Review

The added value of a European Reference Network on rare and complex connective tissue and musculoskeletal diseases: insights after the first 5 years of the ERN ReCONNET

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ABSTRACT

In order to address the main challenges related to the rare diseases (RDs) the European Commission launched the European Reference Networks (ERNs), virtual networks involving healthcare providers (HCPs) across Europe. The mission of the ERNs is to tackle low prevalence and RDs that require highly specialised treatment and a concentration of knowledge and resources. In fact, ERNs offer the potential to give patients and healthcare professionals across the EU access to the best expertise and timely exchange of lifesaving knowledge, trying to make the knowledge travelling more than patients. For this reason, ERNs were established as concrete European infrastructures, and this is particularly crucial in the framework of rare and complex diseases in which no country alone has the whole knowledge and capacity to treat all types of patients.

It has been five years since their kick-off launch in Vilnius in 2017. The 24 ERNs have been intensively working on different transversal areas, including patient management, education, clinical practice guidelines, patients' care pathways and many other fundamental topics. The present work is therefore aimed not only at reporting a summary of the main activities and milestones reached so far, but also at celebrating the first 5 years of the ERN on Rare and Complex Connective Tissue and Musculo-skeletal Diseases (ReCONNET), in which the members of the network built together one of the 24 infrastructures that are hopefully going to change the scenario of rare diseases across the EU.

Introduction

Over 30 million people in Europe are affected by more than 6.000 rare diseases. Unfortunately, many of them still have limited access to timely diagnosis and high-quality treatment. Moreover, the scientific evidence in rare diseases may be scarce because of low numbers of patients and improving the evidence by pooling data in small populations can often be a challenge. In order to address these challenges, the European Commission launched the European Reference Networks (ERNs), virtual networks involving healthcare providers (HCPs) across the European Union (EU). The mission of the ERNs is to tackle low prevalence and rare diseases that require highly specialised treatment and a concentration of knowledge and resources. In

fact, ERNs offer the potential to give patients and healthcare professionals across the EU access to the best expertise and timely exchange of lifesaving knowledge, trying to make the knowledge travelling more than patients. For this reason, ERNs were established as concrete European infrastructures, and this is particularly crucial in the framework of rare and complex diseases in which no country alone has the whole knowledge and capacity to treat all types of patients (1).

It has been five years since the kick-off launch in Vilnius in 2017 (2). The 24 ERNs have been intensively working on different transversal areas, including patient management, education, clinical practice guidelines, patients' care pathways and many other fundamental topics. At their inception, the networks comprised more than 900 highly specialised healthcare units located in 313 hospitals in 26 EU countries. These numbers have been recently expanded after the second 2019 call and, on January 1st 2022, 620 new applicants have joined the ERNs as Full Members. This expansion will significantly increase both the geographical and the disease area coverage of the Networks and will certainly improve the capacity of the Networks in addressing the different challenges of rare diseases.

The ERN ReCONNET (European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases) (3) is aimed at improving the management of rare connective tissue and musculo-skeletal diseases (rCTDs) across the EU. This network groups rCTDs into three main thematic areas represented by: i) rare autoimmune, ii) complex autoimmune and iii) rare hereditary connective tissue and musculoskeletal diseases. Specifically, the diseases covered by the ERN ReCONNET are antiphospholipid syndrome (APS), Ehlers-Danlos syndromes (EDS), idiopathic inflammatory myopathies (IIM), IgG4-related diseases (IgG4), mixed connective tissue diseases (MCTD), relapsing polychondritis (RP), Sjögren's syndrome (SS), systemic lupus erythematosus (SLE), systemic sclerosis (SSc) and undifferentiated connective tissue diseases (UCTD).

In 2017, at the time of its constitution, ERN ReCONNET counted 25 Full Member Healthcare Providers (HCPs), directly caring for about 28.500 rCTDs patients from 8 different countries: Belgium, France, Germany, Italy, Portugal, Romania, Slovenia, and The Netherlands. As of January 1st 2022, ERN ReCONNET counts 55 Full Members and 9 Affiliated Partners over 23 European countries: Austria, Belgium, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Italy, Latvia, Lithuania, Luxembourg, Malta, Poland, Portugal, Romania, Slovenia, Spain, Sweden, and The Netherlands.

