



EURORDIS CEF

Update on ERNs

Matt Bolz-Johnson and Ines Hernando
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EURORDIS.ORG

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1. Expansion of ERNs

1. Expansion of ERNs

**Full Members
Today 900 HCPs**

- Call for new members 30 Sept-30 Nov
- 8 ERNs have expanded their scope (53 new diseases): ENDO, ERNICA, eUROGEN, Genturis, GuardHeart, Rare Liver, VASCERN, Lung
- The objective is to cover gaps (MS have been invited to avoid endorsing centres for ERNs in which they are well represented)

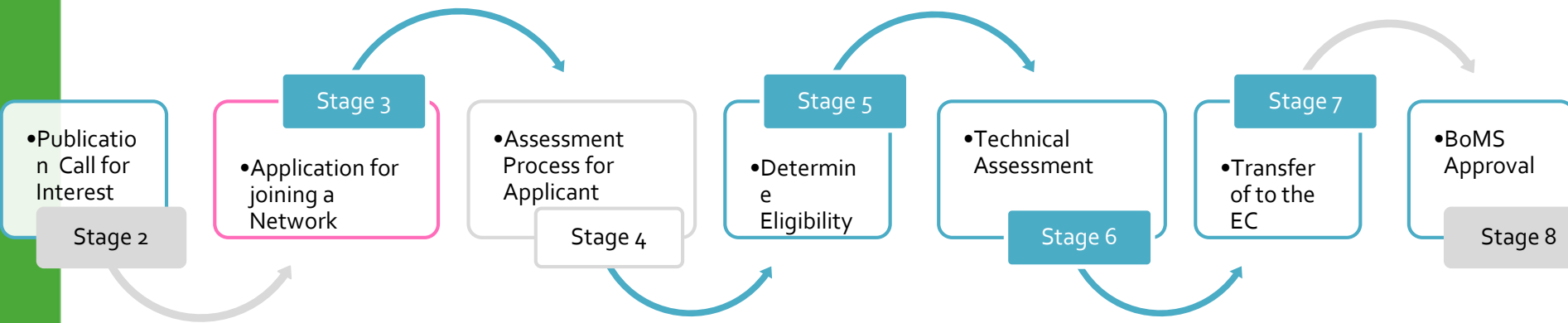
**Affiliated Partners
250 designated by MS of
which 3 are Coordination
Hubs**

- Designation process closed on 30 Sept
- ERNs are signing bilateral agreements. Final list has not yet been published.

3. HCP Member Applicant & Assessment Process

Overview of the Process

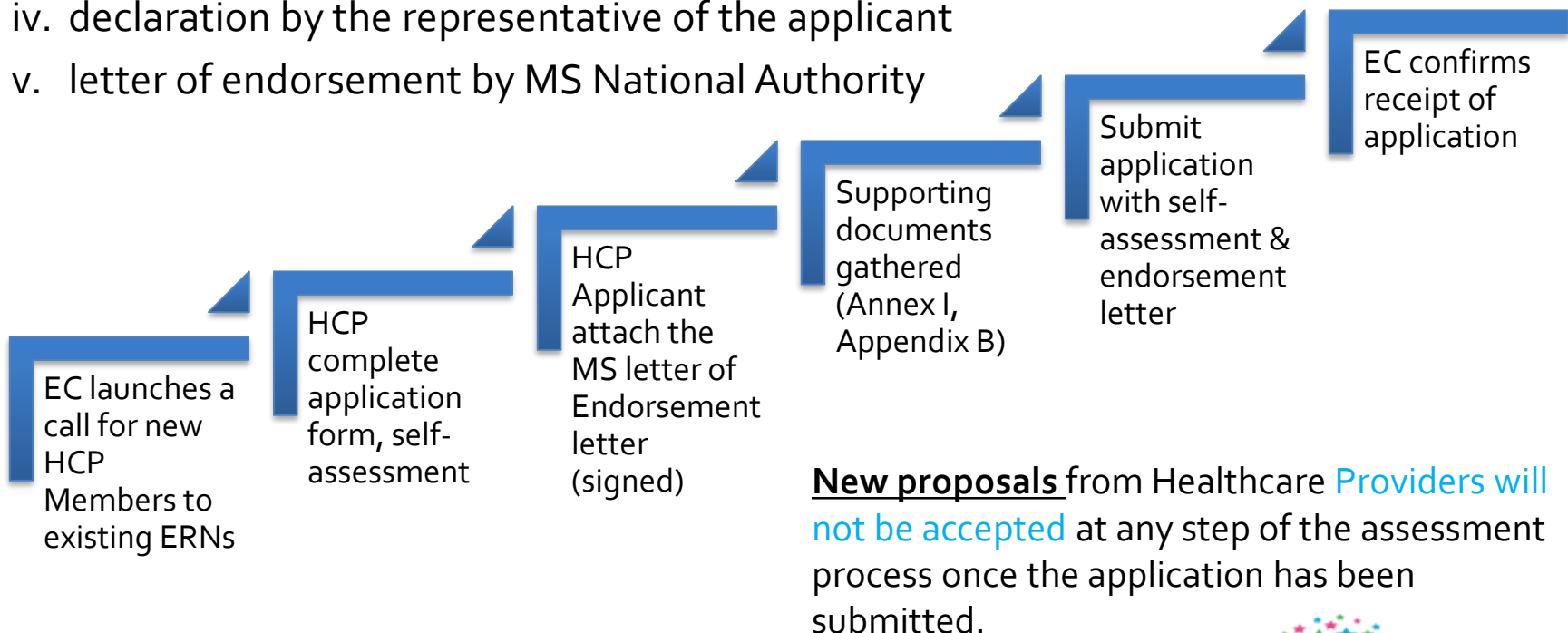
- National Endorsement - HSE Acute Operations (one applicant per ERN)
- Ten-Stage Process in minimum 12 months Timeline
- Tools: Assessment Manual (Description & Procedures); Technical Toolbox and Operational Criteria for HCP Applicants



5. Application for joining an existing Network (stage 3)

Complete on-line forms and submitted within the deadline of the call of interest (30 November 2019) and documents must be signed:

- i. application form
- ii. self-assessment
- iii. declaration of the CEO/Hospital Director
- iv. declaration by the representative of the applicant
- v. letter of endorsement by MS National Authority



Source: EC ERN Assessment Manual for Applicants – Technical Toolbox (2019)

6. All information available here -

https://ec.europa.eu/health/ern/consultations/2019_call_membership_en









Deadline for applications:





30 September - 30 November 2019

❖ How to apply to become a member of an ERN?

