

# 4th European Reference Networks Hospital Managers Meeting

*Bridging the gaps and creating opportunities*

21 & 22 October 2021

## **Executive summary**

The 24 European Reference Networks (ERNs), launched in March 2017, are designed to connect European experts in rare and low prevalence complex diseases. Approximately 30 million European citizens are affected by rare and complex conditions. They face major challenges in diagnosis, treatment and care. ERNs use a bespoke IT platform (Clinical Management Support System – CPMS) to review patient cases and share expertise. Where possible, they ensure that information travels rather than the patient.

The ERN Hospital Managers' community includes CEOs or Directors of more than 300 hospitals across the EU. They play a key role in the healthcare system and their active engagement is crucial to the success of the networks. Hospital managers, along with ERN Coordinators, patients' representatives, representatives of the ERN Board of Member States and the European Commission, participated in a virtual event on 21 & 22 November 2021. The lively meeting featured presentations and debate, driven by plenary sessions and four parallel breakout sessions. Participants also took advantage of virtual networking opportunities during and after the meeting, which was streamed live online. The event was co-hosted by the European Commission and the Medical University of Gdansk, with the support of the European Observatory on Health Systems and Policies.

This is an important moment for ERNs as the networks prepare for a significant expansion in 2022, almost doubling the number of members (healthcare units) to around 1,500. The coming year will also see two reviews: one evaluating the Cross-Border Healthcare Directive which provided the legal basis for establishing the networks, and a more technical five-year review of the performance of ERNs and their members (due for completion in 2023). The initial five-year funding cycle will also come to an end in March 2022. The coming year will be a time of transition as ERNs should move to a simpler financing structure in 2023.

For ERN Coordinators, stable and sufficient funding is vital to the sustainability of the growing networks. There is also a strong desire for a reduced administrative burden and simpler IT platforms to facilitate virtual consultations. Integrating the networks into the new European Health Data Space will open new opportunities for patient management and for research. Further opportunities for ERNs may arise from the new EU4Health programme (2021-2027) which will support initiatives that can deliver EU added value. The integration of ERNs into national healthcare systems is a key priority for the future, and an area where hospital managers will play a significant role. A Joint Action is being developed to support this work and will be launched next year. Participants also addressed the need to develop clear pathways for young patients with rare diseases as they transition from paediatric to adult care.

While ERNs are a work in progress, the networks are viewed as an example of how European cooperation can add value for vulnerable citizens. Communicating this to stakeholders should be a priority for the next chapter of the ERN story.

## Introduction

An estimated 30 million people in Europe are affected by rare and low prevalence complex conditions. Patients and their families face major challenges in timely access to diagnosis, treatment and medical care. The 24 European Reference Networks (ERNs), launched in March 2017, are designed to connect European healthcare providers in rare and low prevalence diseases. By sharing expertise, the networks improve knowledge across Europe and enhance patient access to specialists. The ERNs use IT platforms and telemedicine tools to review patient cases, collaborate on the production of clinical guidelines, and create opportunities to deepen understanding of rare diseases through research.

Hospital managers play a vital role in the healthcare system and their active engagement with ERNs is crucial to the success of the networks. Together, they can ensure the efficient performance of ERNs, provide support and resources, and contribute to training and research activities. The ERN Hospital Managers' community includes CEOs or Directors of more than 300 hospitals. This group, along with ERN Coordinators, patients and representatives of the ERN Board of Member States, participated in a virtual event on 21 & 22 November. The lively meeting featured presentations and debate, driven by plenary sessions and four parallel breakout sessions. Participants also took advantage of virtual networking opportunities during and after the meeting, which was streamed live online. The event was co-hosted by the European Commission and the Medical University of Gdansk, with the support of the European Observatory on Health Systems and Policies.

**24 ERNs**

**>300 hospitals & 900 healthcare units in 2021**

**Significant expansion in 2022 to ~1,500 members**

Opening the meeting, **Tomasz Stefaniak**, Director of Gdansk University Hospital, said the shared goal of ERN members was to build bridges between specialties, between health professionals and between European hospitals. 'Sometimes the answer to your question can be found at another hospital in another country. That is why the ERNs were created,' he said. 'We are learning from each other, sharing good practices and discussing the most challenging patient cases. This can improve the quality of patient care and the experience of those working in our hospitals. As managers, we have a key role in making this happen.'