One of the most relevant added values of the ERN ReCONNET is the involvement of Patients' Representatives within all the activities of the Network. In fact, an intense collaboration has been established with the ERN ReCONNET European Patient Advocacy Group (ePAG). Their role is to provide patients' opinion and input in all the activities, to give the opinion and views of the patient groups, to collaborate in the evaluation of how the ERN acts on feedback from patients, to promote and encourage a patient-centric approach, to develop and disseminate patients' information, to ensure that patient rights and choices are considered in decision-making and to identify relevant national patients' organisations to work with the ERN's HCPs.

Globally, the ERN ReCONNET is conceived as an infrastructure going beyond geographical boundaries which purpose is to serve as a meeting point of needs, feedbacks and expertise for HCPs and the external environment (other networks, authorities, health systems, private sectors, etc.). Furthermore, it aims to act as a promoter of harmonised strategies and actions to (i) improve the standards of care across EU, (ii) reduce inappropriate practice variation and disparities in health care, (iii) support transparent decision making, (iv) enhance translation of research into practice, (v) support efficient use of resources, (vi) reinforce research and epidemiological surveillance and (vii) improve knowledge for physicians, healthcare providers, patients and families.

Thus, the present report is aimed not only at reporting a summary of the main activities and milestones reached so far, but also at celebrating the first 5-years of the ERN ReCONNET, in which the members of the network built together one of the 24 infrastructures that are changing the scenario of rare diseases across the EU.

Clinical practice guidelines

It is well known that clinical practice guidelines (CPGs) can serve as a blueprint of excellence, to advise healthcare professionals and patients on how to treat and manage the disease(s) in a way that reflects the best possible evidence. This recalls one of the main missions of the ERNs, that is to promote and ensure equity of care across EU countries. For this reason, CPGs can be considered a very powerful tool for promoting equity in the field of rare diseases; as a matter of fact, they can make the difference between no care/substandard care and patients living longer, healthier lives with fewer complications and a better quality of life. Thus, from the beginning, the ERN ReCONNET considered CPGs an important macro area on which the Network focused. Before planning any potential new CPGs, a deep revision of the existing guidelines related to rCTDs was performed by the Network to obtain a formal "state of the art" on CPGs related to the 10 diseases included in the ERN ReCONNET. The huge work of the disease-specific working groups was then finalised into specific publications (4-13), gathered in a supplement dedicated to the CPGs and ERN ReCONNET in *RMD Open*, an official journal of the European Alliance of Associations for Rheumatology (EULAR). Notably, a very important added value of the supplement is represented by a section in each paper dedicated to the unmet needs of the specific rCTD addressed in the paper, that was prepared by the ERN ReCONNET ePAGs. The "*ERN ReCONNET Supplement on the state of the art on CPGs in rCTDs*" (14, 15) was then disseminated both in scientific meetings, international conferences, and during the meetings with the other ERNs' coordinators and the Commission and highlighted that

well-constructed and valid CPGs exist for some rCTDs, while other diseases have very few or no CPGs.

Another important activity conducted by the network was to assess the real adaptation of CPGs in clinical practice by clinicians as well as the knowledge and awareness of CPGs for their diseases among patients/family members/caregivers. To do that, two surveys were developed, one on the use of CPGs for HCPs that was dedicated to healthcare professionals and another one aimed at addressing CPGs knowledge and awareness in rCTDs among rCTDs patients, caregivers, and family members (16). Even though all the respondents stated that CPGs are crucial tools to improve patient care, interesting findings have emerged from the results of the study. Some difficulties and barriers in the adoption of CPGs in the actual clinical setting still exist, and they are mainly caused by local legislative restrictions and time constraints during the assessment of patients. Many proposals from clinicians have been suggested to implement the application of CPGs, mainly related to having easier and more practical versions of existing CPGs (such as phone and/or computer applications or an online platform), increasing knowledge and education for both patients and professionals on CPGs, having more dedicated time during the routine clinical assessment and having government support for reducing any local legislative restrictions. At the same time, patients, family members and caregivers underlined that CPGs should be more widely disseminated and possibly adapted to the different health systems in Europe, also emphasising that patient-friendly versions of CPGs and patients' lifestyle guidelines could play a relevant role in the process of empowering patients in the management of their rCTDs disease.

