

# Deliverable 3

## Report on ERN-EuroBloodNet members activity/facilities for RHD health provision



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**Short description:** Report on ERN-EuroBloodNet's members' profiles, including data on the HCPs, experts, members of the multidisciplinary teams, diseases covered, number of patients and age range and core facilities for health provision. This will be also accessible through ERN-EuroBloodNet website.

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## **Disclaimer:**

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# 1-Background and rationale

## 1.1 Cross-border Health

Directive 2011/24/EU of the European Parliament and of the Council on the application of patient rights in cross-border healthcare was approved on 9 March 2011. An important difference with the Council Recommendation on an action in the field of rare diseases adopted in 2009 by the EC is that, as a legal binding document, MS had to bring into force the national regulations to comply with the Directive by 25 October 2013. The Directive seeks to facilitate access to healthcare for EU citizens and encourages cooperation between EU Member States in the field of health.

Cross-border health care includes mobility of patients, professionals and services, such as a blood samples or images taken from a patient in one country but analyzed in another country.

Although the vast majority of health care is obtained from providers within the patient's country, as people are usually unwilling to travel significant distances for care, in some situations, especially in the context of rare diseases, the most accessible or appropriate care may be in another Member State, and where movement does take place it raises complex questions about its impact for patients, health systems and health professionals. The free movement of people within Europe has also resulted in substantial mobility of health professionals, an issue which has received less attention, but has important implications for access and quality of health services.

Accordingly, crucial fields requiring legal and ethical action have been identified within ERN-EuroBloodNet for the real achievement of the main expected outcome of the network, including the improvement of quality of life of patients affected by RD independently of the patient's country of origin:

- Patient rights and access to cross border health services

Directive 2011/24/EU on patient rights in cross-border healthcare provides rules regarding access and reimbursement for healthcare received in another EU country. In this framework, the "national contact points" will provide information about healthcare quality and patient safety that will allow patients to make informed choices before going abroad for healthcare.

All EU Countries have passed their own laws to implement the Directive. In the context of the pilot European Network on Rare and Congenital Anaemias (e-ENERCA, [www.enerca.org](http://www.enerca.org)), legal experts from 10 Member States analyzed the implementation of the directive in each legal

system. The differences observed will be taken into account when developing and implementing ERN-EuroBloodNet action plan.

- Data protection and safe and security exchange of data

Safe and security exchange of data shall be taken into account when establishing cross border patients pathways and referral system for patients and/or clinical data in accordance with the new Regulation (EU) 2016/679 of the European Parliament and the Council 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation), that will entry into force the 25<sup>th</sup> May 2018 with direct implementation to all MS.

In general terms, according to the General Data Protection Regulation, the processing of data concerning health or data concerning a natural person's sex life or sexual orientation shall be prohibited unless a) explicit consent is provided or b) is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes under certain legal conditions and assuring specific measures to safeguard the fundamental rights and the interests of the data subject. Accordingly, data must be secured through precautions to prevent access by unauthorized persons and ensuring that patient confidentiality and data integrity are not compromised.

In addition, coded data related to health will also be considered as personal data, meaning that security measures should be implemented and allowing its sharing only when consent is provided. However, with adequate safeguards and under certain conditions, express consent of the patient will not be a requisite to send coded clinical information to a physician in other Member State.

- Rights and duties of health professionals involved in cross-border health services

Clinical advice for complex cases is a service required for ERNs, in which members from a multidisciplinary team are required and are often located in different countries. In this context the EC has developed the Clinical Patients Management System, a platform dedicated for interprofessional consultation for complex cases and secure sharing of clinical data among ERNs.

As stated by Directive 2011/24/EU (article 4), systems of professional liability insurance, or a guarantee or similar arrangement must be in place for treatment provided on a territory. Responsibility of the diagnosis, treatment and follow up concerns the physician in charge of the patient healthcare. Actors involved in the relationships and functions of tools like telemedicine platforms must be well identified.

- Health services suitable for reimbursement at the Member State level

Directive 2011/24/EU has no impact on the rights of each Member State to determine which health benefits they will provide. Thus, if a particular treatment is not reimbursed in a patient's home country, it will not be reimbursed if accessed in another Member State. Member States would be able to require prior authorisation for "hospital care" and reimbursement would match the amount that patients would receive in their home country.

- Pan European framework for the exchange of human samples for diagnosis and research

There is a general EU regulatory framework for the management of data, but regulation relating to specific topics is different between Member States (e.g. in the regulation of genetic testing and genetic counselling, or in the regulation of the use of human samples for biomedical research).

There are international documents relating these subjects (e.g. The new Recommendation of the Council of Europe Rec(2016)6 on research on biological materials of human origin; the Additional Protocol to the Convention on Human Rights and Biomedicine concerning Genetic Testing for Health Purposes) but with no binding force, or not adopted by MS.

It is therefore necessary to agree on and implement policies in each particular project or tool to harmonize national legislations.

## **1.2 Patients' pathways**

Patient pathways show the complete patient journey for a medical condition. It describes the steps and decision points in the management of the disease based on medical guidelines, recent evidence, and expert consensus. Therefore, a patient pathway is like a map including care points that are connected together as a series of options and recommendations to show how individual care decisions are related to the patient's journey. Patient pathways in rare haematological diseases must be established at the European level in order to ensure robust evidence base, however they could be customised to represent how services are delivered within a particular country.

Establishment of patient pathways is in line with the patient centred and multidisciplinary care; they result from the application of a process management aiming at the improvement of patient healthcare and re-centering the focus on the patient's overall journey, rather than the independent contribution of each specialty. In this scenario, emphasis is put on the medical team's common work, as a cross-functional team.

Patient pathways capture actions which will most frequently represent best practice for most patients most of the time. They include prompts for those actions at the appropriate time in the pathway document, to determine if they have been carried out, and if results have been as expected. In this way results are systematically recorded, and important questions and actions are not unobserved.

However, those pathways are not rigid; the patient's journey is an individual one, and an important role of the pathway documents is to capture information on "variations" where, due to circumstances or clinical judgment, different actions have been taken, or different results unfolded. The combined variations for a sufficiently large population of patients are then analysed to identify important or systematic features, which can be used to improve the next iteration of the pathway. This is even more important when talking about very rare hematological diseases.

### **1.3 Rationale**

As in other Rare Diseases, expertise in Rare Hematological Diseases (RHD) is scarce and distributed heterogeneously across the EU and there is no accessible repository of human and technical resources available to challenge the difficulties of RHD at the EU or national levels. As a result, healthcare professionals working in the field (i.e. hematologists, pediatricians and /or primary care general practitioners) feel isolated when dealing with a patient affected by a RHD, especially those with ultra rare prevalence.

Deficiencies in knowledge and information regarding health services for RHD are responsible for an increase in the time of diagnosis and the number of patients misdiagnosed, as well as a lack of decision-making support for best treatment options. This situation leads to patients and relatives, but also health professionals' anxiousness.

The Directive 2011/24/EU on Cross-border health provides the keys for the establishment of a referral system for patients and samples in order to ensure the same level of access to healthcare across Europe. However, previous information on the services available at each Member State is mandatory for the identification of needs and the establishment of evidence- based patients and cross-border pathways leading to a best healthcare care for each individual European patient, improvement of health services delivery for RHD across EU and better use of resources.

In this context, the mapping of experts and services available in Europe for best clinical care in RHD represents the starting point on the process in order to identify what is available and lacking at Member State level for the implementation of patient pathways and the establishment of a

model for cross border referral system for patients and samples based on the patient pathways implemented and in accordance with Directive 2011/24/EU implementation.

ERN-EuroBloodNet inventory of members and services is being created based on healthcare providers, departments and experts profiles. The information gathered through the online application forms including diseases of expertise and covered by the members as well as services offered, will constitute the basis for the mapping of experts and services and thus, the first step for the cross-border pathways implementation in the coming years of the network.



## 2-Objectives

ERN-EuroBloodNet established five specific objectives as priorities to be accomplished in the frame of the 5 years of implementation, including the specific objective 1: Improve equal access to highly specialized healthcare delivery for RHD across Europe.

This objective aims to establish a model of cross-border referral system in the field of RHD for patients and samples in accordance with the Directive 2011/24/EU on the application of patients rights in cross-border healthcare and promote policies at the EU and MS level to address specific needs of patients affected by a RHD.

In line with the specific objective 1, the main goal of the TFA on Cross-border health is to identify those services that are not available in all the countries and thus, where cross-border health is needed. Two specific goals were defined to be accomplished in the first year:

- To create a protocol for the development and update of the European inventory of ERN-EuroBloodNet members profiles, including data on HCPs, experts profiles and professionals of the multidisciplinary team. This would include data on trainees, disease coverage, the number of patients and their age range (children-adults).
- To create the European inventory of ERN-EuroBloodNet members profiles and a repository of RHDs covered by ERN-EuroBloodNet, related codes (ORPHA, ICD), documents and links of interest. The repository will be endorsed by ERN- EuroBloodNet's website.

Both objectives have been addressed within the creation of the ERN-EuroBloodNet dynamic and public inventory of rare hematological diseases (RHD) members and services, specifically to:

- Map the centres, experts and key services available across ERN-EuroBloodNet
- Identify the potential patients' pathways to be established at Member State level based on what is available
- Identify the gaps given in a Member State to be addressed through cross-border pathways implementation.
- Monitor the excellence of the members

## 3-Methods

### 3.1 Transversal Field of Action on Cross-Border Health

The implementation of the ERN-EuroBloodNet action plan has been assured through the establishment of five Transversal Fields of Action (TFAs) in line with each specific objective of the network. In this context, the TFA on Cross-border health was established aiming to implement all tasks and activities related to the achievement of the specific objective 1.

At the beginning of the network, it was agreed that every TFA would be coordinated by one representative from the oncological hub, one representative from the non-oncological hub, and one ePAG representative in order to ensure a balanced coordination of the actions performed. The TFA on Best Practices is coordinated by:

- Jane Apperley, Imperial college Healthcare NHS Trust - Oncological representative: Jane was trained in internal medicine and haematology in Birmingham, London and Cambridge, UK and Boston, USA, with sub-speciality interests in the management of acute and chronic leukaemia, allogeneic stem cell transplantation and the use of tyrosine kinase inhibitors in chronic myeloid leukaemia. She was appointed full professor in 2002, Clinical Director for Clinical Haematology within Imperial College Healthcare NHS Trust in 2003 and Chair of the Centre for Haematology at Imperial College, London in 2004.
- Raffaella Colombatti, AO Padua – Non oncological representative: Raffaella is Pediatric Hematologist and Oncologist with main Clinical and Research interest in non malignant hematology. She has always worked in a tertiary care University Teaching Hospital, reference Center for many malignant and benign conditions in the field of pediatric hematology. She is Consultant (attending physician) at the Clinic of Pediatric Hematology-Oncology, Department of Child and Maternal Health, Azienda Ospedaliera-Università di Padova since 2009 and Pediatric Member of the Ethics Committee of the Provincia di Padova, that includes 5 hospitals, 1 University Teaching Hospital and 3 territorial health units since 2013. She also focuses on developing Transitional Services for patients with genetic hematologic conditions such as organization of a Transitional Service with Adult Hematologist preparing Educational sessions for teens and parents.
- Ananda Plate, Myeloma Patients Europe- ePAG representative: Ananda is Chief Executive Officer at Myeloma Patients Europe. She holds a law degree from the University of Barcelona and a Master's degree in Health Policy. Her main field of interest is cross border healthcare within the EU and health data protection. She started getting involved in patient advocacy in 2007. Since

then she has collaborated with a number of patient organizations across Europe. She has worked at the leading Institute of Public Law (IDP Barcelona) and the European Commission (DG Health and Consumers). Currently she is also a legal advisor in the clinical ethics committee of the Hospital de Mollet (Barcelona).