**Andrzej J. Rys**, Director for Health Systems medical products and innovation at the European Commission DG SANTE, said hospital managers are leaders with the potential to drive change. As ERNs approach the end of their first five years in operation and prepare for a significant expansion in membership, he said the event was an opportunity to rethink how to maximise the impact of the networks in health systems across the EU. 'Let's be innovative,' he said. 'Let's review our ideas and do more of what worked. But let's also look at what could be done better or faster.' Rys added that ERNs continue to break new ground, which comes with challenges as well as opportunities. The two-day meeting set out to illustrate how far ERNs have come and to explore the work required to build on what has been achieved to date.

## Plenary session

### ERN state of play and lessons learned

**After five years in operation, the 24 networks are preparing for expansion. At the same time, two evaluation exercises will help to review how the ERNs benefit people with rare diseases and healthcare systems.**

The ERNs are the fruit of years of collaboration that began long before the establishment of the networks in 2017. They were built on a clear legal and institutional framework and, together, stakeholders have developed a unique governance structure. The networks benefit from political support at EU and national level, and they are perceived as a good example of European cooperation. Since their launch, the ERNs have expanded their clinical work with patients through the Clinical Patient Management System (CPMS), published academic papers and guidelines, and initiated research collaborations and training.

New challenges lie ahead as the networks enter the next phase of development. The ERNs are on the cusp of the biggest expansion since their launch. In 2021, the networks included 846 full members and 251 associated centres. By early 2022, more than 600 new full members are expected to join the existing networks, bringing the total number to 1,500. This represents significant growth and indicates the attractiveness of the ERNs. It also comes with additional responsibility and complexity for network coordinators and hospital managers.

**Martin Dorazil**, Deputy Head of Unit, Digital Health and ERNs, at DG SANTE, outlined the tasks ahead, while highlighting two evaluation exercises that will take place in 2022, and opportunities arising from the EU4Health programme. ‘The challenge for coordinators will be consolidating the networks and integrating new members. The Commission will support the process by adapting the IT system used for virtual consultations,’ he explained. ‘Making ERNs an integral part of national health systems is also essential to their success.’ At the same time, ERN knowledge generation activities, such as the development of clinical practice guidelines, will continue while training and research activity expands.

#### Evaluation timeline

- Q1 2022: The Assessment, Monitoring, Evaluation and Quality Improvement System (AMEQUIS) project will be completed
- First half of 2022: A new Independent Assessment and Evaluation Body will be appointed
- Second half of 2022: ERN 5-year evaluation takes place
- 2023: Final evaluation reports on each network and each ERN member will be issued

As the ERNs approach the end of their first five years in operation, there will be two important opportunities to demonstrate the added value of the networks and focus on areas where there is room for improvement. The first evaluation exercise is part of a wider strategic review of the Cross-Border Health Directive. This is under way and will conclude in the first half of 2022. There will also be a more technical evaluation of the performance of ERNs and their members. This is a legal requirement after each five-year period and will conclude in 2023.

The coming years will also bring potential funding opportunities through the EU4Health programme which runs until 2027 and has an overall budget of more than €5 billion. It specifically mentions the ERNs, which are viewed as a success story, as one of the specific

objectives to be supported under the programme. The programme will award direct grants to the ERNs covering up to 100% of eligible costs, rather than requiring co-funding. ‘ERNs have had many important achievements in their first five years and will soon expand,’ said Dorazil. ‘Looking to 2022 and beyond, the goal is to turn these challenges into opportunities and bring benefits of ERNs to more patients.’

**Hélène Dollfus**, Chair of the ERN Coordinators Group and coordinator of ERN-EYE, said the networks had weathered a range of challenges over the first five years, including Brexit and the loss of UK-based members. Despite this, the ERNs have improved patient care, published multiple guidelines, built 30 registries, and boosted research on much-needed therapies. Along the way, coordinators have struggled with financial sustainability and the complexity of the CPMS while delivering healthcare during a global pandemic. Dollfus noted that the ERNs are diverse: some were built upon pre-existing professional societies and networks, while others were created from scratch. However, all ERN Coordinators share the common goal of improving patient care in Europe.

A new CPMS, currently in development, should help to make it easier to review patients virtually, she said, while the imminent expansion of the networks had the potential to improve the reach of ERNs in central and eastern Europe. Managing health data remains complex but the new European Health Data Space has potential to streamline this.