Lay versions are an adaptation of the original documents (recommendations, clinical practice guidelines, etc.) into an English-lay version, to facilitate the patients' access to information about their disease and thank to this to make well-informed decision about their health. On this regard, a great effort is being conducted by ePAGs, who are working with clinicians and other patients to develop lay versions of existing CPGs, as well of lay versions of the state-of-the-art supplement. One ERN ReCONNET ePAG is working as Task Leader of the Lay versions and, besides working on the already available lay version dedicated to SSc, another one for SLE is under development.

While the main CPGs existing for rCTDs are available on the ERN ReCONNET website for consultation, a huge activity has started over the last years and it is still ongoing, regarding the adaptation of the existing CPGs to the different geographical contexts. The adaptation of existing CPGs, mainly related to four diseases (SS, SLE, IIM, SSc), is being conducted by means of the ADAPTE methodology (17). The objective of this process is to take advantage of existing CPGs to enhance the efficient production and use of high-quality adapted guidelines. The adaptation process has been designed to ensure that the final recommendations address specific health questions relevant to the context of use and address the needs, priorities, legislation, policies, and resources in the target setting and it is particularly crucial for CPGs for rCTDs. The process foresees some main principles that are represented by the respect for the evidence-based approach of guideline development, the use of reliable methods to ensure the quality of the adapted guideline, the participative approach involving all key stakeholders, the explicit consideration of context during adaptation as well as the flexibility to accommodate specific needs and circumstances. From all these considerations, the adaptation of CPGs can be regarded as almost mandatory in the context of the ERNs and the different EU countries. Lastly, ReCONNET participated actively and endorsed EULAR recommendations for the management of some CTD. It is the case for the management of treatment in patients with pSS for which EULAR recommendations were provided on the supervision of M. Ramos-Casals and X. Mariette (18).