### **3.2 Action plan for the first year of ERN-EuroBloodNet implementation**

In the context of the TFA on Cross-border health, the mapping of services (clinical and diagnosis) available in Europe for best clinical care was foreseen for the first year of implementation of the network. For this aim, the following subtask was foreseen under the 1<sup>st</sup> year Action Plan:

#### Task 1. Inventory of ERN-EuroBloodNet members profiles

As starting point for the further mapping of clinical care services available at EU level for RHD, an inventory of ERN-EuroBloodNet members profiles would be created including their area/s of expertise, diseases covered and numbers of patients involved, as well as their age range, and facilities for delivery of health provision covering both diagnosis and clinical care. To create a smooth exchange in the network, a representative for each sub-area of expertise will be selected as a contact point for the centre.

### **3.3 Activities implemented in the first year of ERN-EuroBloodNet**

The need for gathering the expertise among ERN-EuroBloodNet members, especially for very rare diseases and/or highly specialised procedures, is a cornerstone task for the implementation of ERN-EuroBloodNet activities.

Contributions from the coordination team, TFA on Cross-border health coordinators and SSB consolidated the strategy to be followed for the creation of the inventory of ERN-EuroBloodNet members profiles based on two main activities: a) Implementation of ORPHANET classification for RHD in the back office of ERN-EuroBloodNet website allowing the selection of diseases of expertise/covered directly from the database b) Design and implementation of the members/departments/experts profiles

### **3.3.1 ERN-EuroBloodNet collaboration with Orphanet**

Orphanet and ERNs represent a common endeavour to improve rare diseases patients' lives in Europe, by increasing the knowledge and providing equal access to expertise.

In the spirit of this joint effort, ERN-EuroBloodNet website has been envisaged to become not only the portal for the network, but also the disease centred IT tool for the endorsement of all its components through an international recognized and uniformly implemented disease classification as Orphanet.

Orphanet classification has been chosen as the one to be implemented in the back office of ERN-EuroBloodNet website due to:

- Orphanet represents nowadays the only structured nomenclature specifically created for RDs and the one with wider coverage of RDs when compared to ICD, SNOMED or OMIM.
- Orphanet classification provides the direct link to other existing or under development codes, eg.ORDO, in order to ensure interoperability among different coding.
- Ensure the update of ERN-EuroBloodNet back-office disease database when produced in ORPHA.

#### **3.3.1.1 ORPHA classification for RHD revision**

Hematological diseases involve a large group of disorders resulting from quantitative or qualitative abnormalities of blood cells, lymphoid organs and coagulation factors, generally divided in about 6 groups of oncological or non-oncological diseases.

With the possible exception of diffuse B cell large cell lymphoma, classical myeloma and chronic lymphocytic leukemia, hematological diseases are rare ORPHA97992, including rare anemias ORPHA 108997, rare coagulation disorders ORPHA 98429, polycythemia ORPHA 98427, and myeloid and lymphoid tumors ORPHA 68347. Rare hereditary hemochromatosis.

ORPHA220489 was also included in our network following a request from well-established patient groups and experts. Accordingly, the most updated classification for ORPHA97992 (rare hematologic diseases) and ORPHA220489 (Rare hereditary hemochromatosis) were requested to Orphanet.

The diseases included in the compiled RHD classification were classified according to the subnetworks established by the network and was circulated among subnetwork coordinators for its review requesting:

- The “reallocation” of diseases to other subnetworks: subnetworks coordinators should check if all of diseases were correctly included in their subnetwork or should be moved to another one.
- The “reallocation” of diseases belonging to other ERNs: Subnetworks coordinators should specify those diseases they considered better to be covered by other ERNs, and to which one of the 24 ERNs existing they considered appropriate.
- The “creation” of new codes: If subnetworks coordinators missed some specific disease in the file, they should “create” an ORPHA number to proceed with the official request to Orphanet.

**After the revision and with the aim of contributing to the improvement of the Orphanet nomenclature, ERN-EuroBloodNet will officially request 12 new codes to ORPHA, including:**

- **7 new codes related to Hemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis subnetwork.**
- **3 new codes related to Myeloid malignancies subnetwork.**
- **2 new codes related to Lymphoid malignancies subnetwork**

### **3.3.1.2 ORPHA classification implementation in ERN-EuroBloodNet website**

After the revision undertaken by ERN-EuroBloodNet subnetworks coordinators, the ERN-EuroBloodNet website developers contacted ORPHA technical team in order to obtain the sql format required for its implementation in the website back office. ORPHA RHD classification was programmed and implemented as the basis for the next steps website development.

As final result, disease database has been programmed ensuring interoperability with ORPHA, meaning that in collaboration with ORPHA staff, we have developed a database that will allow the easily identification of ORPHA updates to be incorporated in ERN-EuroBloodNet and sharing of

information. Thus, experts, healthcare providers, and all contents in general endorsed within ERN-EuroBloodNet website (eg. Guidelines) will be linked through ORPHA classification.

### **3.3.2 ERN-EuroBloodNet members profiles**

As one of the main pillars for the European mapping of experts and services for the provision of healthcare on RHD, different profiles and application forms have been defined in order to gather not too many information, but the essential from the members to nourish the objective.

#### **3.3.2.1 Profiles and application forms definition**

A dynamic inventory of the RHD covered and scope (adult/pediatric), data on HCPs, departments, facilities and experts, has been created in order to identify the gaps of expertise in a given field and country. This information is being gathered through ERN-EuroBloodNet online applications endorsed within ERN-EuroBloodNet website.

Members, departments and experts' database and public profiles have been designed as dynamic IT tool allowing the expansion/modification of the network members directly by the experts and the coordination team members.

The information to be gathered through members profiles was deeply discussed with the ERN-EuroBloodNet Scientific and Strategic Board (SSB) with the aim to compile not large quantity of information but the key for both, identifying gaps on services and expertise on the different fields across Europe and showing publicly useful information for patients and health professionals through the website.

##### **3.3.2.1.1 Members and HCPs profile**

This profile gathers the basic information on the Healthcare provider/s constituting the member.

Members, by definition, can be formed by one or more Healthcare providers (HCPs). If member is formed by more than one HCP, this shall be stated clearly in the Endorsement from the Ministry. Accordingly, information on the two HCPs will be available in the member profile.

Roles for edition:

- Only the coordination team can add new HCPs to the members.
- Member representatives and substitutes can add collaborating centers (other medical

centres with agreements for some procedures but not officially part of the member...) to be listed and described in a specific section of the member profile.

Items requested in the application form can be found in the Annex I Healthcare providers application form.

#### **3.3.2.1.2 Departments profile**

ERN-EuroBloodNet SSB agreed to take into consideration the pivotal role of the departments in the provision of healthcare within the HCPs. Accordingly, it was agreed to create specific profiles for the departments for the gathering of information of the diseases covered and specific services provided, among other data.

In order to provide with accurate information to the mapping of services and for website visitors, each department is linked not only to subnetworks, but also to specific diseases. For this, the selection from the ORPHA classification implemented in the back office of the ERN-EuroBloodNet website is shown in the department application form profile to be selected according to the diseases dealing in the department.

Roles for edition and minimum criteria:

- Only members representatives and substitutes can add new departments and edit them.
- Every department has at least one expert.
- Every subnetwork has at least one person as representative.

Items requested in the application forms can be found in the Annex II Departments application form.

#### **3.3.2.1.3 Experts profile**

As one of the pillars of the inventory, every expert must mandatory be linked to an existing department of the member. In addition, in line with the departments' profile, each expert are not only linked to subnetworks of expertise, but also to specific diseases through their selection from the ORPHA classification implemented in the back office of the ERN- EuroBloodNet website to be selected according to the diseases of expertise.

Roles for editing and inviting new experts:

- Every expert can edit his/her own profile.

- Members representatives and substitutes are able to send invitations to the rest of the experts on the HCPs, that will be necessary linked to a department.

Items requested in the application forms can be found in the Annex III Professional information application form.

### **3.3.2.2 ERN-EuroBloodNet members profiles implementation**

Members representatives and substitutes are the responsible of creating the members profiles having full access to the edition of HCP and departments profiles of their members.

ERN-EuroBloodNet coordination team decided that as first step, the transfer and implementation of information regarding HCPs, departments and experts would facilitate this task rather than giving them a “blank” profile to be filled from the scratch.

Accordingly, coordination team gathered the information that would become the skeleton of the whole inventory.

#### **3.3.2.2.1 Sources of information: Profiles skeleton**

##### **a) Members’ endorsements from the Ministry**

The endorsements from the Ministries approving the participation of a given member in ERN-EuroBloodNet were reviewed in order to define those members with more than one HCP participating in the same member.

Those cases where the endorsement clearly stated the participation of more than one HCP, information on the two HCPs is available in the member profile.

In order to avoid possible problems and misunderstandings, the addition of further HCPs to a member has been restricted to the coordination team.

##### **b) ERN-EuroBloodNet members’ application forms**

The information provided in the members’ application form was used not only to extract the information related to the members representatives and substitutes, but also for the subnetwork/s that each member cover in the context of ERN-EuroBloodNet prior approval of criteria defined by the network.



### c) Members' departments

Departments directly involved with the ERN and their link to specific subnetworks were gathered by the coordination team from members representatives and substitutes, allowing the building of skeleton for the members profiles.

For this, coordination team informed members representatives and substitutes on all the subnetworks covered by its membership and were requested to list all hematological department(s) involved in the network (even if they did not belong to) indicating the specific subnetwork(s) the department(s) deal with. All subnetworks needed to be covered by at least one department.

#### **3.3.2.2.2 Pilot test**

Based on all the information gathered, members and HCP profiles and departments profiles were created including their link to the subnetworks. In parallel, member representatives and substitutes profiles were also created, including their link to the members, HCPs and departments.

