

# BACKGROUNDER TO THE PARALLEL SESSION ON PATIENT-CLINICIAN PARTNERSHIP. 22 NOV 2018, 4<sup>TH</sup> ERN CONFERENCE, BRUSSELS

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*This document has been prepared by the leaders of the parallel session, Dr. Guillaume Jondeau (VASCERN ERN Coordinator) and Inés Hernando/EURORDIS for the sole purpose of contextualizing the panel discussion.*

*This document largely draws on the ERN Patient Involvement Guide developed by EURORDIS/ Matt Bolz-Johnson on Nov 2017 and on EURORDIS experience of supporting patient advocates who are involved in the 24 European Patient Groups (ePAG patient advocates). The examples included on Annex II have been provided by some of the ERN Coordinators and ePAG patient advocates. This document represents the view of EURORDIS but not of the other patients organisations that are currently involved in the ERNs system.*

Disclaimer: This paper should be solely regarded as a basis for discussion representing the positions of its authors and cannot in any circumstances be regarded as the official position of the Commission and its services

## 1. Background

European Reference Networks (ERNs) have been established on the founding principle of patient empowerment, participation and patient-centricity, to improve access, safety and quality of diagnosis, care and treatment for people living with a rare or complex condition, or who require highly specialist interventions that call for the centralisation of cases, expertise and resources<sup>1</sup>. Membership of the 24 ERNs is diverse, drawing together clinicians, and researchers from 900 expert centres, and patients, connecting 300 hospitals in 26 Member States, and currently including over 300 patient advocates from across the European Union. These patient representatives are active in the ERNs decision and opinion-making structures.

EURORDIS, in collaboration with the European rare disease community, has established 24 European Patient Advocacy Groups (ePAGs)<sup>2</sup> corresponding to the 24 ERNs as forums to optimise the involvement of patient and ensure completeness, unity, solidarity and equity of representation of the rare disease patient community in the 24 ERNs.

Patient representatives and organisations are recognized as integral to the strategic and operational delivery of European Reference Networks in rare diseases (RD ERN) and play an active role in the Networks decision-making structures<sup>3</sup>, together with the other stakeholders involved – notably, healthcare professionals and researchers. This is why the success of ERNs will depend, among other factors, on the ability of healthcare professionals and patients to build successful collaborative partnerships.

Patients participation may enhance the capacity of ERNs to improve health outcomes through better representation of their needs in the Networks' discussions and activities and also at national level. Patient advocates involved in the Networks can contribute to co-build ERNs by conveying the patient community perspective and needs, based on their expertise and experience of living with a rare disease.

The early collaboration between the clinicians/researchers and the patient community involved in the development and implementation of the 24 ERNs, clearly demonstrates the Networks' commitment to ensuring meaningful patient involvement. Network Coordinators recognise the critical role that patients play in the structure and decision-making processes of ERNs, as representatives of the rare disease patient community and as experts by experience and co-producers of knowledge.

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<sup>1</sup> European Commission ERN Delegated Decision, Network Criteria and Conditions, Annex 1(2b) (2014/286/EU)

<sup>2</sup> European Patient Advocacy Groups are patient forums specific to each European Reference Network, established by EURORDIS to optimise patient involvement in the ERNs' decisions and activities. They are integrated by ePAG Patient Advocates who are active in the ERN governance structure including its working groups.

Rare disease Patient Organisations, EURORDIS members and non-members established in Europe, may designate ePAG Patient Advocates. Patient were initially appointed through an election process and later co-opted. They need to be officially endorsed by one or more Patient Organisation and/or a European Federation; be experienced in living with the rare disease included under the scope of the ERN or hold relevant expertise corresponds to the scope of the ERN Transversal Working Groups; agree to meet the criteria and conditions for ePAG Patient Advocates outlined in the [ePAG Constitution](#); agree to adhere to the set of core values adopted in the [ePAG Constitution](#) and able to speak fluent English (spoken and written).

<sup>3</sup> European Union Committee of Experts for Rare Diseases Addendum: Rare Disease European Reference Networks (2015)

Patients have a wealth of experience that can be drawn in the operational delivery of the ERNs. Having a common understanding of their role in the ERNs, will enable patients, clinicians and researchers, to share expectations of their contribution into the ERN discussions, and in turn will optimise their involvement.