Patient care pathways

As reported by the European Pathways Association (EPA) "a care pathway is a complex intervention for the mutual decision making and organisation of care processes for a well-defined group of patients during a well-defined period" (19). Thus, considering that the main purpose of patients' care pathways (PCPs) is to enhance the quality of care, their role is particularly crucial in the field of RDs and of complex diseases as well. It is therefore clear how the framework of the ERNs might represent the best setting for the creation of organisational reference models for PCPs across Europe, thanks to the patient-centred approach and the multistakeholder involvement. Many approaches are already existing for the creation of PCPs from the clinical point of view, but to promote a pragmatic improvement of the PCPs and the application of CPGs in real life we needed to consider in a profound way the organisational aspects of PCPs. For this reason, in the framework of the collaboration between the ERN ReCONNET and the group of Health Economics of the Institute of Management of the Scuola Superiore Sant'Anna, an extensive effort has been made towards the creation of an *ad hoc* methodological approach aimed at providing organisational reference models for PCPs in rCTDs across the different Member States. In fact, to develop the reference model, a structured methodology was created to enable the design of the PCPs based on an extensive sharing of expertise on high-quality care and characterised by a strong patient-centred approach: RarERN Path™ (20). RarERN Path™ represents a specific methodology aimed at improving organisation in real life and it was created implementing the existing approaches already in use for the assessment of PCPs with different approaches aimed at considering the organisation. As by principles of the methodology, RarERN Path™ foresees the integration of the perspectives of large communities of patients, expert clinicians, health economists, hospital managers, and healthcare providers from different EU countries. This is particularly relevant and useful in the field of RDs, in which different perspectives means sometimes different challenges
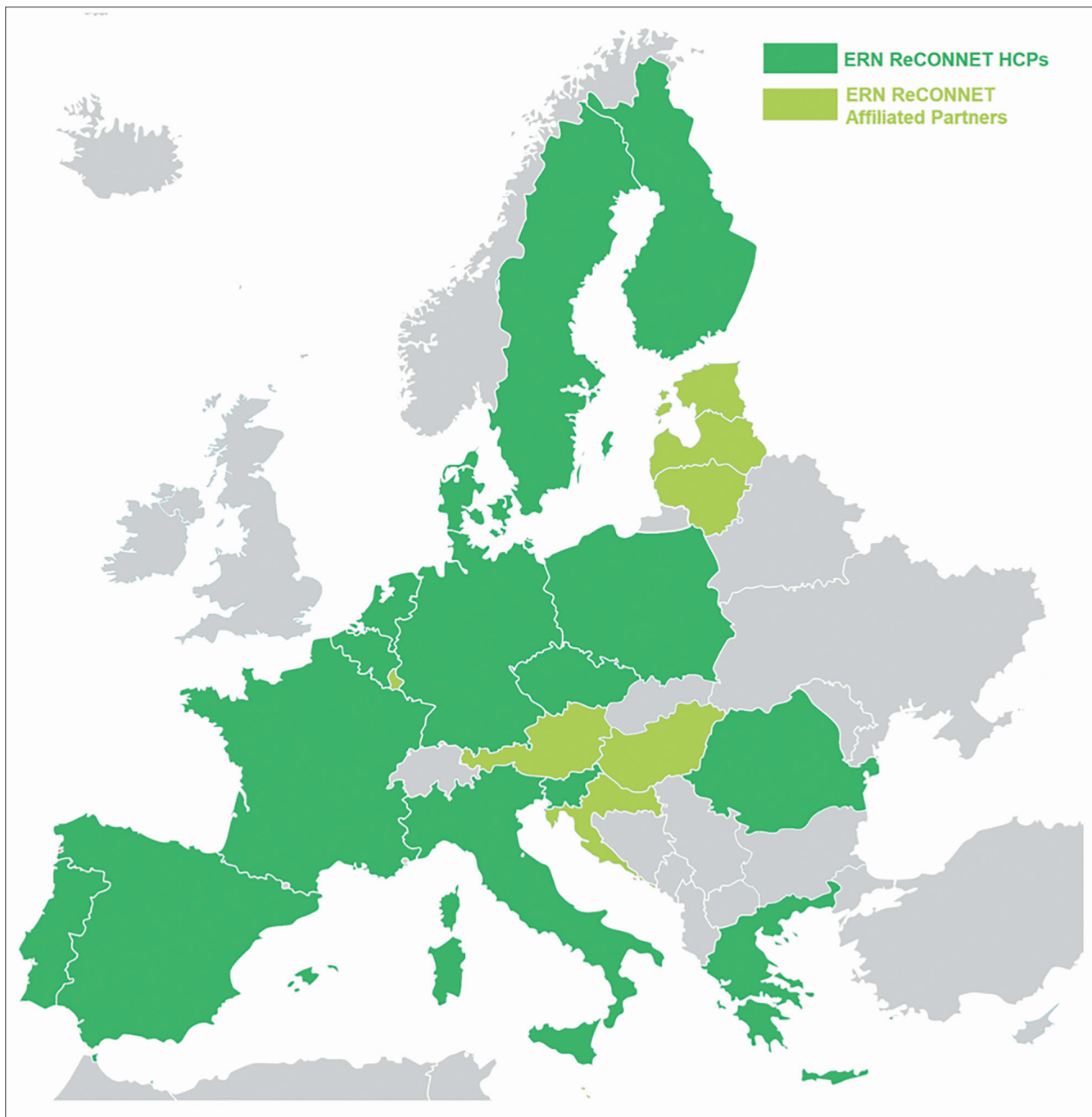
Fig. 1. EU countries involved in the European Reference Network (ERN) ReCONNET. ERN ReCONNET covers the following countries: Belgium, Czech Republic, Denmark, Finland, France, Germany, Greece, Italy, The Netherland, Poland, Portugal, Romania, Slovenia, Spain, and Sweden with HCPs full members; Austria, Croatia, Estonia, Hungary, Latvia, Lithuania, Luxembourg, and Malta with the affiliated partners.

and good practices, that are fundamental to guarantee organisational models of PCPs that are integrated, flexible and adaptable to the different healthcare systems in Europe. In fact, RarERN Path™ starts from mapping of existing PCPs and patients' stories, order to find a consensus among the stakeholders on an optimised PCP. Moreover, as for the application of any reference model, the most important aspect is to monitor its application, and it is foreseen by the methodology, by means of both common and specific key performance indicators (KPIs). Besides the multi-stakeholder approach, another important aspect of this methodology is also the strong patient-centred approach, which is translated in RarERN Path™ in the active involvement of patients in all the phases of the methodology. In fact, both individual patients and patients' representatives are highly engaged in its the application of RarERN Path™, since they can express their perspectives, needs and priorities also thanks to the analysis of patients' stories and to their involvement in the different co-design processes and multi-stakeholder discussion on the pathways. The appli-

cation of RarERN Path™ is ongoing for the different diseases included in ERN ReCONNET, being in a more advanced phase for SSc (in which the pilot application was started) and for EDS.

As Network we learned from direct experiences of our clinicians and patients that focusing the attention on organisation can make a difference in caring for individuals living with rCTDs, and the last two years of pandemic show how important organisation is, especially in rCTDs management.