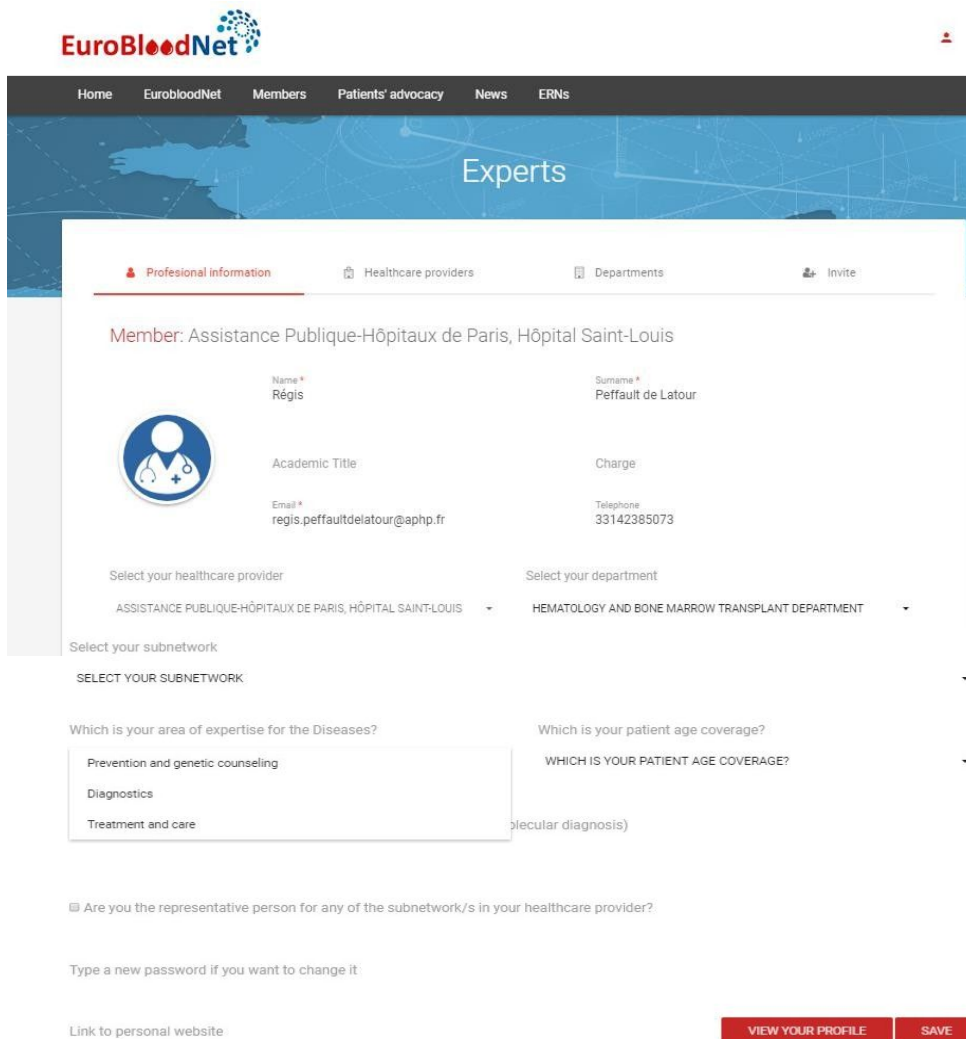
Edition of all the profiles was available through the application forms. With the aim of testing the correct functioning of the applications forms and before sharing to all the members representatives and substitutes, it was agreed to implement a brief pilot phase in order to correct potential failures that may appear during its use.

One month-pilot phase was performed by the ERN-EuroBloodNet Scientific and Strategic board members of the network, who provided their feedback for the correction of minor programming problems encountered. Errors found were successfully repaired prior the open of the profiles to the rest of ERN-EuroBloodNet members.

## 4-Results

### 4.1 Profiles' application forms

As final result, Experts, Departments, Healthcare Providers and Members profiles can be edited through different applications forms. Members representatives and substitutes can complete and edit the different profiles by clicking on the different tabs. The professional information provides the basic information on the professional area of work and expertise.



**EuroBloodNet**

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## Experts

Professional information Healthcare providers Departments Invite

Member: Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis

Name \* Régis Surname \* Peffault de Latour

Academic Title Charge

Email \* regis.peffaultdelatour@aphp.fr Telephone 33142385073

Select your healthcare provider ASSISTANCE PUBLIQUE-HÔPITAUX DE PARIS, HÔPITAL SAINT-LOUIS

Select your department HEMATOLOGY AND BONE MARROW TRANSPLANT DEPARTMENT

Select your subnetwork SELECT YOUR SUBNETWORK

Which is your area of expertise for the Diseases?

Prevention and genetic counseling  
 Diagnostics  
 Treatment and care

Which is your patient age coverage? WHICH IS YOUR PATIENT AGE COVERAGE?

Are you the representative person for any of the subnetwork/s in your healthcare provider?

Type a new password if you want to change it

Link to personal website

VIEW YOUR PROFILE SAVE

Select diseases of expertise from 1 level

Rare anemia

Select diseases of expertise from 2 level

Constitutional dyserythropoietic anemia  Rare deficiency anemia  Aplastic anemia  Rare hemolytic anemia

Select diseases of expertise from 3 level

Pancreatic insufficiency-anemia-hyperostosis syndrome  Majeed syndrome  Congenital dyserythropoietic anemia

Constitutional deficiency anemia  Rare acquired aplastic anemia  Rare constitutional aplastic anemia

Rare acquired hemolytic anemia

Select diseases of expertise from 4 level

Congenital dyserythropoietic anemia type IV  Congenital dyserythropoietic anemia type II

Congenital dyserythropoietic anemia type III  Congenital dyserythropoietic anemia type I

X-linked dyserythropoietic anemia with abnormal platelets and neutropenia

Thrombocytopenia with congenital dyserythropoietic anemia

Vitamin B12- and folate-independent constitutional megaloblastic anemia

Constitutional megaloblastic anemia due to folate metabolism disorder

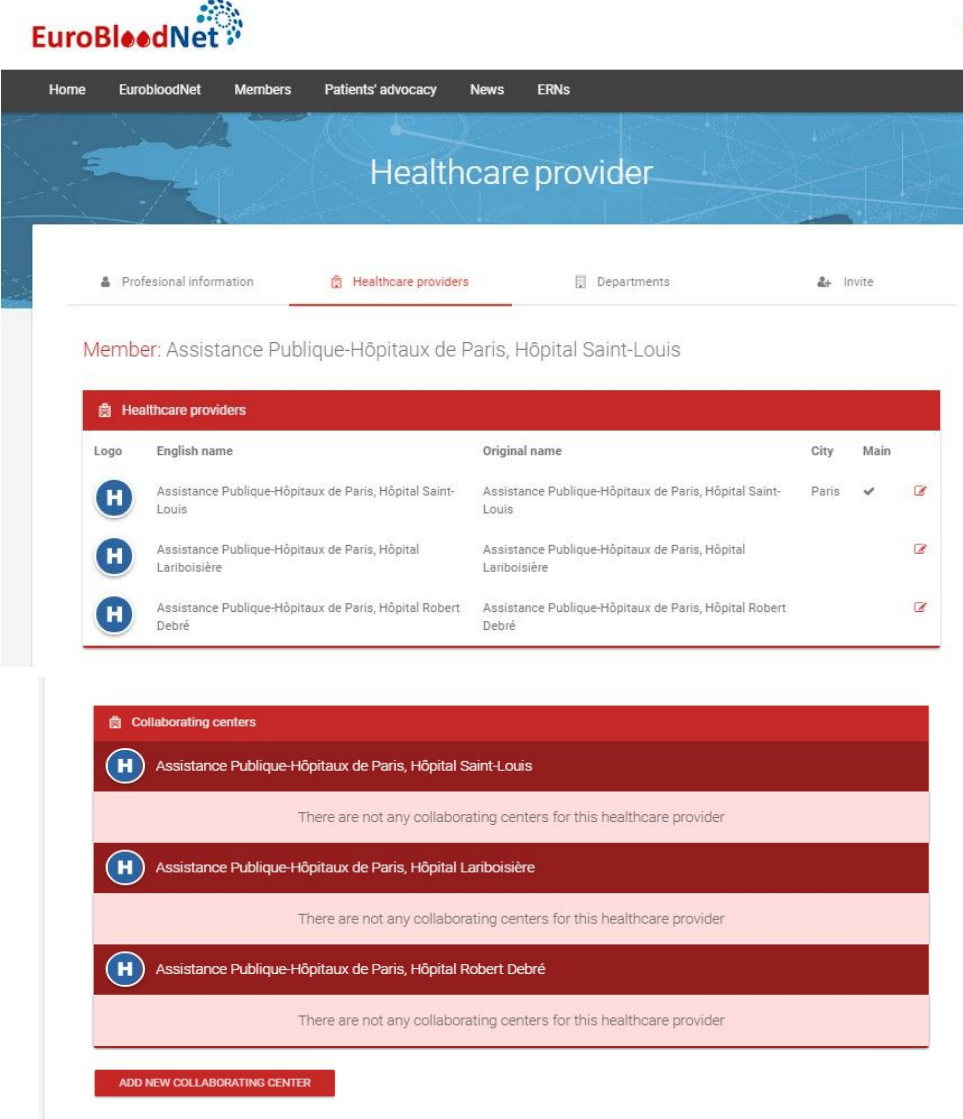
Constitutional megaloblastic anemia due to vitamin B12 metabolism disorder  Red cell aplasia  Idiopathic aplastic anemia

Primary myelofibrosis  Monocytopenia with susceptibility to infections  Pancytopenia-developmental delay syndrome




Hereditary isolated aplastic anemia  Autosomal dominant aplasia and myelodysplasia  Shwachman-Diamond syndrome

The diseases of expertise can be selected from the ORPHA classification. Based on the subnetwork selected, a group of diseases are shown in the first level. Then, based on this selection, diseases from the second level are listed... and so on until the fourth phase, providing complete information on the area of expertise.

Members representatives and substitutes can also edit the information regarding the healthcare providers forming the member, and add collaborating centers linked to the healthcare providers.



The screenshot shows the EuroBloodNet website interface for managing a healthcare provider. The top navigation bar includes 'Home', 'EurobloodNet', 'Members', 'Patients' advocacy', 'News', and 'ERNs'. The main header area displays 'Healthcare provider' with a background image of a hand holding a globe. Below this, there are tabs for 'Professional information', 'Healthcare providers', 'Departments', and 'Invite'. The 'Healthcare providers' tab is active, showing the member 'Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis'. A table lists three healthcare providers with columns for Logo, English name, Original name, City, and Main. Below the table, there are sections for 'Collaborating centers' for each provider, each showing a message: 'There are not any collaborating centers for this healthcare provider'. At the bottom, there is a red button labeled 'ADD NEW COLLABORATING CENTER'.

Logo	English name	Original name	City	Main
	Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis	Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis	Paris	✓
	Assistance Publique-Hôpitaux de Paris, Hôpital Lariboisière	Assistance Publique-Hôpitaux de Paris, Hôpital Lariboisière		
	Assistance Publique-Hôpitaux de Paris, Hôpital Robert Debré	Assistance Publique-Hôpitaux de Paris, Hôpital Robert Debré		

In the tab “Departments”, members representatives and substitutes can edit the information of the different departments and create new ones. Selection of the diseases covered by the department is also available based on the ORPHA classification.