To frame the discussion of the parallel session on patient-clinician partnership that will take place in the framework of the 4<sup>th</sup> ERN Conference, this document describes the role of ePAG patient advocates in the ERNs. It provides some suggestions on how to best engage with patients and identifies some challenges for patient-clinician partnership in ERNs and remedial actions. Annex I provides a list of specific examples of activities where patients can be involved and Annex II illustrates with real examples how patients and clinicians are working together.

## 2. ePAG Patient Advocates Role in ERNs

The role of ePAG patient advocates in ERNs is pivotal in representing the voice of the wider patient community in Networks' discussions and activities and, therefore, conveying the community collective experience of living with a rare disease directly into the ERNs Board and working groups discussions and decisions.

ePAG patient advocates represent the voice of patients within ERNs to ensure that the needs of people living with a rare disease are well understood and included in the strategic and operational delivery of the Networks. They create a bridge between the ERN and the patient community, contributing to the development of ERN services so that they respond to the needs and expectations of rare disease patients and therefore improve access to high quality diagnosis, care and treatment.

Patients have a **dual role** to play in providing the patient perspective in ERNs.

### 1. At a global and strategic level, ensuring in partnership with ERNs clinicians and researchers:

- that the strategic and operational discussions are patient-centred, including for example the prioritisation and development of research and educational activities;
- the transparency of decisions and outcomes;
- the ethics, quality and safety assurance of patient care and research;
- a two-way communication between the ERN governance and the patient community;
- the sustainability of ERNs, helping to identify financial mechanisms and new sources of funding;
- good awareness of ERNs activities and dissemination of the scientific knowledge generated by the Networks through patient networks and organisations.

### 2. At a micro level, providing the patient perspective into disease-specific working groups, specifically to:

- inform the work of the ERNs by bringing the needs and experience of people living with a specific rare disease to the Board, committees and working groups;
- prioritise, develop and disseminate clinical guidelines and healthcare pathways, scientific research, patient information and educational activities;
- provide specific advice on ethical issues, balancing patient and clinical needs appropriately;
- ensure transparency in quality of care, safety standards, clinical outcomes and treatment options in the different activities.

To do this successfully they need to be actively involved in executive and clinical discussions and debates, and may need support to understand and interpret technical, scientific, legal and medical terminology and concepts.

ePAG patient advocates hold a privileged position in ERNs and have a valuable contribution to make in the strategic development and operational delivery of these networks. The value that patients can bring to ERNs stems from their unique position as a stakeholder:

1. Patients hold the **unique knowledge or personal experience of a specific disease**, and have the potential to convey the needs and challenges of living with this disease into network discussions, decisions and activities.
2. They **have a stake in every stage of the research and healthcare pathways** and as such **are in well position to have a holistic view of the whole process** – from diagnosis, care and treatment, from early research through to orphan drug authorisation.
3. Patients should be encouraged to participate in discussions, as they often have very **relevant questions that should be answered to allow a holistic and comprehensive** understanding of the issues.
4. Patients can bring **their own professional expertise, skills and knowledge** outside the medical/research field (legal, IT, training, communication, etc.) that can enrich network discussions and offer a new or alternative perspective.

### 3. Fostering Active Patient Participation – tips for clinicians

Patients are not scientific or medical experts and may be overwhelmed or intimidated being the only patient within of a large committee of experts, professors and/or scientists, especially in technical or scientific debates.

Before discussing some suggestions to foster patient participation in ERNs, it is useful to remember that ePAG patient advocates involved in ERNs should bring the voice of the wider European patient community. This means that their role is quite distinct from the one that they play when they are partners in their own/ family member's care. While patient advocates are experts on their condition and will draw on this knowledge to contribute to ERNs discussions – notably when contributing to the disease specific subnetworks -, they will need to:

- Learn to work and engage with the wider patient community to legitimate their advocacy activities and ensure that ERNs remain responsive to the patient community's collective needs.
- Understand how to put their experience into perspective and create their own authority and legitimacy when representing a wider community, which is not based on their knowledge and experience of living with a rare disease

In summary, ePAG patient advocates need to unlock and focus their experiential knowledge to maximise the impact of their voice and messages, and not let their passion and personal experience be the barrier to the patient voice being heard. To address this training need, EURORDIS will develop a leadership training programme that will help them to develop these skills.