Education

One of the main objectives of the ERNs is to exchange and disseminate existing knowledge on rare and complex conditions. In order to do that, ERNs are specifically requested to organise teaching and training activities on the specific conditions they cover. Within ERN ReCONNET, different educational activities were performed over the past years. Experts of the ERN ReCONNET have shared their expertise in webinars dedicated to the main target groups of the Network: healthcare professionals and patients. Different webinars were specifically designed for healthcare professionals regarding the diseases covered by ERN ReCONNET (*e.g.* EDS, RP, SLE etc), while other webinars were dedicated to transversal topics that are relevant for all the diseases covered by ERN ReCONNET (*e.g.* nutrition, vitamin D). A webinar was also organised in collaboration with another Network, VASCERN, the ERN on Rare Multisystemic Vascular Diseases. These webinars were very well received by the scientific community and they collected more than twelve thousand YouTube views in total. Thanks to a close collaboration with the ePAG Advocates, webinars were also specifically co-designed for patients and caregivers (Pregnancy in rheumatic diseases and CPGs). To this end, a checklist was co-designed with the ePAG Advocates to ensure that the webinars produced by the ERN for patients are meeting the needs of the patient community. The checklist also includes the specific format that the webinar should have (the speakers included should always involve both a patient and an expert in

the field) and the processes needed to establish a close collaboration between both speakers. After an initial webinar pilot, it was also decided to develop, for each webinar, an infographic summarising the main information included in each webinar and list of useful references on the specific topic that patients and caregivers can consult to expand their knowledge on the specific topic. The recording of the webinar, the infographic and the list of references are always publicly available on the ERN ReCONNET website. Another important dimension of the educational activities of ERN ReCONNET is related to the webinars organised on health economics by the Scuola Superiore Sant'Anna. The webinars were aimed at providing a basic knowledge on health economics, such as for example the main cost drivers of healthcare expenditure in Europe and the main economic evaluation techniques that are currently used in healthcare. All the webinars are publicly available on the ERN ReCONNET website and YouTube channel and every participant is asked to fill a satisfaction survey in order to monitor the quality of the webinars performed and to ensure quality improvement over time.

The EC has also recently launched the ERN Exchange Programme, whose main aim is promoting knowledge sharing and stimulating collaboration among the Network. The programme allows ERNs to organise exchange visits among the ERN centres and currently three different editions of exchanges are taking place. The EC has identified a contractor to support the 24 ERNs in the organisation of the exchanges. Within ERN ReCONNET, a call for interest was launched among all the HCPs and ePAGs Advocates and 6 exchanges were already approved by the Steering Committee. Unfortunately, due to the COVID-19 pandemic, the Programme was suspended until March 2022 and the exchange visits will be organised as soon as the programme will be restarted.

In the last months, a survey was launched by ERN ReCONNET to map the current educational and training needs of the rCTDs patients and healthcare professional community. The

survey was co-designed together with the ERN ReCONNET Education Task Force and the ePAG Advocates and translated in 15 languages. The results of these survey will represent a crucial starting point to co-design the education and training strategy of ERN ReCONNET for the coming years.

The Clinical Patient Management System and National Hubs

The Clinical Patient Management System (CPMS) is a secure IT platform developed by the EC to support ERNs in the diagnosis and treatment of rare or low prevalence complex diseases or conditions across national borders. The CPMS enables healthcare professionals across Europe to enrol patients who have given consent for their data to be shared on the virtual platform, and to upload any relevant patient data (as well as diagnostic examinations, images, etc.) to discuss the clinical cases in a safe environment within a panel of experts (21). (https://cpms.ern-net.eu/login/)

Bringing together highly specialised healthcare providers in complex, rare or low prevalence diseases and intensifying the collaboration between the ERN ReCONNET expert centres, the CPMS can contribute to the diagnose, treatment and improvement of the quality of life of people living with rCTDs. (https://reconnet.ern-net.eu/our-network-ern-it-services/)

The Connecting Europe Facility (CEF) is a funding instrument designed by the European Union that "supports the development of high performing, sustainable and efficiently interconnected trans-European networks in the fields of transport, energy and digital services" (https://ec.europa.eu/inea/en/connecting-europe-facility). One of the main objectives of CEF-funded action 2017-IT-IA-0084, aimed to set up the ERN ReCONNET Operational Helpdesk (OH), is to maintain the OH already established and to establish National Hubs.