Professional information Healthcare providers **Departments** Invite

Member: Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis

**Departments**

**H** Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis

English name	Original name	Subnetworks of expertise	
Hematology and Bone Marrow Transplant Department	Service d'Hématologie Greffe	Bone marrow failure	✎
Senior Hematology Department	Service d'Hématologie Séniors	Myeloid malignancies, Lymphoid malignancies	✎
Hematology Department for adolescent and young adults	Service d'hématologie Adolescents et jeunes adultes (AJA)	Bone marrow failure	✎
Dermatology Department	Service de Dermatologie	Lymphoid malignancies	✎

**H** Assistance Publique-Hôpitaux de Paris, Hôpital Lariboisière

English name	Original name	Subnetworks of expertise	
Department of laboratory hematology and clinical hemostasis	Service d'Hématologie Biologique	Bleeding - Coagulation	✎

ADD NEW DEPARTMENT
CLOSE

### New department

Department name (English) \*

Department name (Original) \*

Healthcare provider

**HEALTHCARE PROVIDER** ▼

Subnetwork(s) dealing in the department

**SUBNETWORK(S) DEALING IN THE DEPARTMENT** ▼

**Diseases covered by the department**

WHICH ARE THE SERVICES OFFERED BY THE DEPARTMENT ▼

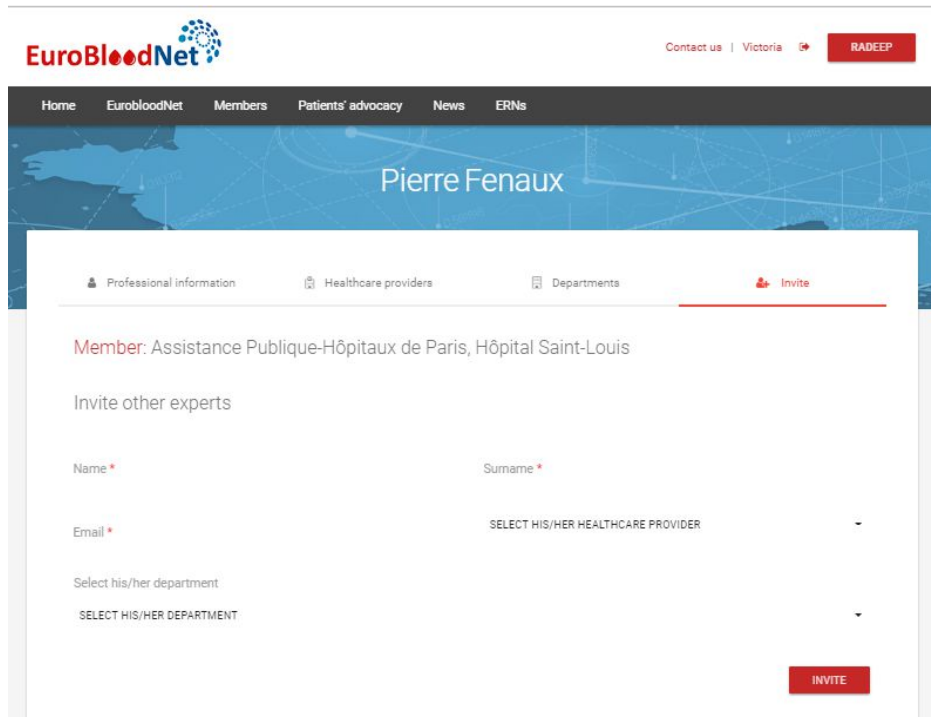
WHICH IS THE PATIENT AGE COVERAGE? ▼

Department e-mail

Department phone number

Description

Members representatives and substitutes can also invite other experts to create their personal profiles.

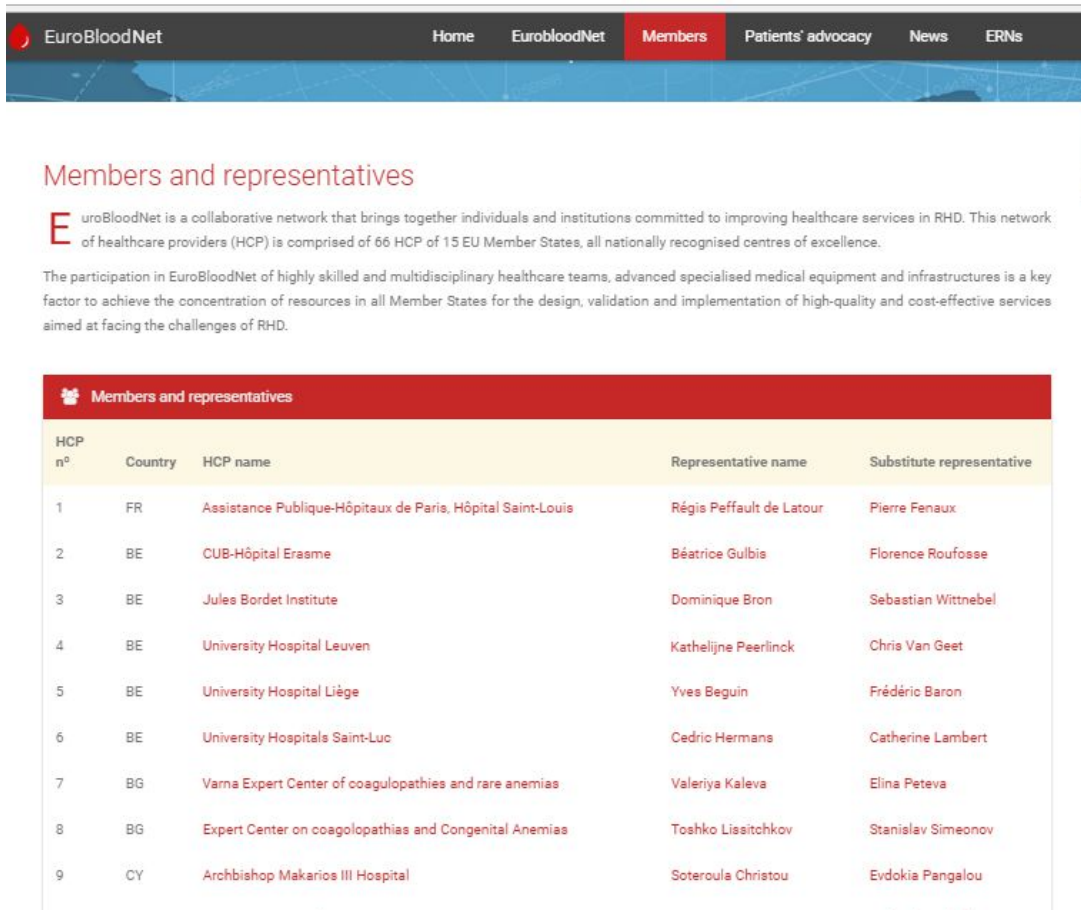


The screenshot shows the EuroBloodNet website interface. At the top, there is a navigation bar with the EuroBloodNet logo on the left and links for 'Contact us', 'Victoria', and a red 'RADEEP' button on the right. Below the navigation bar is a dark header with menu items: 'Home', 'EurobloodNet', 'Members', 'Patients' advocacy', 'News', and 'ERNs'. The main content area features a blue background with a network diagram and the name 'Pierre Fenaux'. Below this, there is a white panel with a tabbed interface. The 'Invite' tab is selected and highlighted in red. The 'Member' information is listed as 'Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis'. The 'Invite other experts' section contains a form with the following fields: 'Name \*' and 'Surname \*' (text inputs), 'Email \*' (text input), and two dropdown menus labeled 'SELECT HIS/HER HEALTHCARE PROVIDER' and 'SELECT HIS/HER DEPARTMENT'. A red 'INVITE' button is located at the bottom right of the form.

As a security measure for data introduced by experts, every modification is performed and not saved is detected by the system and asks you if you are sure to leave without saving.

## 4.2 Public visualization at ERN-EuroBloodNet website

Profiles information is accessible through [ERN-EuroBloodNet website Members section](#). The table is linkable providing direct access to the Members profiles and Members' representatives and substitutes.



HCP n°	Country	HCP name	Representative name	Substitute representative
1	FR	Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis	Régis Peffault de Latour	Pierre Fenaux
2	BE	CUB-Hôpital Erasme	Béatrice Gulbis	Florence Roufosse
3	BE	Jules Bordet Institute	Dominique Bron	Sebastian Wittnebel
4	BE	University Hospital Leuven	Kathelijne Peerlinck	Chris Van Geet
5	BE	University Hospital Liège	Yves Beguin	Frédéric Baron
6	BE	University Hospitals Saint-Luc	Cedric Hermans	Catherine Lambert
7	BG	Varna Expert Center of coagulopathies and rare anemias	Valeriya Kaleva	Elna Peteva
8	BG	Expert Center on coagulopathias and Congenital Anemias	Toshko Lissitchkov	Stanislav Simeonov
9	CY	Archbishop Makarios III Hospital	Soteroula Christou	Evdokia Pangalou

The design of the inventory ensures the linkage of all the information through the different profiles. Thus for instance, all information related to Departments profiles as well as other experts invited by members representatives and substitutes are accessible from either Member, Healthcare providers or experts profiles.



## About me

-  **Name:** Régis
-  **Surname:** Peffault de Latour
-  **Academic title:** Full professor of hematology
-  **Link to personal website:**  
[www.aplasiemedullaire.com](http://www.aplasiemedullaire.com)

### Which is your area of expertise for the "Disease/group of diseases"?

- Prevention and genetic counseling
- Diagnostics
- Treatment and care

### Specify your expertise for the "Disease/group of diseases" (eg SCT, Molecular diagnosis):

Molecular and genetic diagnosis ; treatments : allogeneic stem cell transplantation, immunosuppressive therapy, targeted therapy, chemotherapy, supportive care , therapeutics trials ; Lab research

### Diseases:

Rare anemia , Aplastic anemia , Rare constitutional aplastic anemia , Rare acquired aplastic anemia

### Which is your patient age coverage?

- Adults
- Ageing

### ☆ Member Representative

### 👤 Scientific and Strategic Board member

### ☆ Subnetwork Coordinator:

- Bone marrow failure

### ☆ Subnetwork representative:

- Bone marrow failure

## Member [Go to member](#)

-  **Name english:** Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis
-  **Name original:** Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis

## Healthcare provider [Go to healthcare provider](#)

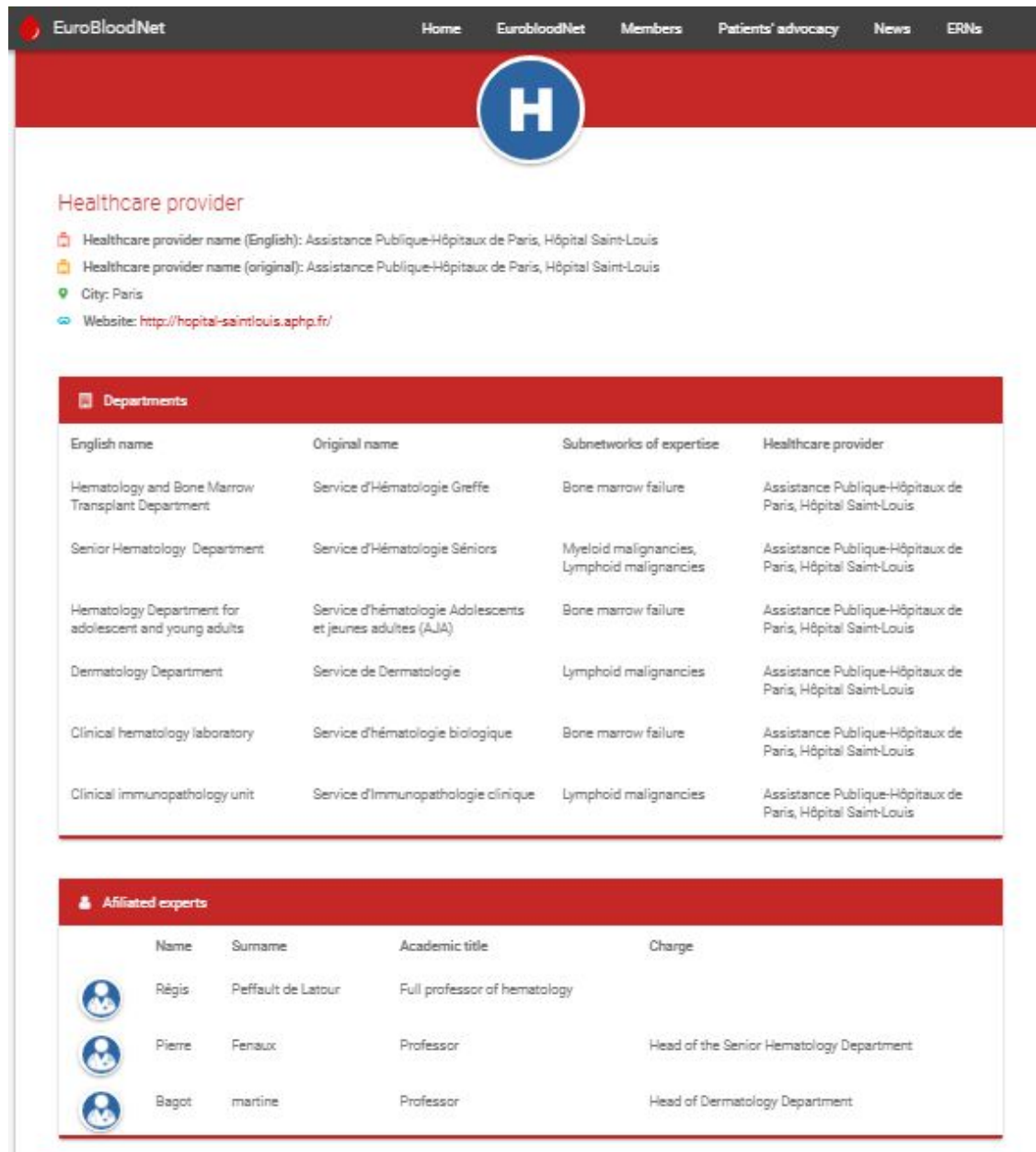
-  **Name english:** Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis
-  **Name original:** Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis