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*‘We must avoid any funding gaps in 2022’*  
*Helene Dollfus, ERN Coordinators Group*

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The big challenge for the future will be financing, Dollfus said, noting that the current funding cycle ends in March 2022. ‘Our major concern is how the budget will evolve to meet the missions we are asked to achieve,’ she said. ‘We need to ensure there is no funding gap for management teams as we transition to a new era.’ Dollfus said previous estimates for the costs of running an ERN ranged from €900,000 to €1 million per year, and this may rise as the networks enlarge.

**Till Voigtländer**, Chair of ERN Board of Member States, highlighted the novelty of ERNs and the value of reviewing progress in order to make improvements together. ‘The concept of ERNs has intrinsic challenges by nature,’ he said. ‘There is no template for us to follow. Instead, ERNs might one day serve as a model for other regions.’ There can also be conflict between the common vision set out at EU level and practicalities of implementing this in diverse healthcare systems.

Voigtländer said the size of the ERNs are a testament to their appeal. The Board of Member States initially expected each network to have 10 full members in eight countries. ‘We are now entering a totally different dimension with 1,500 members,’ he said. ‘This shows the system is highly attractive, despite the funding issues for participating healthcare professionals and hospitals.’ However, he acknowledged that rapid expansion would pose new operational challenges.

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*‘ERNs are still a work in progress’*  
*Till Voigtländer, Board of Member States*

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Looking ahead, Voigtländer said integration of the ERNs into national systems is a key issue. An EU Joint Action on ERN integration would be launched in 2022. One approach under discussion among Member States is to develop national reference networks that mirror the

ERNs. These could be connected by nodes linking national and European networks. In the meantime, a new CPMS, progress on the EHDS, and better communication between all actors in the ERN community would put the networks on a sustainable path. ‘ERNs are still a work in progress,’ he said. ‘Together we can ensure they reach their full potential.’

### **Key points**

- 2022 marks the beginning of a new chapter for ERNs
- A significant expansion is under way
- Two evaluation exercises (of the legal framework and of the performance of ERNs and their members) will take place and will provide an evidence base for further development of the ERN system
- A new CPMS is in development
- New funding opportunities will arise but 2022 will be a year of transition
- ERN Coordinators are concerned about sustainable funding
- Embedding ERNs in national health systems is a priority

## Breakout session

### Digitalisation and data management

Chaired by **Ioana Gligor** (Head of Unit, B3 Digital Health, European Reference Networks)

*A redesigned Clinical Patient Management System and integration into the new European Health Data Space bring opportunities, but data management challenges remain*

ERNs are well placed to benefit from the creation of a European Health Data Space (EHDS), which will support the use of health data for the provision of healthcare, empower citizens to access and control their own data, and support the reuse of health data by researchers, policymakers and industry. Investment in hospital IT systems and efforts to ensure interoperability of data are essential to securely moving patient records between healthcare facilities and across borders. **Ioana Gligor**, Head of Unit, Digital Health and ERNs at the European Commission DG SANTE, said the EHDS would build on existing legislation, including the General Data Protection Regulation and the Commission Recommendation on Electronic Health Record Exchange Format.

ERN registries provide a unique opportunity to collect information on rare and low prevalence diseases. In 2018, five ERNs were funded to develop patient registries, with the remaining 19 receiving support in 2019. The European Joint Programme on Rare Diseases (EJP-RD) has also provided funds to help ERN registries comply with the FAIR principles, making data Findable, Accessible, Interoperable and Reusable, explained **Franz Schaefer**, coordinator ERN ERKNet. 12,500 patients in 50 hospitals have been enrolled in ERKReg, the ERKNet registry, allowing monitoring and benchmarking which can benefit hospital managers.

Looking ahead, ERN registries can become a ‘use case’ for the new EHDS but must overcome challenges associated with dynamic informed consent and support for those who invest time in populating registries with data. In addition, the challenges of interoperability, data fragmentation and lack of standardisation remain, according to **Ana Rath**, Director of Orphanet. ‘If we don’t standardise data for rare diseases, we will never achieve a seamless data ecosystem,’ she said. ‘Coding, using ORPHA codes, will allow us to answer important questions on how many people are affected and whether the system meets their needs.’ A number of supports are available to help ERNs use this system, including guidelines and a helpdesk developed through the RD CODE project and train-the-trainers programmes created by the EJP-RD.