The membership application process will involve several steps:

- Review the information that is included on the [Commission webpage](#) related to the European Reference Networks and the applicable legislation
- Contact your [national representatives](#)   in the ERN Board of MS. They will provide you with more specific information on the national endorsement process
- Fill in the application and self-assessment in the [online tool](#)
- Include all required documents that are specified in the online tool and described in the [assessment manual](#)  , which include the following:
 - [Letter of Endorsement for Healthcare Providers](#)  
 - Declaration signed by the Director or the CEO of the hospital (*to be provided in the online tool*)
 - Declaration signed by the Healthcare provider Representative (*to be provided in the online tool*)

❖ Before submitting the application, the following information shall be reviewed by the healthcare providers

1. Applicable legislation
2. The scope, criteria and thresholds of the diseases covered by each of the 24 ERNs  
3. Information provided by the Networks on their websites
4. [Assessment manual](#)   and [operational criteria](#)  

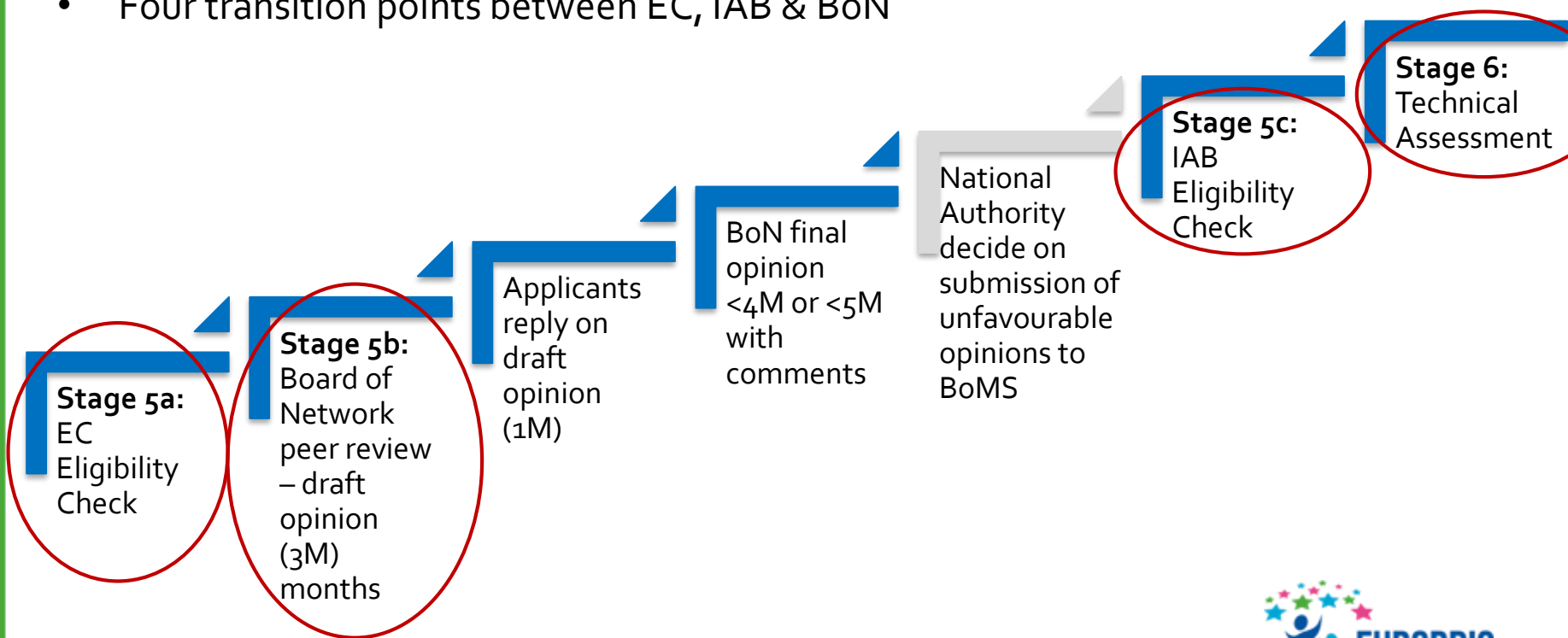
❖ Further information for the applicants

- [Instruction of the online application tool](#)  