The following tips on how to involve patients can be helpful to consider:

- Include patients in all meetings<sup>4</sup> and ensure the aim and scope of the meeting is clearly understood by everyone.
- Take a partnership approach, decide together how can patients contribute and help, rather than identifying unilaterally a set of tasks for patients.
- Develop terms of references for all Network Boards, Committees and Working Groups and ensure that they are discussed and understood by everyone.
- Explain the key topics or functions outlined in the terms and explore possible areas for ePAG patient advocates to contribute prior to the meeting.
- All stakeholders should be open and actively invite patients to contribute before, during and after the meeting. This can be direct verbal feedback or informally via email.
- Minimise technical jargon and abbreviations. Explain terminology when required. Even if patients cannot understand everything, getting their perspective at all stages is important and will facilitate the understanding and buy in of the wider patient community.
- Provide the opportunity for patients to give evidence and testimony that can inform the Network's developments.

## 4. Challenges for patient-clinician partnership and remedial actions

Challenge	Actions
Ability to speak and work in English	<ul style="list-style-type: none"> <li>• Added as a requirement for ePAGs patient advocates in the <a href="#">ePAG Constitution and Rules of Procedure</a></li> </ul>
Develop the soft skills required to be effective and heard as an equal partner within ERNs and be able to successfully share their unique knowledge and personal experience of living with a rare disease in Network's discussions, decisions and activities (communication, presentation, leadership skills etc.)	<ul style="list-style-type: none"> <li>• Training for patients (provided by EURORDIS, ERNs or others)</li> </ul>
Understand the ePAG patient advocate role as: a) representatives of their own disease community, when sitting in disease specific groups, b) representatives of the wider patient community when sitting in the Board or transversal-topic groups (as opposed to being partners in their own care or the care of a family member)	<ul style="list-style-type: none"> <li>• Training for patients (provided by EURORDIS, ERNs or others)</li> </ul>
Need to learn how to build on their experiential and general knowledge to contribute to the ERN	<ul style="list-style-type: none"> <li>• Training for patients (provided by EURORDIS, ERNs or others)</li> </ul>

<sup>4</sup> Where they are eligible to participate according to the applicable law or Code of Conduct governing the meeting

Challenge	Actions
work (clinicians bring the medical knowledge and experience, patients their experiential knowledge and expertise on different areas)	
To improve the understanding of the technical aspects relevant to ERNs activities (clinical guidelines, registries, outcomes measurement, research)	<ul style="list-style-type: none"> <li>• Training for patients (provided by EURORDIS, ERNs or others)</li> </ul>
Limited time available (affects both patients and clinicians).	<ul style="list-style-type: none"> <li>• Recruit more patients who can be actively involved in the different working groups and activities</li> <li>• Clinicians to get support from their Hospital management teams</li> </ul>
Limited involvement of patients (only involved in certain activities) or involvement limited to low value activities	<ul style="list-style-type: none"> <li>• Exchange of good practices on patient-clinician partnership in ERNs to raise awareness of the value that patients can bring in the different activities</li> <li>• Training for patients and clinicians to provide them with a new set of skills and tools to make real collaboration and partnership with patients become possible</li> <li>• Measure patient involvement and its impact</li> </ul>
Limited resources available within ERNs to remunerate patients for their work	<ul style="list-style-type: none"> <li>• Explore alternative sources of funding to complement the European Commission Grant</li> </ul>

## Annex I: Practical guidance on where to involve patients in ERNs activities

Patients should be involved and participate in all ERNs' activities in the same way as clinicians and researchers, as full members of ERNs Boards and working groups. The table below provides a non-exhaustive list of potential ways to involve patients so that ERNs can fully benefit from their experiential knowledge across different areas of activity.