ERNs are designed to ensure that information travels, rather than the patient. This makes capturing, coding and using health data essential to patient care. Health data also holds opportunities for research to better understand rare diseases and to assess the impact of care. The Clinical Patient Management System (CPMS) – a secure, online environment that facilitates virtual consultation and expert collaboration – is central to the work of ERNs. However, some users find it complex, inflexible and time-consuming. A new CPMS is scheduled to launch in late 2023/early 2024. It aims to be more flexible and customisable at the

hospital level and will provide hospital managers the possibility to monitor the hospital participation in the work of the ERNs, allowing for more informed management decisions.

- **ERN registries could be a ‘use case’ for the new EHDS**
- **ORPHA Codes provide a multi-lingual, interoperable, computable and free way to standardise data on rare diseases**

## **Breakout session**

### **Research and development opportunities**

**Chaired by Holm Grässner (Managing Director ZSE Tübingen, ERN-RND Coordinator)**

*The ERNs have significant potential to drive research in rare diseases – a number of initiatives are available to support collaboration, including ERICA and EJP-RD*

Research is among the key objectives of ERNs. Not only are the networks directly engaged in reinforcing research by the creation of registries and training healthcare professionals, but they are tasked with exploiting innovation in medical science, pooling knowledge, and facilitating the mobility of experts. All of which contributes to the generation and sharing of information. In addition, the networks are well placed to join clinical trials on new therapies.

**Hélène le Borgne**, Policy and programme officer, European Commission, DG Research & Innovation, provided an overview of the role of ERNs in the rare disease research landscape. She showed that EU funding for collaborative research and innovation on rare diseases has increased steadily with each EU research programme: ‘It makes sense to support rare disease research as it has a high EU added value,’ she said. ‘The research programme budget, and the number of projects it supports on rare disease research, has only grown over the years.’ The past and current programmes, respectively Horizon 2020 and Horizon Europe (2021-2027), aims to reinforce the EU as an effective hub for rare disease research and innovation. After specific calls related to rare diseases under Horizon 2020 in 2015 and 2017 (but also many rare disease projects funded under more generic calls, such as on diagnostics or treatments), other opportunities are foreseen under Horizon Europe, for example with the first stage of a two-stage call for funding the development of new rare disease therapies, open until 1 February 2022.

In addition, the European Joint Programme co-fund on Rare Diseases (EJP-RD, 2019-2023) has a budget of more than €100 million – €55 million of which comes from the EU. It has four core pillars: 1) research funding; 2) coordinated access to data and services for research; 3) capacity building and empowerment; 4) accelerating translation of research and therapy development. Hospitals with ERNs from across Europe are well represented among the beneficiaries of this funding, but it also has to be noted that ERN members do not need to be official partners within EJP RD to benefit from EJP RD support, webinars etc. Further support for the clinical research activities of ERNs comes through ERICA – the European Rare disease research Coordination and support Action, launched in May 2021 for four years. ERN members were advised to subscribe to the newsletters of the EJP-RD and ERICA to learn more about the available supports, including training and webinars. **Andrzej Rys** of the European Commission



added that the forthcoming EU Clinical Trials Regulation, coming into force at the end of January 2022, would support multinational trials and could make ERNs attractive to sponsors.

The group discussed models that some hospitals have introduced to enable clinicians to balance clinical care with research. **John Kelly**, a hospital manager in Ireland said his organisation is trying to reduce the administrative workload for clinicians to make it easier to find funding, but doctors can still struggle to make time for research. The large Dublin hospital where Kelly works launched a research strategy just over one year ago. This established a research office to support doctors applying for funding and provides an online system for seeking research ethics approval. This structure streamlines administrative processes and reduces delays that can arise if paperwork is not completed correctly. However, while the hospital is reducing the administrative burden, conducting research remains a challenge. While some clinicians have university links which provide them with some time for academic work, many doctors have a heavy clinical workload which is prioritised.

**Arthur Wilde**, ERN GUARD-Heart, said his hospital in Amsterdam has found a way to allow clinician-scientists to spend more time on research. Most clinicians have at least one day per week ring-fenced for research-related activities. **Holm Grässner**, ERN-RND Coordinator and Director of the Rare Diseases Centre at the University Hospital Tübingen, added that this kind of support is crucial to the ‘research readiness’ of ERN hospitals.