## 📄 Departments

English name	Original name	Subnetworks of expertise	Healthcare provider
Hematology and Bone Marrow Transplant Department	Service d'Hématologie Greffe	Bone marrow failure	Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis



Accordingly, experts profiles do not only provide the specific information related to experts' diseases and area of expertise, patient age coverage or role of the network but also provides a direct link to the Member, Healthcare provider and Department they belong to.



**EuroBloodNet** Home EurobloodNet Members Patients' advocacy News ERNs

**H**




### Healthcare provider

- Healthcare provider name (English): Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis
- Healthcare provider name (original): Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis
- City: Paris
- Website: <http://hopital-saintlouis.aphp.fr/>

#### Departments

English name	Original name	Subnetworks of expertise	Healthcare provider
Hematology and Bone Marrow Transplant Department	Service d'Hématologie Greffe	Bone marrow failure	Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis
Senior Hematology Department	Service d'Hématologie Séniors	Myeloid malignancies, Lymphoid malignancies	Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis
Hematology Department for adolescent and young adults	Service d'hématologie Adolescents et jeunes adultes (AJA)	Bone marrow failure	Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis
Dermatology Department	Service de Dermatologie	Lymphoid malignancies	Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis
Clinical hematology laboratory	Service d'hématologie biologique	Bone marrow failure	Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis
Clinical immunopathology unit	Service d'Immunopathologie clinique	Lymphoid malignancies	Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis

#### Affiliated experts











Name	Surname	Academic title	Charge
	Régis	Pieffault de Latour	Full professor of hematology
	Pierre	Fenaux	Professor Head of the Senior Hematology Department
	Bagot	martine	Professor Head of Dermatology Department

In the same way, Members and Healthcare providers profiles provides a direct access to the departments and experts involved.






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D

### About the department

-  **Department name (English):** Clinical hematology laboratory
-  **Department name (original):** Clinique d'hématologie
-  **Subnetworks of expertise:**
  - Bone marrow failure
-  **Healthcare provider:** Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis
-  **Diseases covered by the department:**
  - Rare anemia
  - Aplastic anemia
  - Rare constitutional aplastic anemia
  - Fanconi anemia
-  **Service offered**
  - Prevention and genetic counseling
  - Diagnostics
-  **Patients covered**
  - Adults
  - Ageing
-  **Department e-mail:** [email@departement.com](mailto:email@departement.com)
-  **Department phone number:** +33153724047
-  **Description:**  
Expertise in cytogenetics, genomics and morphology

### Related departments

-  [Hematology and Bone Marrow Transplant Department](#)
-  [Senior Hematology Department](#)
-  [Hematology Department for adolescent and young adults](#)
-  [Dermatology Department](#)
-  [Clinical immunopathology unit](#)

Departments' profiles offer, apart from the general data, the information on the diseases covered by the department, services offered and patients covered, as well as provide direct link to the Healthcare provider and other departments within the same Healthcare provider.

### 4.3 Current state of the directory of members and experts

ERN-EuroBloodNet members representatives and substitutes were invited to edit and complete the data on their profiles in a 30-days period before publishing the data in ERN-EuroBloodNet website, including also the possibility of inviting other experts within their Healthcare providers.

A total of 181 experts have already created their profiles in the ERN-EuroBloodNet directory, including both members representatives and substitutes and experts invited by them. 96 of them have fulfilled completely their profiles while the rest is in progress.

With the aim to integrate the relevant data introduced so far in the ERN-EuroBloodNet directory of members, the results reported in this deliverable are focused on the profiles completely fulfilled.

As previously explained, experts are able to select not only the subnetworks they deal with, but also the specific diseases on which they show expertise from the ORPHA classification displayed while completing their profiles.

Results of the number of experts by Member State dealing with oncological or non-oncological subnetworks are shown in table 1. In addition, the specific subnetworks by Member State are detailed in Figure 1.

MS	Experts	Non-Onc	Onc
BE	4	3	1
BG	1	1	
CY	1	1	
DE	3	1	3
ES	2	2	
GB	3	2	1
FR	17	14	3
IT	50	32	19
NL	7	7	
PL	4		4
PT	4	3	1
<b>Total</b>	<b>96</b>	<b>66</b>	<b>32</b>

Table 1. Number of experts dealing with non-oncological and oncological subnetworks by Country

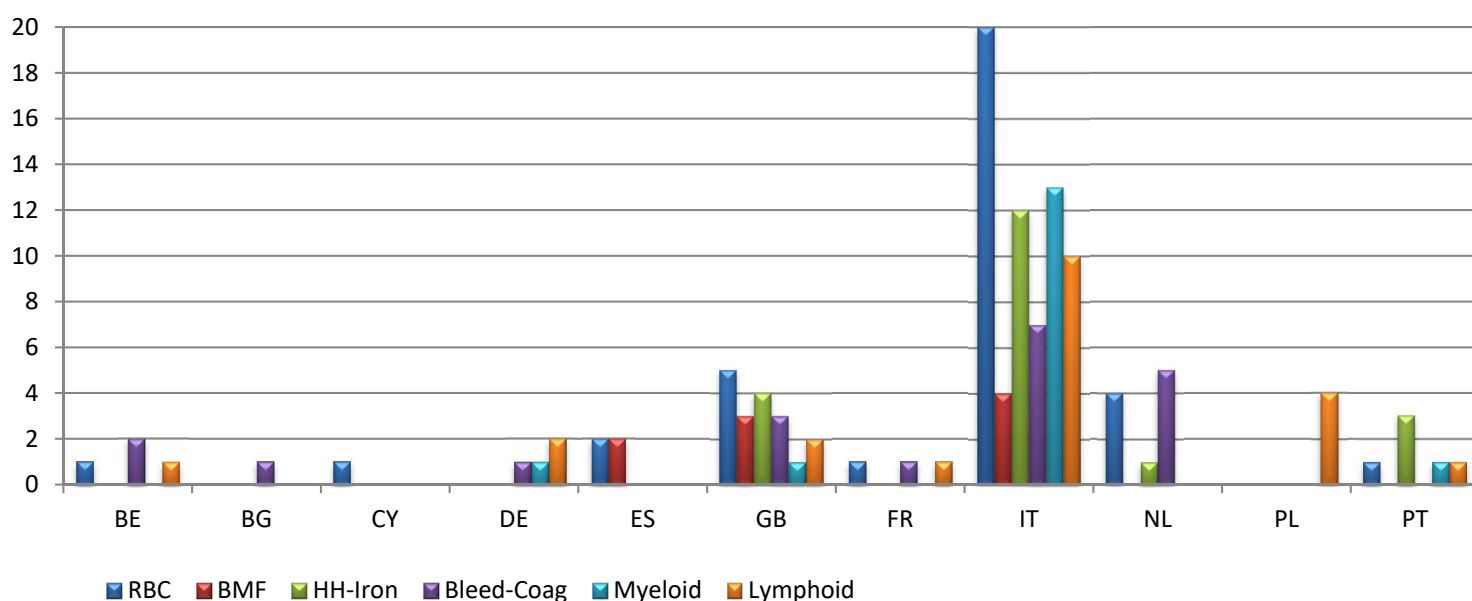


Fig 1. Number of experts by subnetwork and country. Subnetworks: Red blood cell disorders (RBC), bone marrow failures (BMF), Haemochromatosis and iron defects (HH-Iron), bleeding and coagulation (Bleed-Coag), Myeloid malignancies and lymphoid malignancies

It is remarkably the high number of Italian experts already included in the European inventory of experts, which is normal taking into consideration that the number of Italian members is the highest in ERN-EuroBloodNet (21 from 66 members). Also their involvement in the Red Blood Cell disorders subnetwork is logic given the high prevalence of Thalassaemia in this area.

Some differences can be observed among the oncological and non oncological hub attending to the area of expertise. Figure 2 shows the percentage of experts based on their expertise and hub.

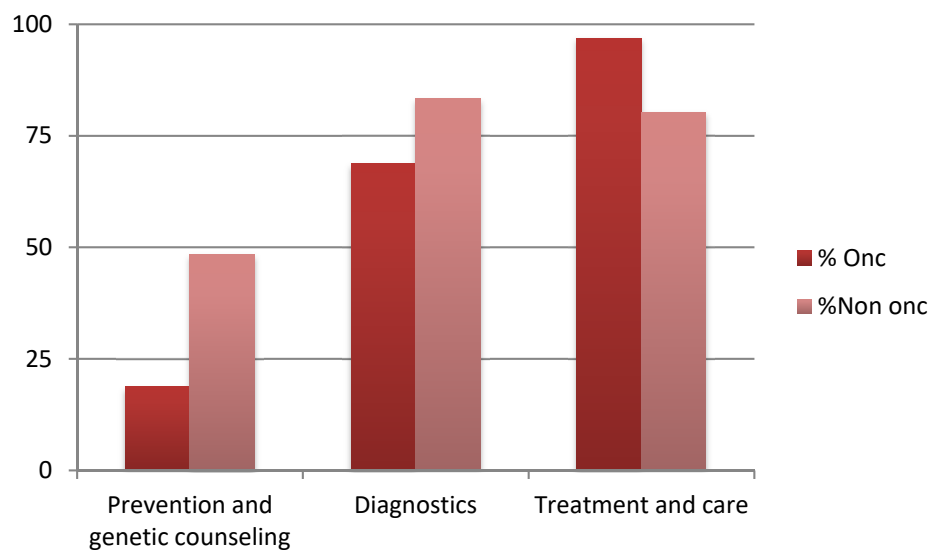


Fig 2 Percentage of experts by their area of expertise and dedicated hub

When focusing on the oncological diseases we can observe that almost 100% of the clinicians are involved in the area of treatment and care, followed by diagnostics field with an involvement of around 70% of the experts, while only the 19% of them are dedicated to the prevention and genetic counselling.

