge and expertise among hospitals in the ERN.

Exchange offers

Some ERNs have identified specific knowledge and expertise that can increase the general level of highly specialised knowledge and palliate disparities within the Network. Together with leading HCPs on these topics, they elaborated exchange offers for which professionals of all member HCPs can enlist and participate under the Exchange Programme.

Group exchanges to strengthen the network

A third variant are group visits that strengthen the ERN as a whole by sharing expertise, experiences and highly specialised knowledge. For example, group meetings for new and/or affiliated partners to pull them closer into the activities of the ERN; group visits to observe and discuss patient pathways, guidelines or registries.



Tom Gevers and Romée Snijders, participants of an exchange from ERN RARE-LIVER

Romée: "After I visited the Medical University of Warsaw for three days, I had seen and learned a lot about patients with auto-immune and cholestatic liver diseases. Morning ward rounds and the radiology meeting were the highlights. Many thanks to Prof. Piotr Milkiewicz and Prof. Maciej Wójcicki. I hope to see you again soon!"

Tom: "Great experience at the Medical University of Warsaw, really impressed by the experience of Prof. Piotr Milkiewicz and Prof. Maciej Wójcicki in liver transplantation in patient with auto-immune and cholestatic liver diseases. Thanks for the hospitality!"



Consult the FAQ



Consult the Flyer

For further information, we refer to the flyer and FAQ. If you have additional questions, please contact us via ERNexchange@ecorvys.com.