- **EU research funding for rare diseases has grown steadily**
- **ERNs are well-placed to conduct clinical studies, but clinicians need administrative support and time to focus on research**

## Breakout session

### **Integration of ERNs into national systems and engagement of underrepresented countries**

**Chaired by Dimitra Pantelli (European Observatory on Health Systems and Policies)**

*Some Member States are host to several ERNs, which are embedded in their health system, while others have a long way to go in joining and integrating the networks*

Participation in ERNs varies across Europe, as does the degree to which the networks have become an integral part of healthcare structures. While several factors are at play, the most successful countries tend to be those that began working on rare diseases earliest. France is viewed as being a leader in the field, having published its first national plan for rare diseases in 2005 and it plays host to eight network coordinators. Indeed, France’s 23 national networks for rare diseases provided inspiration for the creation of the 24 ERNs. In France, the European networks link directly to reference centres hosted at French hospitals.

‘With more than 15 years’ experience of what works and what does not, France has developed a lot of knowhow,’ said **Ladislav Karsenty**, hospital manager and head of research at APHP Nord. ‘There is a strong advantage in having funded centres which have worked in this field for a long time.’ France has navigated challenges around how to build databases, structure

research, fund staff and connect healthcare centres in rare disease clusters. These clusters provide a platform for working with patients, hosting webinars and addressing issues such as the transition from paediatric to adult care. Karsenty said he hopes France's third rare diseases plan will further integrate the networks, improve access to information for hospital managers, and attract and keep skilled staff to drive data sharing.

Contributors from the Netherlands, Poland and Austria expressed a degree of envy for the level of funding available to networks in France, with one also noting that centralised healthcare systems confer some advantages. Most Member States are not as engaged in ERNs as France. **Birute Tumiene**, Vilnius University Hospital and a member of the ERN Board of Member States, explored the need to address this. She highlighted large differences in five-year survival rates across Europe for people with rare diseases. The ERNs should offer a way to close the gap. However, when the networks were established, representation from the EU13 (Member States that joined in 2004 or later) was 11% – despite accounting for 20% of EU inhabitants. Participation rose to 20% after the second wave. 'Even after the third wave there may still be some gaps,' said Tumiene. 'We must take care not to increase inequity.'

It was noted that affiliate membership could be a good first step for centres in underrepresented countries, while the potential of ERNs to reduce waste could appeal to hospital managers in Member States where engagement is limited. It was also suggested that there is an increased willingness at European level to work on healthcare issues such as cancer or COVID-19 and that this may strengthen support for the networks across the board.

- **Best practices from countries such as France could be further exchanged as they can provide examples of models for connecting European networks and national reference centres**
- **ERNs can address outcome disparity between patients across the EU, but greater inclusion of under-represented countries is essential**

## **Breakout session**

### **Care continuity: transition from childhood to adulthood**

**Chaired by Ruben Diaz Naderi (Deputy CEO for International Affairs, Hospital Sant Joan de Déu, Barcelona)**

*Health systems usually require patients to transfer from paediatric to adult services when they reach 18 years of age, presenting medical and psychological challenges*

Adolescents undergo a range of physical and psychological changes which can mark a period of personal growth, emotional development and increased autonomy. For young patients, these changes may occur in parallel with a major transition in how and where they receive care. For these vulnerable patients, moving from paediatric services to adult care can mean losing contact with a familiar team of professionals and having to take a more proactive role in managing their own care.

In people with rare diseases, the risks are even higher than in the general patient population, as they may struggle to access the right combination of expertise, according to **Susanne Greber-Platzer**, General Hospital Vienna. Paediatricians, psychologists and others can work with patients to understand their needs and concerns well in advance of adulthood. ‘Transition should begin around puberty,’ she said. ‘It is important that the process is structured and standardised.’ Members of the European University Hospital Alliance (EUHA) are working to develop minimal requirements for managing transition, which could help to standardise the process for people with rare diseases across Europe.

**Rubén Díaz**, Sant Joan de Déu Hospital, Barcelona, said involving patients and their families in managing this shift can help to reduce the risks associated with transition. In Barcelona, a Transition Area has been created to ensure a standardised approach to care is taken across the hospital. ‘We aim to promote a culture of transition in the whole hospital and with adult hospitals to ensure continuity of care,’ he said. The change is managed by a case manager who coordinates education and training, a psychological plan, transfer to an adult centre and subsequent evaluation of the plan. Since 2019, the hospital has worked with 37 adult hospitals to transition almost 1,900 patients.