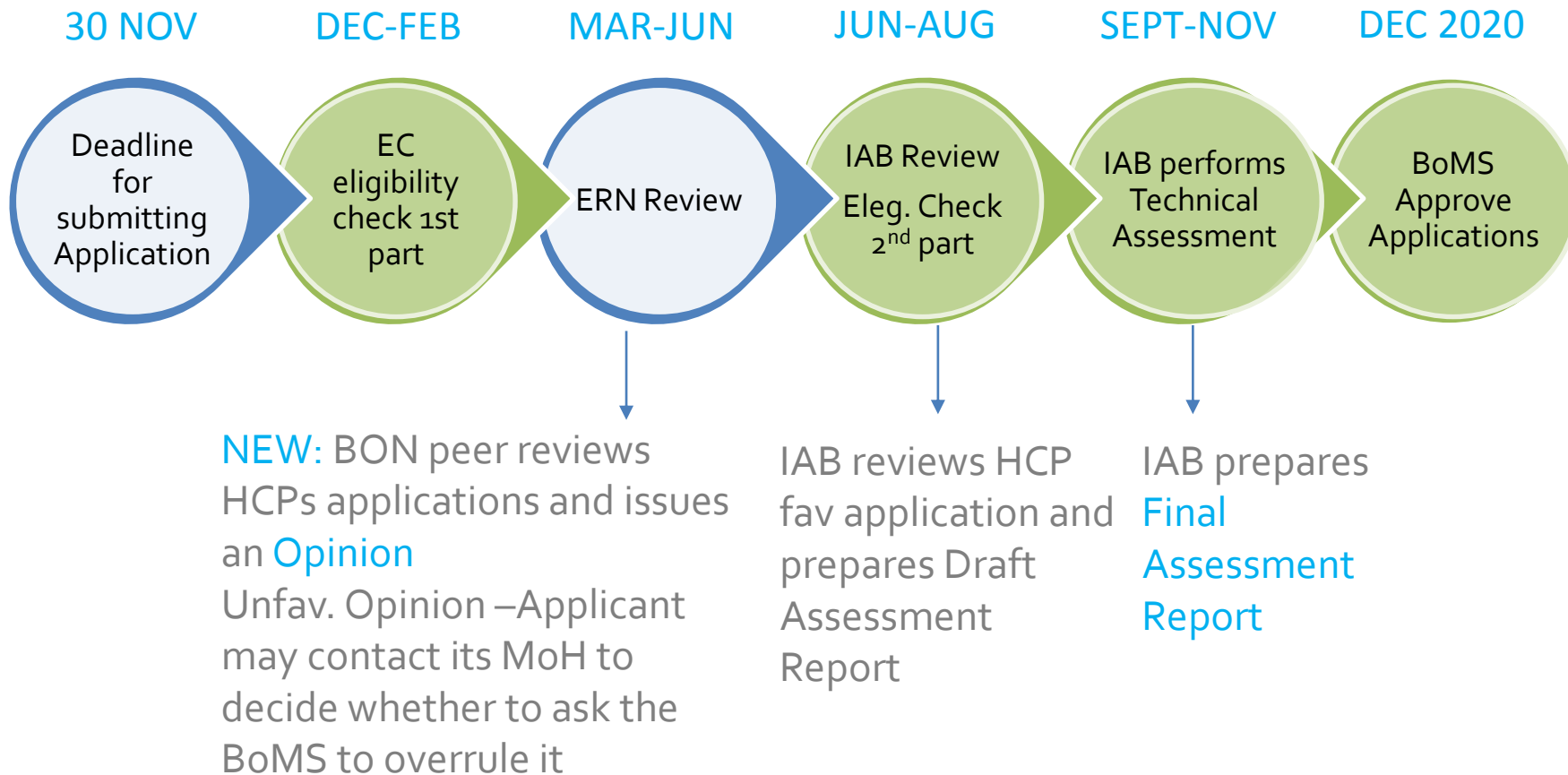
7. Overview of the Assessment Process for the Applicant (stage 5 & 6)

Description

- Assessment process consists of two key stages - Eligibility Check & Technical Assessment
- Four transition points between EC, IAB & BoN



8. Call for new full members. 4 Decision points, 2 recommendations/opinion

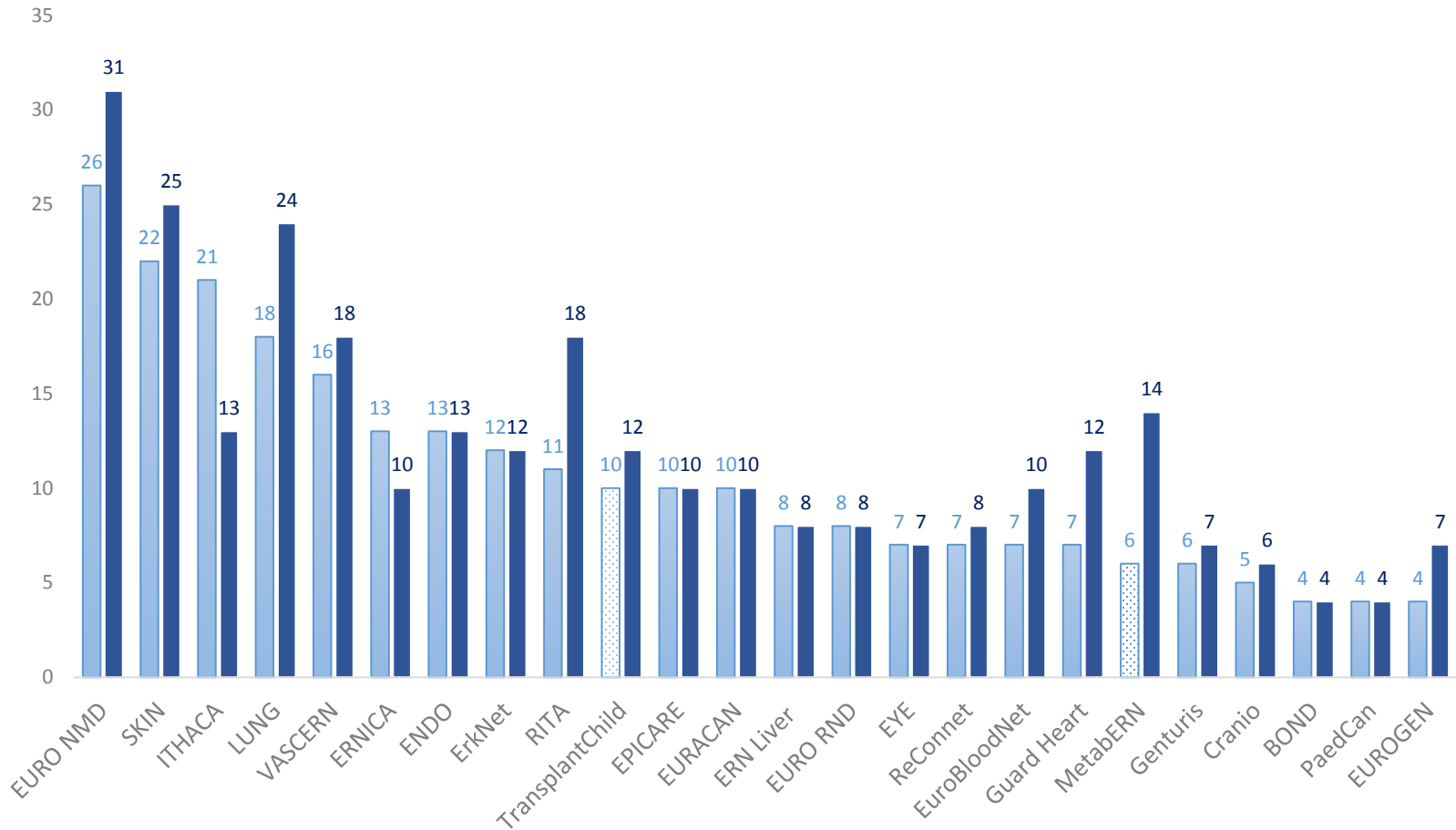


NEW: It is possible that a single HCP submits the application on behalf of a consortium (legal or functional) or a multidisciplinary team including members belonging to different HCPs (Centres or Hospitals).