Area of Activity	Examples of Patient Involvement
Implementation of ERNs	<ul style="list-style-type: none"> <li>Contribute to inform the expansion of ERNs in terms of scope and coverage by contributing to identify the expertise and geographic gaps through their experience and networks</li> </ul>
Communication	<ul style="list-style-type: none"> <li>Develop and provide access to information adapted to the specific needs of patients</li> <li>Establish mechanisms to hear from and incorporate the voice and opinion of patients and families</li> <li>Disseminate, raise awareness and share information with the wider patient community, through the relevant channels</li> </ul>
Research	<ul style="list-style-type: none"> <li>Contribute to setting of research priorities</li> <li>Help to draft consent forms and other information materials</li> <li>Contribute to the development of clinical trials protocols (translate in non-medical language the protocol, the information forms, informed consent, etc.)</li> <li>Contribute to identify and select health and quality of life outcomes</li> <li>Identify and help to address the practical difficulties associated with recruitment of patients in clinical trials</li> <li>Increase recruitment to clinical trials and studies</li> <li>Disseminate research project information and results</li> </ul>
Knowledge Generation & Dissemination	<ul style="list-style-type: none"> <li>Share experience, exchange knowledge and best practice and expertise within ERN, between ERNs and the wider patient community</li> <li>Discuss new treatments, therapies, and healthcare technologies. Review and disseminate expertise, best practice and evidence</li> </ul>
Training & Education	<ul style="list-style-type: none"> <li>Identify gaps on therapeutic patient education resources</li> <li>Contribute to disseminate quality guidance on life style and diet as well as other relevant information materials</li> <li>Provide education and training to other patients</li> </ul>
Care and clinical guidelines	<ul style="list-style-type: none"> <li>Help to develop patient pathway based on patient needs, work with appropriate bodies to implement these and evaluate their practical implementation of the pathway</li> <li>Ensure clinical guidelines relevance (help prioritising and suggesting areas in which guidelines should be developed)</li> <li>Contribute to the literature review and play a full part in expert consensus groups making recommendations.</li> <li>Writing plain-language guideline versions</li> <li>Identify important populations and outcomes for guidelines development</li> </ul>

	<ul style="list-style-type: none"> <li>• Assess how guidelines recommendations interact with patient values and assess how guideline recommendations reflect patient values</li> <li>• Disseminate guidelines through networks and organisations</li> <li>• Improve the safety and quality of care based on patients' experience</li> <li>• Enable reporting possible safety incidents or adverse events</li> <li>• Contribute to develop standards of care</li> <li>• Inform the development of clinical governance standards for the virtual consultations conducted through the CPMS</li> <li>• Disseminate information on patient safety standards and safety measures</li> </ul>
Monitoring and assessment	<ul style="list-style-type: none"> <li>• Develop a standardised common patient experience tool</li> <li>• Provide their input in the development and use of PROMs and PREMs</li> </ul>



## Annex II: Examples of patient-clinician partnership in ERNs

<b>Endo-ERN</b>	<ul style="list-style-type: none"> <li>• The eight ERN's main thematic groups are jointly chaired by three chairs: an adult endocrinologist, a paediatric endocrinologist and an ePAG patient advocate. The governance of the five work packages (WP) is also structured in the same way. This ensures active patient's involvement in any strategic decision and action.</li> <li>• Patient representatives are explicitly involved in the ENDO-ERN register project EuRRECa – through a specific work package (patients, parents &amp; ethics WP). Specific deliverables of this work package include the following reports: report on the needs of patients in registries; report on the patients' perspectives regarding the use of the Patient Reported Outcomes tool; and report on the patients perspectives regarding the use of a core endocrine registry for assessing generic and condition-specific Patient Centred Outcome Measures.</li> </ul>
<b>ERKNet</b>	<ul style="list-style-type: none"> <li>• Patients have developed together Patient Healthcare Pathways to complement the clinical guidelines, that are pathology or treatment oriented, by underlining the grey areas along the life of a patient with Chronical Kidney Disease. These grey areas are typically not well addressed in Clinical Guidelines. Clinical Guidelines are usually focused on a specific renal pathology or on one type of renal pathology and are effective once the diagnosis is firmly pronounced. While Clinical Guidelines define the WHAT, Patient Healthcare Pathways focus on the HOW, providing recommendations from a patient perspective.</li> </ul>
<b>ERN BOND</b>	<ul style="list-style-type: none"> <li>• Patients and clinicians have drafted together the White Book on Diagnosis of Osteogenesis Imperfecta that provides an overview of the current situation relating to diagnosing OI in the 10 Member States represented within the ERN</li> </ul>
<b>ERN EpiCARE</b>	<ul style="list-style-type: none"> <li>• Patients and clinicians have worked together on the definition of requirements and 'purpose' of the ERN registry, inclusion of the full common data set as proposed by the European Commission Joint Research Centre to facilitate future interoperability across ERN registries and exploring future opportunities for integration or expansion including collaboration with existing patient registries.</li> <li>• Information on the Ketogenic Diet has been developed jointly by patients and clinicians</li> </ul>
<b>ERN EURACAN</b>	<ul style="list-style-type: none"> <li>• EURACAN is structured in 10 domains, representing 10 rare adult cancers, and 7 Transversal Task forces linked to the working packages defined within EURACAN.</li> <li>• Two ePAG patient advocates lead the Transversal Task Force on Communication/Interaction with ePAGs and the Dissemination Task force. They are as such responsible for the development of the ERN's leaflets, website, newsletters, social media channels, translation of the website and Clinical Practice Guidelines. They participate to the Steering Committee meetings with the same voting rights as other participants.</li> <li>• There is an ePAG patient advocate involved in each of the 10 domains. Patients and clinicians collaborate especially on the development of</li> </ul>