**Andrea Limbourg**, L'hôpital universitaire Robert-Debré in Paris, said her hospital formed a working group in 2016 and, with the support of a grant, constructed a small unit outside the children’s hospital. Funding for staff allowed the group to create a website with information and resources about transition for patients, parents and healthcare professionals. A key element of the work involves a Transition Preparation Consultation which assesses the patients’ readiness for moving to adult care. This, along with ‘transition days’ and other awareness-raising outreach efforts, help to introduce patients to the issues they may encounter as they change healthcare providers.

The discussion, which included input from patient representatives, concluded that patient input is essential to successful transition and that tailored approaches are needed to cater to the unique needs of each individual.

- **Several hospitals have set up structures for transitioning patients; the process should be standardised but personalised**
- **An ERN Transition Working Group could help tackle this relevant issue and ensure care continuity for people with rare and complex conditions**

## Plenary session

### Long-term vision of the ERN system

*The networks inspire unprecedented enthusiasm for tackling rare diseases. Building trust, supporting coordinators, managing data, and measuring outcomes will shape their future*

The ERNs have laid a foundation on which to construct a new model of European cooperation in the field of rare diseases. The networks themselves are an innovation: a novel system designed to tackle a problem which stakeholders agree is too complex to solve alone. As the networks mature and grow, they will operate in an environment different to the one in which

they were created. New funding opportunities are coming into view, political support for European cooperation on health has never been stronger, and a new era for capturing and using health data is on the horizon. However, the networks are imperfect, and the journey is far from over.

This session looked ahead to the long-term future of the ERNs and how to get there. It began with a review of the networks' achievements and challenges to date, before discussing priorities for the years ahead. **Dimitra Panteli** of the European Observatory on Health Systems and Policies presented insights from a scoping study based on a rapid literature review and interviews with ERN stakeholders. Participants cited the creation of clinical guidelines, educational activities, improved care pathways, research collaboration and knowledge pooling among the networks' key achievements.

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*'To make the business case, we need outcome measures'*  
*Dimitra Panteli*

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Coordination issues and the heavy administrative burden on network coordinators were among the top concerns raised by interviewees. It was noted that not all members actively contribute to the network – with some respondents suggesting eliminating inactive members – and that the issue of regional imbalances remains. A key challenge for the future will be to better understand the precise costs of ERNs as well as improving visibility of outcomes. 'A clear costing model of ERN activity is necessary,' Panteli said. 'To make the business case for the networks, we need to determine outcomes and how they should be measured.'

Choosing outcome measures, and deciding how and where to measure them, is far from simple. Criteria could include clinical outcomes and patient

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*'In rare disease care, it's cheap to do it well'*  
*Jean Yves Blay*

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satisfaction; the production of guidelines and publications; public advocacy and professional educational activity – or some combination of these. 'I would add research,' said Jean Yves Blay, a hospital manager based in France. 'In collaboration with partners, there are now rare disease registries and clinical trials under way which would not have happened without ERNs.' He said ERNs have the potential to spread more efficient patient pathways which provide value to hospitals and reduce mortality. 'In France, as in the Nordic countries and the UK, we've demonstrated that it's cheap to do it well. This is a measure we should go for.'

### **COVID response illustrates resilience and flexibility**

The ERNs are powered by experts and their teams working in healthcare delivery. The global COVID-19 pandemic caused disruption across the board, affecting how and where care was delivered, as well as pausing research projects and educational initiatives. For many ERN participants, the crisis absorbed time, energy and resources as they strived to deliver safe and continuous care to their patients.

However, Josep Figueras, Director of the European Observatory on Health Systems and Policies, noted that the pandemic also revealed health systems to be highly adaptable. New payment systems were adopted to allow for innovation, care pathways were reinvented, staff

were redeployed, and digital health tools were suddenly commonplace. ‘In France, there was a 100-fold increase in the use of telemedicine,’ Figueras said. ‘The technology was already there but had not been widely used. Then the incentives were put in place, and it was adopted within weeks.’ This experience, he added, holds important lessons on what is possible in healthcare with the right combination of political will, financial incentives, and a culture to adopt innovative solutions.