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2. Update of ePAG Groups

1. ePAG Patient Advocates per ERN

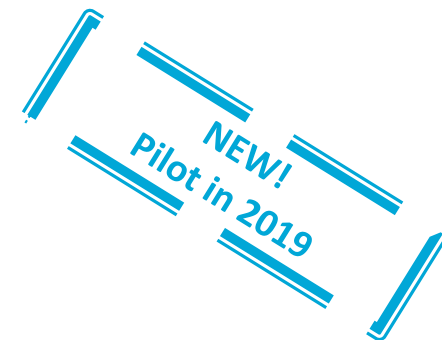


Note: MetabERN and TransplantChild were updating their information in 2018 when this was reported. We are checking the 2019 figures with some ERNs.

2. Support to ePAG advocates in 2019

- 1 Bi-monthly calls per ePAG and Steering Committee Calls each 6 weeks.
- 2 Quarterly induction calls for newcomers. We provide an overview of ERNs and ePAG role + ePAG mission and role factsheet.
- 3 Quarterly calls to exchange of good practices, open to all ePAG advocates (3 in 2019, including f2f workshop in Bucharest, May 2019)
- 4 ePAG impact framework. ePAG SC has started to work in a set of measures to assess the impact of their engagement in the ERNs.
- 5 ePAG Horizontal WG.
 - Registries: 4 calls in 2019, involvement in EJP activities
 - Clinical Outcomes & Guidelines Group COGG: Group will be set up 2020
 - Training. Input to help develop the ePAG Leadership Programme and we will be engaging with them in the design of the 2020 edition

3. EURORDIS Leadership School April- Nov 2019



EURORDIS Leadership School on Healthcare & Research

Face-to-face in Barcelona, Spain
November 26-27, 2019

*Empowering patients to be valued partners in European Reference Networks (ERNs).
A capacity-building programme for European Patient Advocacy Groups (ePAGs) on
leadership, network management, healthcare and research*



4. EURORDIS Leadership School

60 Participants

Advocates Group (30): ePAG patient advocates active in their own disease area

New Leaders Group (30): ePAG patient advocates who are leaders representing the wider patient community in ERN Boards and other WGs

21 external trainers

19 pro-bono and 5 EURORDIS staff as trainers involved in the online courses + f2f training

Programme Structure

- **Online training** April - October (15 webinars Advocates, 10 Webinars for New Leaders)
- **Face-to-face training, 26-27 November. Advocates Group:** Good Communicator & Presenting with Impact and **New Leaders Group:** Creating Authority and Legitimacy & Influencing Without Authority

5. EURORDIS Leadership School - Webinars

Training Unit	Training Level	Training Courses	Target Trainees	Time frame
Leadership	Foundation	<ol style="list-style-type: none"> 1. 360° Self-awareness 2. Model Leaders 3. Good Communicator 4. Presenting with Impact 5. Conflict Resolution Strategies 	Advocates + New Leaders	Sem. 1
	Advanced	<ol style="list-style-type: none"> 1. Creating Authority and Legitimacy 2. Influencing Without Authority 3. Negotiation 4. Programme Management 5. Network Governance & Assurance 	New Leaders	Sem. 2
Technical knowledge	Advanced	<ol style="list-style-type: none"> 1. Networks 2. Digital Health 3. Knowledge Generation 4. Research 5. Healthcare 	Advocates	Sem. 2

6. EURORDIS Leadership School. Feedback on course structure

1. What I missed is the opportunity to discuss face to face with the other participants after the presentations. But globally, I would say that it was **well organized, and the content was interesting**. That was my first leadership webinar. I am looking forward to the f2f session. **Well done Concha**.
2. I think it **has been a great initiative**, not only for the **contents and methodology**, but also for the **profiles that we have participated in, both teachers and students**. I have had the perception of working with a great team. On the other hand, a unique training has been offered in this field, very difficult to find with this approach, professionals and quality. Thank you, thank you very much.
3. A **pre-arranged timetable of webinars would have helped fit the programme in with a busy work schedule**. Regarding length of webinar sessions: **some were about right** for the content that needed to be presented but **some were too long**.
4. I found the **time slot very difficult to combine** with my work as a patient representative. I was a bit **disappointed about planning webinars in the traditional busy periods**
5. Having the **webinars during working hours** was difficult.