	<p>booklets dedicated to a given pathology and on patient healthcare pathways.</p> <ul style="list-style-type: none"> <li>• Each ePAG patient advocate may get involved in at least 2 of the 7 Transversal Task Forces on a voluntary basis.</li> </ul>
<b>ERN EuroBloodNet</b>	<ul style="list-style-type: none"> <li>• All the ePAG patient advocates are included in the whole governance as members of: a) Board of Network (BoN) and Strategic and Scientific Board (SSB). Each of the five Transversal Field Actions (cross-border health, good clinical practice, continue medical education, telemedicine, clinical trials and research) is coordinated by two clinicians and one ePAG patient advocate. This common work has produced, up to now, a number of surveys amongst the members in order to map health and care services provided, ongoing Clinical Trials and Clinical Guidelines available.</li> </ul>
<b>ERN eUROGEN</b>	<ul style="list-style-type: none"> <li>• After extensive discussions, patients and clinicians agreed to include Interstitial Cystitis (IC) within the scope of eUROGEN as one of the disease areas.</li> <li>• Patients and clinicians have worked together to identify appropriate outcome measures for the disease areas included in eUROGEN. This is particularly relevant in a sensitive area like urogenital diseases, where the impact on the quality of life of the patients concerned can be devastating.</li> <li>• In 2019, patients and clinicians will work together to draft a report on transitional and continuity of care from childhood into adulthood.</li> </ul>
<b>ERN EURO-NMD</b>	<ul style="list-style-type: none"> <li>• All the Patient Advisory Board members are also members of the Network Board. Patient representatives are part of all the working groups. The Ethic Working Group is chaired by a patient and the Education Working Group is co-chaired by a clinician and a patient.</li> <li>• Patients and clinicians involved in the Education Working Group have developed and conducted a survey across all HCPs and patient organisations involved in the ERN to map the education and training gaps for rare NMDs.</li> </ul>
<b>ERN EYE</b>	<ul style="list-style-type: none"> <li>• Patient- clinician partnership was initiated since the very beginning of the ERN-EYE (there has been a very close collaboration with Retina International from the beginning), patient representatives actively participated in developing the application and have now a very active role during the implementation stage. They are active members of the Coordinating Committee, the ERN Board and are involved in the Working Groups.</li> <li>• Patients and clinicians worked together to review the ontology and Orphanet coding for the diseases covered by the ERN. They revisited the existing rare eye diseases ontologies/coding with ORPHANET and HPO, as a cornerstone for future sharing of data.</li> <li>• Surveys conducted by ePAG patient advocates are presented in ERN-EYE meetings and often integrated in the whole network discussion and further actions.</li> </ul>
<b>ERN GENTURIS</b>	<ul style="list-style-type: none"> <li>• ePAG patient advocates are included in the 5 ERN Task Forces, as well as in the General Board, setting the strategic priorities of the network and the operational delivery of the network.</li> <li>• Patients are currently developing patient journeys, identifying the needs of patients to inform the development of all the network activities, specifically patient pathway and clinical guideline development.</li> </ul>