Each National Hub serves as national contact point to support the usage and the dissemination of the CPMS at national/local level; it serves as national reference contact for specialists, gen-

eral practitioners and other healthcare professionals for information on the functioning of the platform; and contributes to connecting even the more remote healthcare providers and patients to highly specialised services of the Network.

The National Hub enables a wider diffusion of the CPMS potentialities and of the CPMS usage, making the platform service available for a larger number of patients, even for those living in disadvantaged areas, far from reference centres; by using the local language and helps in overcoming language barriers; ensures that the platform is presented in national/local conferences, meetings and web-conferences; creates guides on the CPMS in national language. (https://reconnet. ern-net.eu/guides_cpms/)

The ERN ReCONNET National Hubs identified so far are: Ghent University Hospital for Belgium, Hôpitaux Universitaires de Strasbourg for France, Universitätsklinikum Düsseldorf for Germany, Azienda Ospedaliero Universitaria Pisana for Italy, University Medical Center Utrecht for Netherlands, Centro Hospitalar de Lisboa Central, EPE for Portugal, County Emergency Clinical Hospital Cluj for Romania, University Medical Centre Ljubljana for Slovenia (22).

Economic dimension

ERN ReCONNET focuses on all the issues that are linked to the care of patients living with RCTDs, including the economic and organisational dimensions of rCTDs as priorities. The main characteristics of RDs such as the small patient populations due to the low prevalence; the heterogeneity and the complexity of the clinical conditions that often affect multiorgan systems; the frequently disability affecting patients life expectancy, the physical impairment; the mental disabilities that impact on patients and their families; and the delay of diagnosis, not only pose great challenges in clinical research but also imply big socio-economic burden putting significant hurdles that the healthcare systems need to consider. The economic pressure on healthcare budgets, the clinical and patients' unmet needs,

the equal access to high-quality healthcare services and to innovative technology across geographical regions from are a few examples. The close collaboration between the Network and group of Health Economics of the Institute of Management of the Scuola Superiore Sant'Anna was delivering fruitful discussion between the main target groups of the rCTDs community (expert clinicians, patient's representatives, hospital managers, regional and national health authorities) of rCTDs community on important unmet needs: healthcare management and organisation of care in reference centre for RDs; the possible roles of the different stakeholders in the process of integration of the ERN in the national healthcare systems; the added value of a multistakeholder approach in the assessment of the economic and social impact of rCTDs in Europe; and in innovative tools for the assessment of the patients' perspective in living with RDs (23, 24).

ERN monitoring

The main aim of the monitoring of the ERNs is capturing the added value following the establishment of the ERNs in terms of improvement of care and treatment for patients with rare and complex diseases. For this purpose, the EC implemented a system for the monitoring and evaluation of the ERNs.

The measurement indicators applied in the monitoring of the ERNs are the 18 ERN indicators developed by the ERN Continuous Monitoring Working Group of the ERN Coordinators Group and the Board of Member States, in which the ERN ReCONNET Coordination Team actively participates as member. This set of indicators is linked with the objectives that each ERN might achieve, and it is common for all the ERNs. In addition, some Network best practices that have been taken into consideration in the finalisation of the ERNs Indicators document of the EC, such as the collection and the validation of KPIs related to the patients' involvement into the ERN governance and activities, to the peer-review publications, to the delivery of webinars, to the clinical trials and the observational clinical studies.

Since 2017, ERN ReCONNET has contributed to the data collection twice a year, with a considerable effort of both the ERN clinicians and ePAG Advocates, that provide the data related to the different indicators. Thanks to an ongoing improvement system and protocols, in 2021 the ERN ReCONNET has reached a 100% response rate to the ERN Monitoring data collection from the ERN ReCONNET Full Members, which is a landmark result, as it shows the commitment of the whole Network to this core activity for the ERNs.

ERN registries

Following the need of harmonising and ensuring data collection across the field of RDs, the European Commission launched a call to develop ERN registries. One of the registries funded was the one related to ERN ReCONNET, the European Registry Infrastructure for data harmonisation in rCTDs, TogethERN ReCONNET (24). The main objectives of TogethERN ReCONNET are to promote a harmonised data collection approach on rCTDs in EU by integrating and implementing existing rCTDs data and facilitating rCTDs research, post-authorisation studies and cost-effective healthcare planning.