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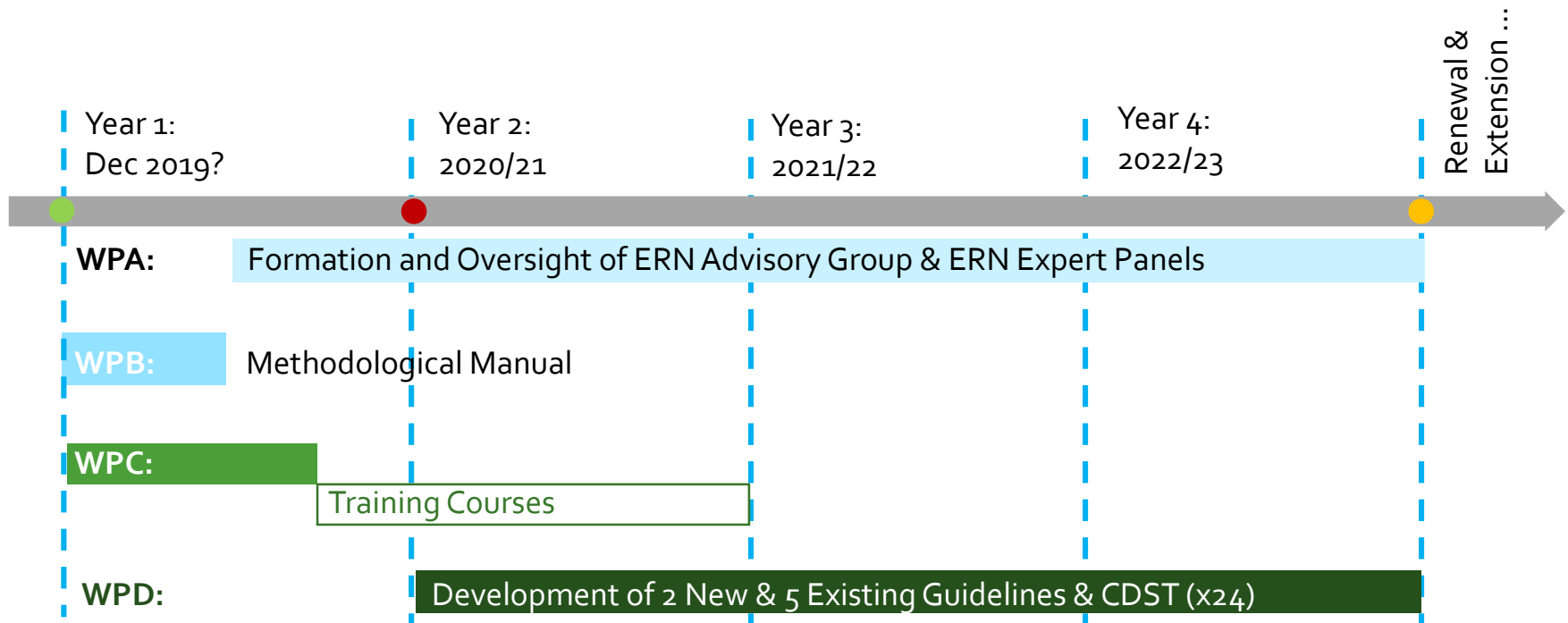
3. Strategic Priorities

1. Clinical Practice Guidelines & CDST Tender

Tender Aims:	To support the ERNs and their healthcare providers in the process of development, appraisal and implementation of CPGs and CDSTs
Funding:	4,000,000€ over 4 years
WP1 Yr. 1-4	<ul style="list-style-type: none"> • EC ERN Guideline Advisory Group – across all ERNs x1 • ERN Expert Panel specific for each guideline x24
WP2 Yr. 0.5	<ul style="list-style-type: none"> • ERN Guideline Mythological Manual and Toolkit with a common methodology for all ERNs to use in WP4
WP3 Yr. 1	<ul style="list-style-type: none"> • Training Course on Guideline methodology, literature review and grading evidence and consensus approaches – F2F and online courses
WP4 Yr. 2.5-4	<ul style="list-style-type: none"> • Each ERNs develop 2 new and assess / adopt 5 existing guidelines and CDST • Prioritisation process to select topic areas

Note: Proposals submitted in March 2019 & Contract start is estimated Sept/Oct 2019

2. Clinical Practice Guidelines Tender Timeline



3. Integrated assessment, monitoring, evaluation and quality improvement system (AMEQIS) for the ERNs Tender

Part 1	Update and improvement of the ERN assessment methodology, manual and toolkit based on the lessons learned since their initial application.
Part 2	<p>Completion and improvement of the Continuous Monitoring and Quality Improvement System:</p> <ul style="list-style-type: none">(i) analysis of the current ERN monitoring system and data sources, develop the quality check and produce an improved Continuous Monitoring and Quality Improvement System.(ii) provide methodological support to the ERNs in the process of election and definition of the Network specific indicators. The work to be carried out must address specific indicators on patient reported experiences (PREMs), and patient reported outcomes (PROMs).
Part 3	The development of the Evaluation Manual and toolkit (i.e. a set of tools designed to be used together by the ERNs, HCP and the Evaluation Body) for the periodic evaluation of the ERNs and their Members.
Funding:	xxx€ over xx years

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4. Advocacy

1. Snapshot of Priority Areas

- EC aim is to secure stable funding/non-competitive for 5-year period/operations ESF+
- Cost-effectiveness study 2020 PHP

Sustainable funding



Continuous monitoring



- Reporting on 18 indicators twice a year
- Managing exit of HCPs that do not meet operational criteria
- Disease-specific indicators
- AMEQUIS tender



Collaboration with industry



Integration into MS healthcare systems



Data policy/registries

- BoMS Statement + Legal and Ethics WG Code of Conduct
- Pilots on clinical trials and registries in 2020?