On the other hand, when analyzing the non-oncological hub, it is remarkable the around 80% of experts deal with both, diagnostics and treatment and care. However, almost 50% of experts also deal with prevention and genetic counselling. This could be given due to the presence of some of the diseases in the national prevention programmes and also to the more preventive character of these disorders in comparison with the oncological diseases.

Experts filling their profiles are also able to select their patients' age coverage. Figure 3 shows the percentage of experts dealing with children, adults or aged people by hub.

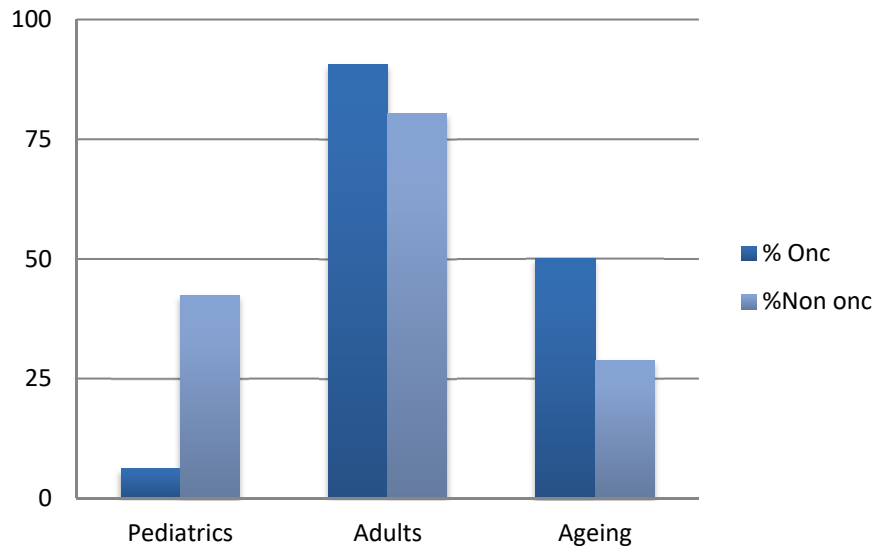


Fig 3 Percentage of experts by the patients' age dealing with and dedicated hub

It is important to clarify that the low number of experts from the oncological hub dealing with pediatrics is given since the oncological diseases in children are out of the scope of our ERN, however these experts declared to deal with pediatrics, adults and ageing.

#### 4.4 ERN-EuroBloodNet Multidisciplinary teams

Multidisciplinary teams are one of the cornerstones of the ERNs given the different approaches and fields of expertise that the management of rare diseases' patients requires. With the aim to compile useful information on the teams involved in ERN-EuroBloodNet, departments' profiles have been constituted as fundamental pieces of the net configuring the inventory of members.

In this context, departments are not only listed in the website, but have their full profile including the diseases covered, services offered, patients aged covered, experts involved...

Annex IV List of departments involved in ERN-EuroBloodNet multidisciplinary teams shows the state of the art of the departments already included in the inventory as well as subnetworks covered by member and country.

## 5-Expected outcomes

### 5.1 Target groups

The implementation of members profiles in ERN-EuroBloodNet is addressed for the following target groups:

- Healthcare professionals non experts in RHD (e.g. general practitioners, primary care paediatricians), searching for expert centres for patient referral.
- Patients suffering from an RHD interested in sharing their views on any problems they may be facing and/or willing to join a patient association.
- Patient associations, especially at the national level, willing to establish interactions with other groups in different Member States.

As final result of the profiles implementation, the establishment of a referral system for patients and samples based on patient pathways will be possible. Thus, final target groups will also be:

- National health authorities responsible for health policies for the implementation of patients' pathways and a model of cross-border health based on the evidences provided by the European mapping of services and experts.
- Other ERNs that may share the same gaps on services provided and that may share the pathways and models for cross-border health to be established in the future.

### 5.2 Expected outcomes

The implementation of ERN-EuroBloodNet members' profiles provides as a result the mapping of resources available through members, setting the basis for patient pathways implementation and for establishing a model for cross border referral system for patients and samples based on patient pathways implementation and in accordance with Directive 2011/24/EU implementation. This will lead to a better use of resources at the MS level while arising gaps on services provided in a given MS or even at the EU level for the clinical management of a specific condition.

In a similar way, the European mapping of experts and services could make visible the lack of expertise for a given condition or procedure at the member, member state or EU level. This is useful information for identifying gaps in the continuing medical education and design the educational annual planning accordingly.

ERN-EuroBloodNet members profiles' edition is available through a set of applications forms that have been designed integrating the ORPHA classification for RHD in a friendly and easy to use format, allowing the provision of detailed evidences by the members and the gathering of the essential data for the establishment of patients' pathways and the model for cross-border health. However, a critical situation that could be faced is the lack of evidence base robust enough for developing a patient pathway, especially in the case of very rare RHD. In these cases, recommendations will be produced and shared with TFA3 on Best practices and/or TFA5 Research and Clinical trials, depending on how much evidence is lacking.

Moreover, another expected outcome from the implementation of ERN-EuroBloodNet members' profiles is the monitoring of excellence of the members. The services provided and specific diseases covered by each member will offer a complementary approach to the systematic gathering of indicators that will be implemented for the regular monitoring of excellence of the members.

## 6-Challenges and conclusion

### 6.1 Challenges encountered

The creation of an accurate and reliable inventory of ERN-EuroBloodNet members and services provided has been one of the main goals to be achieved in this period representing itself a huge challenge for the TFA on cross-border health coordinators, coordination team and SSB.

The possibility of providing the ORPHA RHD classification to the experts for the selection of their specific area of expertise as well as for the diseases covered by each of the departments is offered by levels. This means that based on the subnetworks previously selected, a set of group of diseases are shown as first level. Based on this selection, a group of diseases are shown in the second level for their selection and so on, until forth phase. This turns into facilitation to the selection by the expert, but the design and tool methodology for its implementation represented one of the most time-consuming challenge for the development of the inventory.

Moreover, it is in the internal structure where relies the real complexity of the inventory, envisaged to interrelate all the items (experts with departments with HCPs and members with the ORPHA classification), providing huge possibilities for the disease or group of diseases target data analysis while boosting search engines by either of the above items.

In this context and given this complexity, the design and implementation of the inventory took more time than expected leading to a slight delay in the foreseen timeline. However the coordination team agreed to prioritize the solid and dynamic structure based on the expected results for the mapping of services and experts across EU.

On the other hand, while the participation of many members representatives, substitutes and experts invited has been positive, the number of experts that did not have the opportunity to check and complete their profiles still remains, and therefore the challenge to increase and improve the answer is found. In this context remedial actions are being currently addressed to improve the quality of the directory, as to perform an exhaustive analysis of the existing profiles in short term and reinforce the participation with individual indications to experts by email. Also face to face meetings will become the perfect opportunity to call the attention to this topic and encourage people to adequately fulfil all the fields requested.



## 6.2 Conclusion

TFA on cross-border health will aim to establish a referral system for RHD patients and samples based on patient pathways in order to ensure the same level of access to healthcare across Europe. For this aim, the European inventory of RHD experts and facilities available at the EU and Member State levels has been implemented during the first year of ERN-EuroBloodNet for the identification of gaps and needs to be addressed in the coming years.

The European inventory is based on the implementation of members, healthcare providers, departments and experts profiles in ERN-EuroBloodNet for the gathering of not too many information from the members, but the essential for both, the achievement of the TFA on cross-border health goals and the provision of key information to be public available in ERN-EuroBloodNet website.

ERN-EuroBloodNet profiles' edition is available through a set of applications forms that have been designed integrating the ORPHA classification for RHD in its back office, allowing the selection of health professionals' specific area of expertise as well as for the diseases covered by each of the departments directly from the classification and through a user-friendly disease- level format.

In summary, members, departments and experts' database and public profiles have been designed as dynamic tool allowing both, the edition of the network members directly by the experts and the coordination team members, and ensuring the possibility of expansion of the ERN through the inclusion of new members and affiliated partners in the future stages. Moreover, it is in the internal structure where relies the real complexity of the inventory, envisaged to interrelate all the items (experts with departments with HCPs and members with the ORPHA classification), providing huge possibilities for the disease or group of diseases target data analysis while boosting search engines by either of the above items.

Next steps foreseen envisage the implementation of tools dedicated to exploit to the maximum the data gathered through the inventory of members including:

a) Mapping of diseases and facilities:

- Automatic reports of activity: based on the information gathered in the inventory, automatic reports will be produced for the main medical conditions based on their prevalence, severity, and/ or particular medical management aiming to identify the existing gaps on number of experts, centers of expertise and services provided for a given disease/group of diseases while providing comparative data for the tackle of these conditions.

- Disease search engine: implementation on the website of a search tool that allows the visualization of HCPs and experts dealing with the certain disease/group of diseases by country and other optional filters such as the patient age coverage.

b) Systematic gathering of indicators: an engine for the automatic gathering of indicators from the members will be implemented in the next steps of the network aiming to 1) map the “key” disease-specific criteria for the management of RHD patients and 2) monitor the excellence of the ERN-EuroBloodNet members.

In result, the data already gathered through the inventory of ERN-EuroBloodNet members will not only be exploited but expanded while providing the evidence needed for the establishment of cross-border health pathways in the coming years of the network.

# Annexes

## **Annex I Healthcare providers application form**

Information on the HCPs forming the member is gathered through this application. Editable by members representatives and substitutes, with the restriction of adding new HCPs to the member (restricted to coordination team)

### **Healthcare providers (HCPs)**

HCP name (english)

HCP name (original)

Logo

City Country Web

### **Optional: HCP collaborating centers**

HCP collaborating centre name (english)

HCP collaborating centre name (original)

HCP collaborating city

HCP collaborating centre website

## Annex II Departments application form

All the information of the departments dealing with the diseases covered by a given HCP will be gathered through this application form.

Editable by members representatives and substitutes. When adding a new department, it is directly created linked to representative or substitute' member.

### Department information

Department name (english) Department name (original)

HCP (a list of the HCPs from the member is shown for its selection) Subnetwork (s) dealing in the department (multiple choice):

- Rare red blood cell defects
- Bone marrow failure and hematopoietic disorders
- Rare bleeding-coagulation disorders and related diseases
- Hemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis
- Myeloid malignancies
- Lymphoid malignancies

Diseases covered by the department

1<sup>st</sup> level of the ORPHA classification is shown based on the subnetworks selected 2<sup>nd</sup> level of ORPHA classification is shown based on the 1<sup>st</sup> level diseases selected 3<sup>rd</sup> level of ORPHA classification is shown based on the 2<sup>nd</sup> level diseases selected 4<sup>th</sup> level of ORPHA classification is shown based on the 3<sup>rd</sup> level diseases selected

What are the patients covered by the department (multiple choice):

- Pediatrics
- Adults
- Ageing

Services offered by the department (multiple choice):

- Prevention and genetic counselling
- Diagnostics
- Treatment and care

Department Contact data

- Department mail
- Department phone
- Description

### **Annex III Professional information application form**

Information on professional information of the experts will be gathered through this application form.

Editable by all the experts. Invited professionals will receive a link with a pre-filled profile (including HCP name, surname, and mail) for its completion.