### **Future Priorities for ERNs**

To spark discussion among meeting participants, Josep Figueras, European Observatory on Health Systems and Policies, set out a range of potential priorities for the future of the networks. These included:

- Strengthen collaboration on individual patient cases
- Expand ERN scope into (other) high complexity areas
- Increase research collaboration: networks, funding applications
- Share evidence on new treatments & procedures (joint Health Technology Assessment)
- Strengthen guideline development
- Scale up integration in national health systems.

An interactive poll showed strong support for enhancing the networks’ focus on collaborative research, with similar levels of backing for stepping up efforts to embed ERNs in national health systems. Developing joint approaches to HTA, expanding training, and increasing the scope also attracted some support. Strengthening guideline development was further down the ranking, which may reflect the existing high levels of activity in this area.

The discussion added further topics, including working with payers on cross-border care and the use of data. Essential to all of the above will be improving trust in the system and mutual trust among ERN members. Other contributors stressed the need to consolidate the existing work of the networks and secure appropriate budgets before pursuing new goals and responsibilities.

### **Plenary session**

#### **Future collaboration of ERN hospital managers**

*It is widely agreed that hospital leadership is key to the success of the networks – how can busy managers collaborate in the next phase of ERN development?*

The future priorities discussed during the meeting have one thing in common: they will all require the support of hospital managers. From the integration of ERNs into national health systems to new research and education collaborations, network coordinators and participants

will need buy-in from their directors and CEOs. The final plenary session focused on how best to involve hospital managers in shaping the future of the networks, and on how these key players can come together to share experiences and troubleshoot common problems.

**Tomasz Stefaniak**, Director of Gdansk University Hospital, said hospital managers should try to improve their communication but may need a forum where they can freely connect about topics of interest. ‘We need to get to know one another better, to share good practices, and learn how others have dealt with personnel issues, remuneration, and developing quality indicators,’ he said, adding that hospitals should embrace transparency on treatment outcomes in order to drive improvements.

There were diverse views on what form any new collaborative structure might take. A dedicated ERN working group for hospital managers could provide a forum for addressing a range of issues; some proposed topic-specific working groups on areas of common interest; while others suggested adding managers to existing groups to ensure their views are heard.

The earlier suggestion of a dedicated ERN Working Group on Transition was highlighted by **Rubén Díaz**, Sant Joan de Déu Hospital, Barcelona, as an example of where hospital managers could have a focused discussion. **Inés Hernández**, EURORDIS, welcomed this proposal as a useful way to connect managers, clinicians, Member States and patient advocates. Contributors from France and Spain added that hospital managers can also benefit from interacting with patients at local level on areas including transition and research.

Existing networks, such as the ECHO – an organisation of European Children’s Hospitals – and the European University Hospital Alliance (EUHA) may also offer ways for managers to connect on issues relevant to rare diseases. As hospital managers have limited time, further discussion would be needed to develop an efficient and practical way forward.

Healthcare professionals could also avail of the opportunity to visit their counterparts at other ERN centres. This would provide opportunities for short, practical exchanges on issues around digitalisation and staffing. Site visits could provide intensive learning experiences, but virtual meetings also have potential, according to participants. Commission officials expressed a willingness to provide support if managers need specific logistical help or new tools that would facilitate efficient communication.

- **Hospital managers may be invited to play a more active role in existing ERN Working Groups that address relevant areas**
- **A dedicated forum for interaction could be supported if there was demand from the hospital management community**

## Conclusion

The meeting closed with a reminder that 2022 will be a year of transition for the 24 ERNs. They will grow, new digital tools will be developed, and funding sources will change. By streamlining funding into a single instrument in 2023, the Commission aims to make the system simpler and more sustainable for ERN Coordinators. A bridging grant for coordinators may be required to cover this transition period.

In the meantime, efforts to integrate the networks into national systems will continue, with support from a new Joint Action. Here, hospital managers have an important role to play. Communication between managers – and between managers and other stakeholders – will be crucial to delivering on this key goal. The involvement of patients and patient representatives in this work remains a valuable component of the networks. After all, the ERNs exist to serve the millions of patients in Europe living with rare and complex conditions.

‘We started from zero five years ago,’ said **Martin Dorazil**, European Commission. ‘Now we have a platform which offers hospitals a real opportunity to improve care and participate in research across Europe.’ The networks will now write a new chapter in their story – a story inspired by the need to *share, care, cure*.