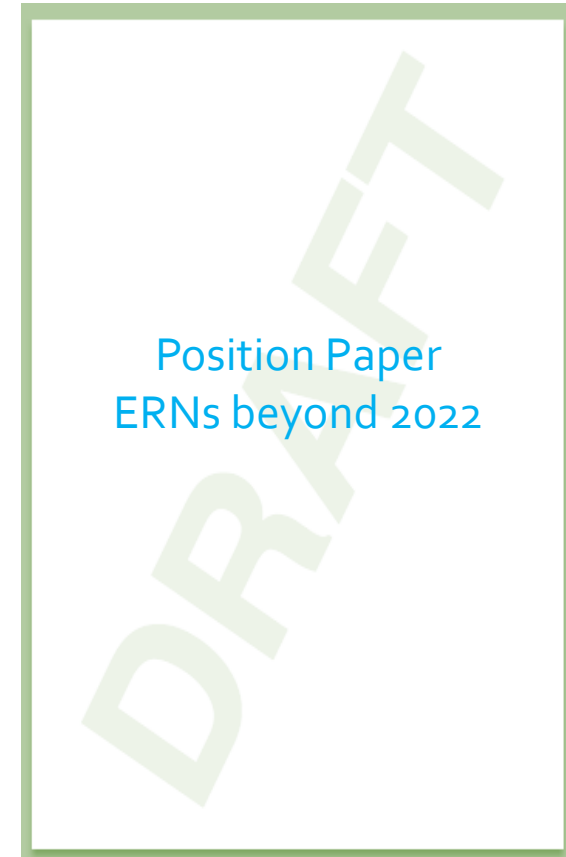
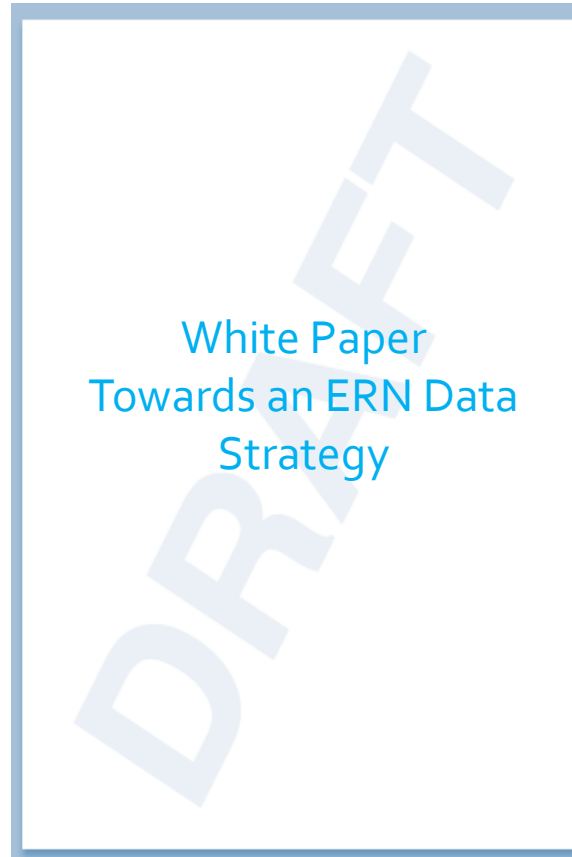
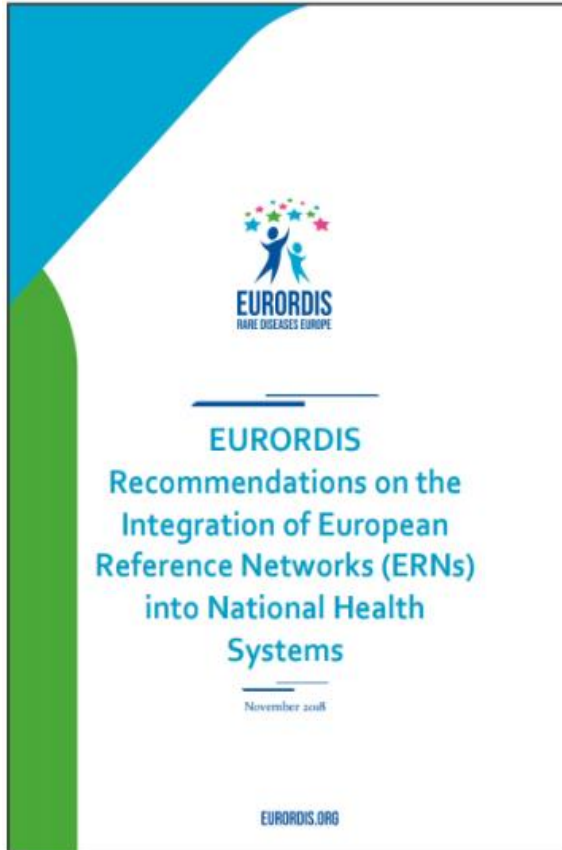
Management mode

- EC relying on MS to develop/agree on ERN referral pathways and address the admin and financial issues
- **EURORDIS Recommendations – follow-up activities with NA**

- ERN Registries
- **EURORDIS proposal towards an ERN Data Strategy**

- Virtual consultations, educational webinars, clinical pathways, etc. Different speeds, but all progressing
- Managing expansion: Governance and relationship with affiliated partners (bilateral agreements) + inclusion of new members Dec 2020

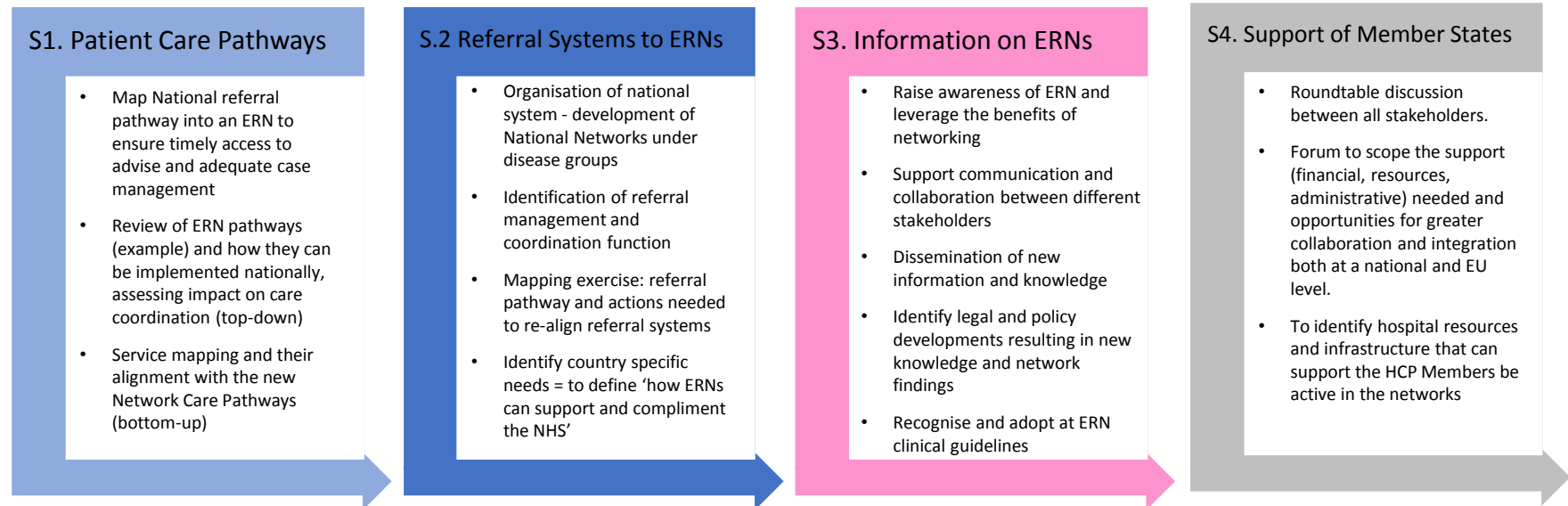
2. EURORDIS Papers



3. National Integration Workshop

Cross-cutting: National rare disease plans/strategies and legal framework for ERN integration:

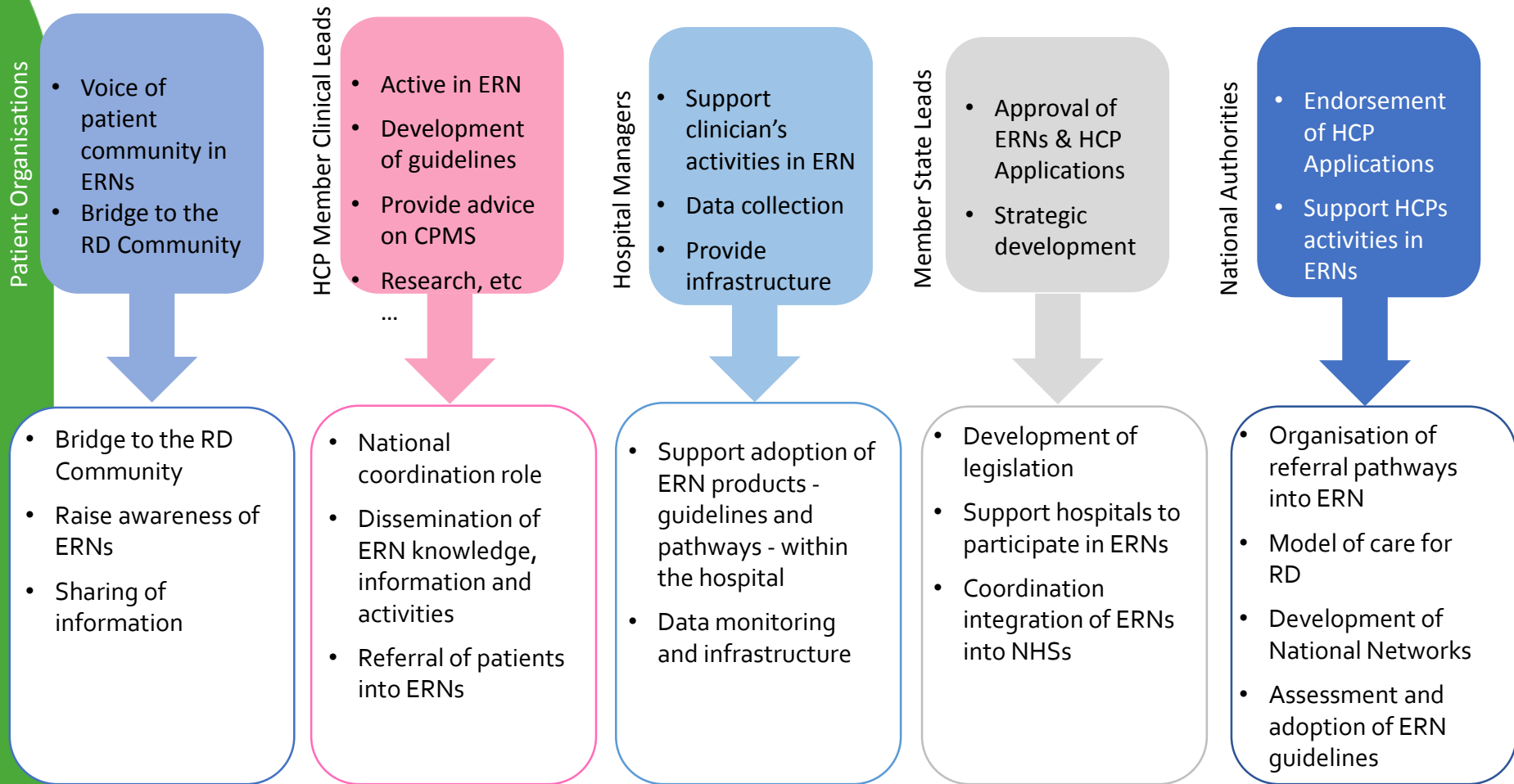
- Assess national rare disease plans/strategies and identify needs for adaption relating to integration of ERNs into national systems.
- Discussion on the need and process for identification and accreditation of national Centres of Expertise
- Streamline the endorsement procedures for healthcare providers that apply for full membership
- Prioritising and managing the enlargement of ERNs at a National level.
- Identification any legal aspects relating to the other 'key areas of intervention' - care pathways, referral system, information sharing, support HCP Members.



Approach:

- One-day "ERN-integration national workshop" in order to make tangible steps to to implement ERNs within each Member State
- Provide a platform for multi-stakeholder discussion, tailored to meet national needs and provide an opportunity to exchange ideas and good practice
- Patient-led (organised by National Alliances), EURORDIS-support

4. How do we implement these high-level Recommendations at national level?



We need a systematic approach and concerted action at national level from PO, clinicians and national health authorities.

5. EURORDIS White Paper. Towards a Data Strategy for ERNs

We want to trigger a high-level strategic discussion on health data and ERNs that will eventually lead to an action plan and concrete proposals on what to do, when, how, by who...

With this paper are suggesting a course of action to build and deliver this strategic vision.

Driven by Guided by the notions of data findability, accessibility, interoperability, and data security, data integration is patients' Overseen by a central data authority, which is responsible for the wide range of data sources, including clinical, research, and health care data. This data is then made available to researchers and clinicians through a secure, interoperable data ecosystem. This ecosystem is designed to support the discovery of new treatments and the improvement of patient care. The data ecosystem is a key component of a data-driven health system, and it is essential for the success of any data-driven health system. The data ecosystem is a key component of a data-driven health system, and it is essential for the success of any data-driven health system. The data ecosystem is a key component of a data-driven health system, and it is essential for the success of any data-driven health system.