#### **Personal information**

Picture Name Surname

Academic title Charge

email (not visible in the web)

Telephone (not visible in the web)

Select your Healthcare provider (a list of HCPs from the member will be shown for its selection)

Select your departments (a list of the departments linked to the HCP selected will be shown for its selection)

Are you subnetwork representative in your department? (if yes multiple choice from the subnetwork covered by the department)

#### **Expertise**

Subnetwork of expertise (List with the subnetworks covered by the department/s selected will be shown for its selection. Multiple choice):

- Rare red blood cell defects
- Bone marrow failure and hematopoietic disorders
- Rare bleeding-coagulation disorders and related diseases
- Hemochromatosis and other rare genetic disorders of iron metabolism and heme synthesis
- Myeloid malignancies
- Lymphoid malignancies

#### Diseases of expertise

- 1st level of the ORPHA classification is shown based on the subnetwork/s selected
- 2nd level of ORPHA classification is shown based on the 1st level diseases selected
- 3rd level of ORPHA classification is shown based on the 2nd level diseases selected
- 4th level of ORPHA classification is shown based on the 3rd level diseases selected

#### Which is your area of expertise for the "Disease/group of diseases"?

- Pediatrics
- Adults
- Ageing

#### Which is your patient age coverage?

- Prevention and genetic counselling
- Diagnostics
- Treatment and care

Specify your expertise for the "Disease/group of diseases" (eg SCT, Molecular diagnosis) Link to personal website

#### **Role in the network** (only editable by coordination team)

HCP Representative / Substitute

Scientific and Strategic Board member Coordination team

Subnetwork coordinator

TFA coordinator

## Annex IV List of departments involved in the ERN-EuroBloodNet multidisciplinary teams

MS	Member Name	English Name	Subnetwork of expertise
	CHU de Liège	Department of Clinical Hematology	Myeloid malignancies, HH-Iron, Red blood cell
		Department of Clinical Biology (including Genetics)	Myeloid malignancies, HH-Iron, Red blood cell
		Department of Pediatric Hematology-Oncology - CHR Citadelle	Myeloid malignancies, Red blood cell
BE	Cliniques universitaires Saint-Luc	Hematology	Bleeding - Coagulation
		Hematology and Pediatric Oncology	Bleeding - Coagulation
		Physical Medicine and Rehabilitation	Bleeding - Coagulation
		Center for Human Genetics	Bleeding - Coagulation
		Institute for health and society research	Bleeding - Coagulation
		Hematological Biology	Bleeding - Coagulation
		Surgery and abdominal transplantation	Bleeding - Coagulation
		Orthopedic surgery and traumatology of the musculoskeletal system	Bleeding - Coagulation
		Stomatology and maxillofacial surgery	Bleeding - Coagulation
		Gastroenterology	Bleeding - Coagulation
		Infectious and Tropical Diseases	Bleeding - Coagulation
	CUB-Hôpital Erasme	Department of Hematology	Myeloid malignancies, Red blood cell
		Department of internal medicine	Myeloid malignancies
		Department of Molecular genetics – Genetic centre ULB	Red blood cell
		Brussels Academic Hospital Laboratory	Myeloid malignancies, Red blood cell
		Department of hemato-oncology, immunology and transplantation – HUDERF (ULB)	Red blood cell
	Institut Jules Bordet	Clinical adult Hematology	Lymphoid malignancies
		Transplant Unit	Lymphoid malignancies
		Cytapheresis	Lymphoid malignancies
		Cellular therapy laboratory	Lymphoid malignancies
		Laboratory of Hematology & cyto-genetics	Lymphoid malignancies
	UZ Leuven	Department of Cardiovascular diseases - Division of Thrombosis and Haemostasis	Bleeding - Coagulation
		Department of Pediatrics Division of Pediatric hemato-oncology	Bleeding - Coagulation
BG	Expert Center on coagulopathias and Congenital Anemias	First Department of Clinical Hematology	Bleeding - Coagulation
		Second Department of Clinical Hematology	Bleeding - Coagulation
		Third Department of Clinical Hematology	Bleeding - Coagulation
		Transplantations Department	Bleeding - Coagulation
		Diagnostic and consulting block	Bleeding - Coagulation
	Varna Expert Center of coagulopathias and rare anemias	Clinic of pediatric hematology and oncology	Bleeding - Coagulation
		Clinic of clinical hematology	Bleeding - Coagulation
CY	Archbishop Makarios III Hospital	Thalassaemia Center	Red blood cell
		Molecular Genetics Thalassaemia Department	Red blood cell
CZ	Fakultní nemocnice Brno	Department of Internal Medicine – Hematology and Oncology	Myeloid malignancies, Lymphoid malignancies, Bleeding - Coagulation, Red blood cell, Bone marrow failure
DE	Charité Universitätsmedizin Berlin	Department of Pediatric Oncology/Hematology/BMT	Red blood cell
		Labor Berlin - Charité Vivantes GmbH, Department of Laboratory Medicine	Red blood cell
	Universitätsklinikum Heidelberg	Medical Department V Amyloidosis Center	Lymphoid malignancies



DE	Universitätsklinikum Köln	Department I of Internal Medicine	Lymphoid malignancies
		Clinic of Nuclear Medicine	Lymphoid malignancies
		Clinic for Radiotherapy	Lymphoid malignancies
	University Hospital Carl Gustav Carus Dresden	Hematology	Myeloid malignancies, Bleeding - Coagulation
		Stem cell transplantation	Myeloid malignancies
		Hemostaseology	Bleeding - Coagulation
		Transfusion medicine	Myeloid malignancies, Bleeding - Coagulation
		Oncology	Myeloid malignancies
	ES	Hospital Universitari Vall d'Hebron	Hematology Department
Pediatric Oncology and Hematology Department			Red blood cell, Bone marrow failure
High risk cancer prevention Unit			Bone marrow failure
FR	Assistance Publique-Hôpitaux de Marseille	Pediatric Hematology/Oncology department, Timone Hospital (AP-HM)	Bleeding - Coagulation, Red blood cell
		Department of Internal Medicine, Timone Hospital (AP-HM)	Bleeding - Coagulation, Red blood cell
		Reference center for thalassemia and other inherited red cell disorders, Timone Hospital (AP-HM)	Red blood cell
		Reference center for inherited platelet disorders, Timone Hospital (AP-HM)	Bleeding - Coagulation
		Reference center for inherited bleeding disorders, Timone Hospital (AP-HM)	Bleeding - Coagulation
		Hemapheresis department, Conception Hospital (AP-HM)	Bleeding - Coagulation, Red blood cell
		Laboratory of Hematology, Timone Hospital (AP-HM)	Bleeding - Coagulation, Red blood cell
		Laboratory of genetic	Bleeding - Coagulation, Red blood cell, Bone marrow failure
	Assistance Publique-Hôpitaux de Paris, Hôpital Henri-Mondor	Genetic red blood cell unit. Sickle cell referral center	Red blood cell
	Assistance Publique-Hôpitaux de Paris, Hôpital Necker-Enfants Malades	Expert center of celiac-disease-associated lymphoma	Lymphoid malignancies
		Reference center for sickle cell disease and other rare diseases of red cell and erythropoiesis	Red blood cell
		French regional treatment center for Hemophilia and other hemorrhagic disorders	Bleeding - Coagulation
		European competent network on mastocytosis	Myeloid malignancies
		Expert center of celiac-disease-associated lymphoma	Lymphoid malignancies
	Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Antoine	Hematology	Bleeding - Coagulation
		Nephrology and Transplant Unit	Bleeding - Coagulation
	Assistance Publique-Hôpitaux de Paris, Hôpital Saint-Louis	Hematology and Bone Marrow Transplant Department	Bone marrow failure
Senior Hematology Department		Myeloid malignancies, Lymphoid malignancies	
Hematology Department for adolescent and young adults		Bone marrow failure	
Dermatology Department		Lymphoid malignancies	
Department of laboratory hematology and clinical hemostasis		Bleeding - Coagulation	
Paediatric hematology Department		Bone marrow failure	
Clinical hematology laboratory		Bone marrow failure	
Clinical immunopathology unit		Lymphoid malignancies	
Assistance Publique-Hôpitaux de Paris, Hôpital Trousseau	Pediatric hemato oncology department	Myeloid malignancies	
	Internal medicine, Hôpital Pitié-Salpêtrière	Myeloid malignancies	
	Neurological department, Hôpital Pitié-Salpêtrière	Myeloid malignancies	
	Pathological department, Hôpital Ambroise-Paré	Myeloid malignancies	
	Pneumology department	Myeloid malignancies	

FR	CHRU de Lille	Internal medicine and clinical immunology	Bone marrow failure	
		Clinical Haemostasis and Transfusion	Bleeding - Coagulation	
	CHU de Limoges	Department of hematology and cellular therapy, University Hospital of Limoges	Lymphoid malignancies	
		Department of nephrology, University Hospital of Poitiers	Lymphoid malignancies	
	CHU de Montpellier	Department of Haematology Biology, Expert centre on rare iron disorders-centre for family screening	HH-Iron	
		Department of Haematology Biology - Regional Centre for the treatment of haemophilia patients and other rare bleeding disorders	Bleeding - Coagulation	
	CHU de Rennes	Liver Disease Department	HH-Iron	
		Molecular genetic department	HH-Iron	
	Institut Curie	Department of Oncology - Hematology Unit	Lymphoid malignancies	
	University Hospital of Guadeloupe	Sickle cell Unit, Reference centre for sickle cell disease and other rare diseases of red cells and erythropoiesis	Red blood cell	
Reference centre for sickle cell disease and other rare diseases of red cells and erythropoiesis		Red blood cell		
Pediatrics department		Red blood cell		
Polyvalent Medicine		Red blood cell		
Emergency department		Red blood cell		
Laboratory of molecular biology and of diagnosis of haemoglobinopathies		Red blood cell		
Intensive Care Unit		Red blood cell		
GB	Barts Health NHS Trust	Clinical Haematology- Royal London Hospital	Red blood cell	
		Paediatric Haematology- Royal London Hospital	Red blood cell	
	Imperial college Healthcare NHS Trust	Haematology department, Hammersmith Hospital	Myeloid malignancies, Lymphoid malignancies, Bleeding - Coagulation, Red blood cell, Bone marrow failure	
		Paediatric Haematology department, St. Mary's Hospital	Red blood cell, Bone marrow failure	
	Oxford University Hospitals NHS Foundation Trust	Department of Haematology	Myeloid malignancies, Lymphoid malignancies, Bleeding - Coagulation, HH-Iron, Red blood cell, Bone marrow failure	
	Sheffield Teaching Hospitals NHS Foundation Trust	Sheffield Haemophilia and Thrombosis Centre, Royal Hallamshire Hospital	Bleeding - Coagulation	
	University College London Hospitals NHS Foundation Trust	POEMS Service, Cancer Division	Lymphoid malignancies	
		TTP and microangiopathy service, Haematology and Blood Transfusion. Pathology division.	Bleeding - Coagulation	
	IE	Our Lady's Children Hospital Crumlin	Pediatric haematology	Red blood cell
			Adult haematology	Red blood cell
IT	A. ULSS6 - Ospedale San Bortolo di Vicenza	Department of Internal Medicine	Bleeding - Coagulation	
		Hematology Department	Bleeding - Coagulation	
		Hemostasis and Thrombosis Center	Bleeding - Coagulation	
	AO di Padova	Department of Child and Maternal Health	Myeloid malignancies, Red blood cell	
		Department of Medicine	Myeloid malignancies, Lymphoid malignancies, Bleeding - Coagulation, Red blood cell	
		Department of Transfusion Medicine	Myeloid malignancies, Lymphoid malignancies, Bleeding - Coagulation, Red blood cell	
	AO Ospedali Riuniti Villa Sofia-Cervello Palermo	Department of Hematology and Rare Diseases- U.O.C. Haematology for Rare Diseases of Blood and Haematopoietic Organs	HH-Iron, Red blood cell, Bone marrow failure	
	AOU Careggi, Firenze	Department of Oncology and Robotic Surgery	Myeloid malignancies, Bleeding - Coagulation, Bone marrow failure	
	AOU Consorziale policlinico di Bari	Pediatric Unit "B. Trambusti"	Bleeding - Coagulation, Red blood cell	
	AOU di Modena	Medicine, Emergency Medicine and Medical Specialties	HH-Iron, Red blood cell	
		Maternal and Child health	Red blood cell	
	AOU Federico II di Napoli	Department of Laboratory Medicine	Red blood cell, Bone marrow failure	
		Department of Clinical Medicine and Surgery	Myeloid malignancies, Bleeding - Coagulation, Red blood cell, Bone marrow failure	