TogethERN ReCONNET is supported by a consortium composed of the ERN Coordinating HCP (AOU Pisana), the Italian Institute of Health (National centre for RDs) and the Scuola Superiore Sant'Anna, that are collaborating to implement the infrastructure. One of the first initiative of the project was to establish a Working Group, composed of both expert clinicians and ePAG Advocate, that supported the identification existing rCTDs registries. A mixed methodology was adopted, and a scientific publication is ongoing to disseminate the results in the rCTDs community, beyond the development of specific data sets for rCTDs and the establishment of formal links with other existing rCTDs registries. Thanks to the creation of the TogethERN ReCONNET infrastructure, new rCTDs knowledge will be generated toward the improvement of the clinical management and care of rCTDs patients in the EU.

COVID-19

When the ERNs were launched, no one could imagine that we would find ourselves in the middle of a pandemic. However, the catastrophe occurred and all the RDs community had to fight against a new enemy. Indeed, the COVID-19 pandemic has led to increasing challenges for both patients and health care professionals managing rCTDs patients. The main challenges included limited access of patients to specialised health care with difficulties in early diagnosis and or routine follow-up, the risk of contracting severe SARS-CoV2-infections in this population, and the need for balancing the infectious risk under immunosuppressive treatment against the risk of uncontrolled disease activity (25-32).

In this scenario, the Network provided a perspective article aimed at assessing the effects of the health emergency on rCTD communities during the initial phase of the pandemic, bringing together input from multiple stakeholders within the ERN ReCONNET, representing patients, families, caregivers, expert clinicians, researchers and health economists (33). Organisational and health economic considerations related to rCTDs in the context of COVID-19 have also been explored, in order to build the basis for specific healthcare plans for rCTDs in the context of possible future health emergencies.

Notably, after the COVID-19 vaccination campaign started in Europe, other burning questions for rCTDs patients concerning its safety and effectiveness have risen. For this reason, ERN ReCONNET has promoted the organisation of a multicentre observational study aimed at gathering sufficient number of cases of rCTDs patients who have received COVID-19 vaccines (VACCINATE); the main objectives of the study are to promote a harmonised data collection approach on COVID-19 vaccination in patients with rCTDs, to evaluate the safety profile of COVID-19 vaccines and to highlight possible disease-specific adverse events. As an ERN for rCTDs, we strongly believe that it will help in better understanding both safety and efficacy of the vaccines in this population.

Moreover, the ERN ReCONNET organised two online workshops gathering patients' and clinicians' opinions to discuss the most critical challenges and to try to define a common approach related to the management of rCTDs during the COVID-19 pandemic. The first workshop was held in March 2021 and aimed at discussing treatment strategies for patients with rCTDs. However, the major points of the first workshop needed to be constantly updated given the new evidence and new challenges rapidly emerging in the ensuing months. Later, patients' representatives from Lupus Europe, an umbrella organisation bringing together national lupus patient organisations across Europe, have expressed the need to provide a common and shared expert opinion on vaccination strategies against COVID-19 in SLE patients. For this reason, a second workshop was held in June 2021, with the perspective that many principles related to SLE can also be applied to other rCTDs (34-38). In addition, ERN ReCONNET promoted the organisation of educational webinars on COVID-19 and rCTDs and has dedicated a page of the website to the main resources available on the topic. Among these resources, ERN ReCONNET has also endorsed the Filière de Santé des Maladies Autoimmunes et Auto-inflammatoires Rares (Fai2R) recommendations for treatment of patients with autoimmune or auto-inflammatory diseases and translated them into 16 languages, thanks to the commitment of the ePAG Advocates. The many challenges that the healthcare system experienced during the COVID-19 pandemic have highlighted, among other things, how essential it is to maintain continuity in the provision of care, especially for the management of rare diseases. On this regard, all the ERNs contributed to promote and good practices that can ensure the continuity of RDs care even also during health emergencies.

Conclusions

The management of RDs still represents a major challenge, supporting the creation of formal collaborative cross-border Networks in the field. In this scenario, the ERN ReCONNET infra-structure represents a major innovation in the field of rCTDs, bringing together patients, clinicians, and other crucial stakeholders to join forces and collaborate towards the improvement of the lives of people living with rCTDs. In the first five years, the Network has built a novel, powerful infrastructure, having the honour and the responsibility of improving the future of rCTDs care and management.

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