	<ul style="list-style-type: none"> <li>• One of the ePAG patient advocates has co-authored a paper on ERN GENTURIS that is currently in press in the journal Familial Cancer.</li> </ul>
<b>ERN GUARD-HEART</b>	<ul style="list-style-type: none"> <li>• Patient representatives from the Patient Advocacy Board and clinicians in the ERN GUARD-Heart have worked together to organize patient educational meetings and to produce standard patient information folders for rare cardiac diseases covered by the ERN GUARD-Heart.</li> <li>• Patients and clinicians are collaborating to develop a mobile app to facilitate the inclusion of patients in clinical trials and patient registries. The main goal of the app is to build a bridge between patients and science and to promote the participation of more empowered patients in scientific research.</li> </ul>
<b>ERNICA</b>	<ul style="list-style-type: none"> <li>• Patients and clinicians are working together on the development of standards of care. Currently there are three patient advocates and four clinicians from different countries working on the standards of care for Oesophageal Atresia and the work is being led and managed by one of the patient advocates.</li> </ul>
<b>ERN ITHACA</b>	<ul style="list-style-type: none"> <li>• Patients and clinicians have identified existing educational resources and the most useful ones have been uploaded to the ERN Collaborative Platform. As a result of this mapping exercise, four e-learning modules have been prioritised for development this year.</li> <li>• Patients and clinicians involved in the expert patient care work package has developed a directory of existing Clinical Practice Guidelines. There are also two new expert patient care pathway documents in progress for Noonan syndrome and Fetal Valproate Syndrome.</li> </ul>
<b>ERN ReCONNET</b>	<ul style="list-style-type: none"> <li>• Patients and clinicians have co-designed a survey to map the knowledge and awareness of CPGs among rare and complex connective tissue diseases (rCTDs). Patients have participated in the design process and also in submitting the survey to the patients organisations.</li> <li>• Currently patients and clinicians are working on a publication that will have an entire section dedicated to the unmet needs of patients. This section will be entirely written by patient advocates, with the support from the ERN methodologists, and will reflect the point of view of the European community of rCTDs patients.</li> </ul>
<b>ERN-RND</b>	<ul style="list-style-type: none"> <li>• The Ataxia disease specific network in ERN-RND, agreed to develop ERN ataxia clinical guidelines based on the UK Ataxia Guidelines that would be reviewed and adapted. A clinician, working in a UK healthcare provider, and two patients were set to kick-start the work this year. This activity now risks to be delayed due to the BREXIT negotiations and the uncertainty about the status of UK healthcare providers in the ERNs after March 2019.</li> </ul>
<b>ERN Skin</b>	<ul style="list-style-type: none"> <li>• Every ERN clinical subgroup (8) and transversal group (4) integrates an ePAG patient advocate, two patients are also part of the ERN Steering Committee and have been actively contributing to all discussions, especially providing insights to develop “patient oriented clinical outcomes”, in order to focus the selection of indicators on actual patient wellbeing in a wider sense, beyond pure health outcomes.</li> <li>• Patients are developing a draft proposal for a patient satisfaction survey.</li> <li>• Training sessions include contributions by patients, in order to train a new generation of professionals already used to collaborate with patients and patient organisations and aware of the importance of</li> </ul>

	<p>integrating the patient perspective to ensure a stronger and more effective patient-clinician partnership.</p>
<b>MetabERN</b>	<ul style="list-style-type: none"> <li>• MetabERN is structured and organized in 7 Subnetworks (SNWs) of homogeneous diseases and 8 Work Packages (WP) for common activities ranging from prevention to clinical trials. Patient representatives are present in and are working with the Health Care Providers (HCPs) in each one of these WPs and SNWs according to a two-way consultative process. To make communication easier and more effective among patients and clinicians, a Single Point of Contact (SPOC) per WP and SNW has been elected; this person is the bridge between the professional leaders of the WPs and SNWs on the one hand, and the patient representatives on the other.</li> <li>• Patients and clinicians have worked together in different activities, including mapping and understanding patients' and HCPs needs and identify possible solutions. Surveys have been developed and translated in several languages. They are now aiming in having the results of these surveys published in a peer-reviewed journal.</li> </ul>
<b>VASCERN</b>	<ul style="list-style-type: none"> <li>• Pills of knowledge, short videos, have been developed by a tandem of patient and clinicians for specific aspects (sport and marfan, diagnosis...). Patients and clinicians have also worked together in developing patients pathways for different pathologies and the production of books for children with rare diseases.</li> </ul>