AOU Policlinico Umberto I di Roma	Hematology - Department of Cellular Biotechnologies and Hematology - Hematology, Oncology and Dermatology ICD	Myeloid malignancies, Lymphoid malignancies, Bone marrow failure
	Department of Radiology	Myeloid malignancies, Lymphoid malignancies, Bone marrow failure
	Infectious Diseases Unit	Myeloid malignancies, Lymphoid malignancies, Bone marrow failure
	Histopathology Department	Myeloid malignancies, Lymphoid malignancies, Bone marrow failure
	Transfusion Medicine and Blood Bank Department	Myeloid malignancies, Lymphoid malignancies, Bone marrow failure
	Laboratory Diagnostics services	Myeloid malignancies, Lymphoid malignancies, Bone marrow failure
	Hematological Emergency Room	Myeloid malignancies, Lymphoid malignancies, Bone marrow failure
	Intensive Care Unit	Myeloid malignancies, Lymphoid malignancies, Bone marrow failure
	Central Venous Access Unit	Myeloid malignancies, Lymphoid malignancies, Bone marrow failure
	General Surgery Unit	Myeloid malignancies, Lymphoid malignancies
	AOU S. Luigi Gonzaga	Division of Pediatrics & Hemoglobinopathies Centre, Department of Clinical and Biological Sciences
Internal Medicine and Hematology, Department of Clinical and Biological Sciences		HH-Iron, Red blood cell
AOU Senese	Hematology Unit	Myeloid malignancies, Lymphoid malignancies
	Medical Genetics Unit	Myeloid malignancies, Lymphoid malignancies
	Pathology Unit	Myeloid malignancies, Lymphoid malignancies
	Radiology Unit	Myeloid malignancies, Lymphoid malignancies
	Radiotherapy Unit	Lymphoid malignancies
	Surgical Oncology Unit	Lymphoid malignancies
AOU University of Campania "Luigi Vanvitelli"	Pediatric Hematology and Oncology, Integrated maternal and child care department	Red blood cell, Bone marrow failure
AOUI di Verona	Department of Medicine	Myeloid malignancies, HH-Iron, Red blood cell
ASST-Monza S. Gerardo Hospital	Medical Genetics, Centre for Rare Diseases	HH-Iron, Red blood cell, Bone marrow failure
	Day Hospital Thalassemia and hemoglobinopathies	Red blood cell, Bone marrow failure
	Hematology	Myeloid malignancies
	Pediatric Unit	HH-Iron, Red blood cell
E.O. Ospedali Galliera, Genova	Department of Medicine - Congenital Anemias and Iron Disemetalism Center	HH-Iron, Red blood cell
Fondazione Policlinico Universitario A. Gemelli - Roma	Blood Bank - Institute of Hematology	Red blood cell
	Division of Hematology - Institute of Hematology	Bone marrow failure
	Blood coagulation Unit - Institute of Hematology	Bleeding - Coagulation
	Division of Hematology - Institute of Hematology 2	Myeloid malignancies, Lymphoid malignancies, HH-Iron
Foundation IRCCS Ca'Granda Ospedale Maggiore Policlinico, Milan	Department of General Medicine - Hemostasis and Thrombosis - Angelo Bianchi Bonomi Hemophilia and Thrombosis Center	Bleeding - Coagulation
	Internal Medicine Department - Rare Diseases Centre	Red blood cell
	Hematology - Patophysiology of Anemias Unit	Red blood cell, Bone marrow failure
	Internal Medicine Department - Metabolic diseases Unit	HH-Iron
Hospital Pope John XXIII - Bergamo	Department of Oncology and Hematology - Immunoematology and Transfusion Medicine Unit	Bleeding - Coagulation, HH-Iron
	Department of Oncology and Hematology - Hematology Unit	Bleeding - Coagulation
	Department of Internal Medicine - Internal Medicine Unit	Bleeding - Coagulation, HH-Iron
	Department of Internal Medicine - Gastroenterology Unit	HH-Iron
	Department of Diagnostic Imaging - Radiology unit	HH-Iron
IRCCS Istituto Clinico Humanitas di Rozzano	Center Cancer Center	Myeloid malignancies

IT

IRCCS Istituto Giannina Gaslini, Genova	Haematology Unit	Red blood cell, Bone marrow failure
	Emostasis and Thrombosis Unit	Bleeding - Coagulation
IT IRCCS Policlinico San Matteo Foundation, Pavia	Department of Hematology Oncology	Myeloid malignancies
	Amyloid Research and Treatment Center	Lymphoid malignancies
	Department of Internal Medicine	Bleeding - Coagulation
	Pediatric Hematology/Oncology Unit	Red blood cell
LT Vilnius University Hospital Santaros Klinikos	Hematology, Oncology and Transfusion Medicine Center	Myeloid malignancies, Lymphoid malignancies, Bleeding - Coagulation, Red blood cell
	Center for Pediatric Oncology and Hematology	Bleeding - Coagulation, HH-Iron, Bone marrow failure
Academic Medical Center Amsterdam	Pediatric Hematology	Bleeding - Coagulation, Red blood cell
	Hematology	Red blood cell
	Internal Medicine, vascular medicine	Bleeding - Coagulation
Erasmus MC: University Medical Center Rotterdam	Hematology	Myeloid malignancies, Lymphoid malignancies, Bleeding - Coagulation, Red blood cell, Bone marrow failure
	Pediatric Hematology	Bleeding - Coagulation, Red blood cell, Bone marrow failure
	Cell Biology Laboratory	Red blood cell
	Hemostasis Laboratory	Bleeding - Coagulation
	Hematology Laboratory	Myeloid malignancies, Lymphoid malignancies, Bone marrow failure
Leiden University Medical Center	Department on Thrombosis and Hemostasis	Bleeding - Coagulation
	Department of Pediatrics, division of Hematology, Immunology and Stem Cell Transplantation	Red blood cell
NL Radboud University Medical Center Nijmegen	Laboratory medicine	Myeloid malignancies, Bleeding - Coagulation, HH-Iron, Bone marrow failure
	Internal Medicine	Bleeding - Coagulation, HH-Iron
	Hematology	Myeloid malignancies, Bleeding - Coagulation, HH-Iron, Bone marrow failure
	Pediatrics	Bleeding - Coagulation, HH-Iron
	Genetics	Myeloid malignancies, Bleeding - Coagulation, HH-Iron, Bone marrow failure
	Radiology	HH-Iron
	Orthopedics	Bleeding - Coagulation
	Physiotherapy	Bleeding - Coagulation
University Medical Center Groningen	Department of Pediatrics	Bleeding - Coagulation
	Department of Hematology	Bleeding - Coagulation
University Medical Center Utrecht	Internal Medicine Department - Van Creveldklinik	Bleeding - Coagulation, Red blood cell
	Hematology	Myeloid malignancies, Lymphoid malignancies
	Pediatric Hematology - Wilhelmina Child Hospital	Red blood cell
PL Centrum Onkologii - Instytut im. Marii Skłodowskiej-Curie	Department of Lymphoid Malignancies	Lymphoid malignancies
	Department of Pathology and Laboratory Diagnostics	Lymphoid malignancies
	Department of Regenerative Medicine	Lymphoid malignancies
	Department of Epidemiology and Prevention - National Cancer Registry	Lymphoid malignancies

PT	Centro Hospitalar do Porto, EPE	Clinical Haematology	Myeloid malignancies, Lymphoid malignancies, HH-Iron
		Internal Medicine	HH-Iron
		Radiology	HH-Iron
		Dermatology	Myeloid malignancies, Lymphoid malignancies
		Anaesthesiology	Myeloid malignancies
		Pediatrics Department	Myeloid malignancies
		Pathology	Myeloid malignancies, Lymphoid malignancies
		Clinical Pathology	Myeloid malignancies, Lymphoid malignancies
		Immunoallergology	Myeloid malignancies
		Ortopaedics	Myeloid malignancies
Centro Hospitalar e Universitário de Coimbra, EPE	Hematology department	HH-Iron, Red blood cell	
	Pediatric hematology	HH-Iron, Red blood cell	
	Laboratory of red cell and iron metabolism disorders	HH-Iron, Red blood cell	
Instituto Português de Oncologia do Porto Francisco Gentil, EPE	Hematology Department	Myeloid malignancies, Lymphoid malignancies	
	Pathological Anatomy Department	Myeloid malignancies, Lymphoid malignancies	
	Genetics Department	Myeloid malignancies, Lymphoid malignancies	
	Flow Cytometry Department	Myeloid malignancies, Lymphoid malignancies	
	Bone Marrow Transplant Unit	Myeloid malignancies, Lymphoid malignancies	
	Radiotherapy Department	Lymphoid malignancies	
SE	Karolinska Universitetssjukhuset	Pediatric Blood Disorders, Immunodeficiency and SCT Service, Astrid Lindgren Children's Hospital	Red blood cell, Bone marrow failure
		Pediatric Oncology and Coagulation Service, Astrid Lindgren Children's Hospital	Bleeding - Coagulation
		Hematology Centre	Myeloid malignancies, Lymphoid malignancies, Bleeding - Coagulation, HH-iron, Red blood cell, Bone marrow failure
		Function Area Clinical Pathology and Cytology, Karolinska University Laboratory	Myeloid malignancies, Lymphoid malignancies, Red blood cell, Bone marrow failure
		Function Area Clinical Immunology and Transfusion Medicine, Karolinska University Laboratory	Myeloid malignancies, Lymphoid malignancies, Bleeding - Coagulation, Red blood cell, Bone marrow failure
		Function Area Clinical Genetics, Karolinska University Laboratory	Myeloid malignancies, Lymphoid malignancies, Bleeding - Coagulation, HH-iron, Red blood cell, Bone marrow failure
		Function Area Clinical Chemistry, Karolinska University Laboratory	Myeloid malignancies, Lymphoid malignancies, Bleeding - Coagulation, HH-iron, Red blood cell, Bone marrow failure
		Function Imaging and Physiology	Myeloid malignancies, Lymphoid malignancies, Bleeding - Coagulation, HH-iron, Red blood cell, Bone marrow failure
		Function Health Professionals	Myeloid malignancies, Lymphoid malignancies, Bleeding - Coagulation, HH-iron, Red blood cell, Bone marrow failure