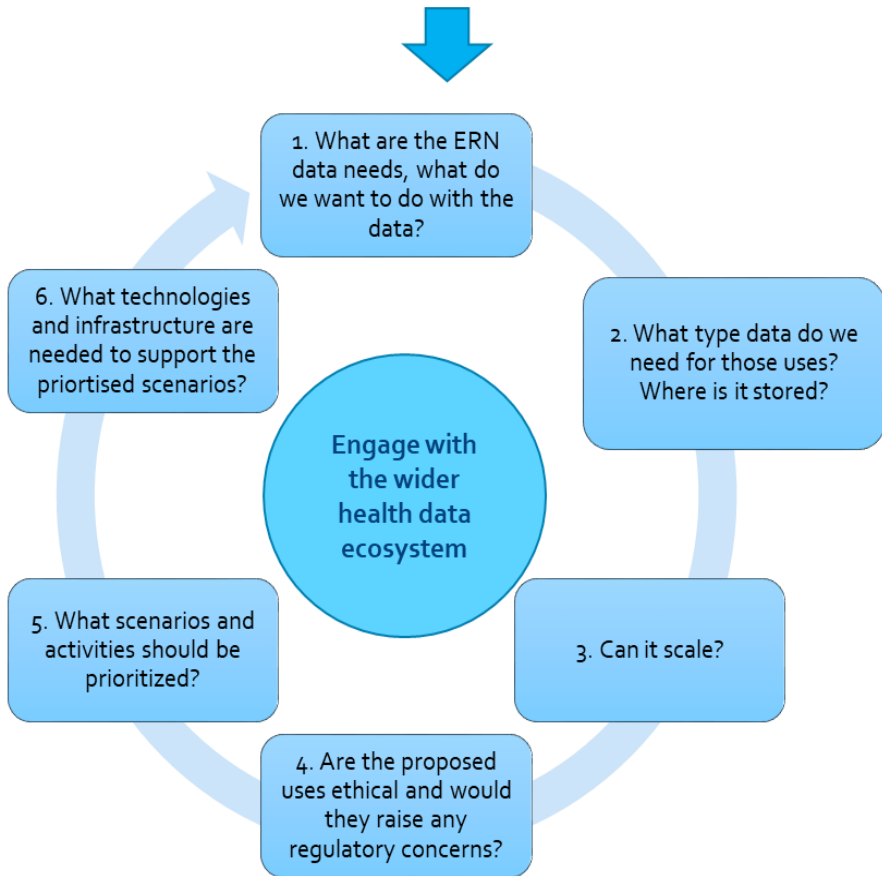
9 Principles for a Thriving ERN Data Ecosystem

Daniel, Williams syndrome

7. EURORDIS White Paper. Towards a Data Strategy for ERNs

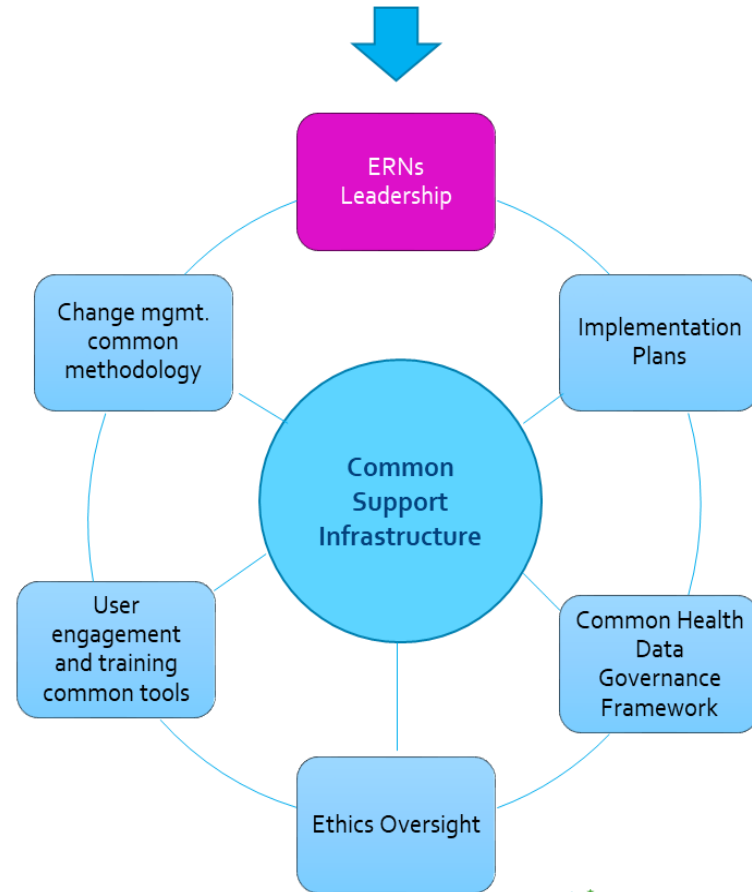
1

START THE CONVERSATION TO DEVELOP A SHARED VISION WITH ALL STAKEHOLDERS



2

SET UP A DELIVERY FRAMEWORK



8. EURORDIS Position Paper. ERNs Beyond 2022

Looking into the 5 year evaluation, we need to recall what are the goals of the Networks so that we measure what really matters (*what needs to be done to achieve those objectives*). The evaluation results should allow us to learn and refine the current structure and arrangements (focus on learning, not just accountability)

improve patients' health outcomes by increasing the provision of evidence-based quality care at the point of care

MEASURING THE IMPACT

3

- Are ERNs of benefit to explain the priority of needs and increasing the capacity and capabilities of national health systems to meet the health coverage and needs, gaps, etc.)
- Research Reference to EUCERD Mapping Objectives (our vision) approach – specialist networks, rationale of grouping evaluation (existing and new ones).
- Analysis of current capacity versus integration of ERNs needs

Objective: Share our vision on ERNs beyond 2022 (how does success look like?) and what needs to be done to deliver it

We expect to see more Cross-ERN collaboration



EpiCARE

@EpiCARE_ERN

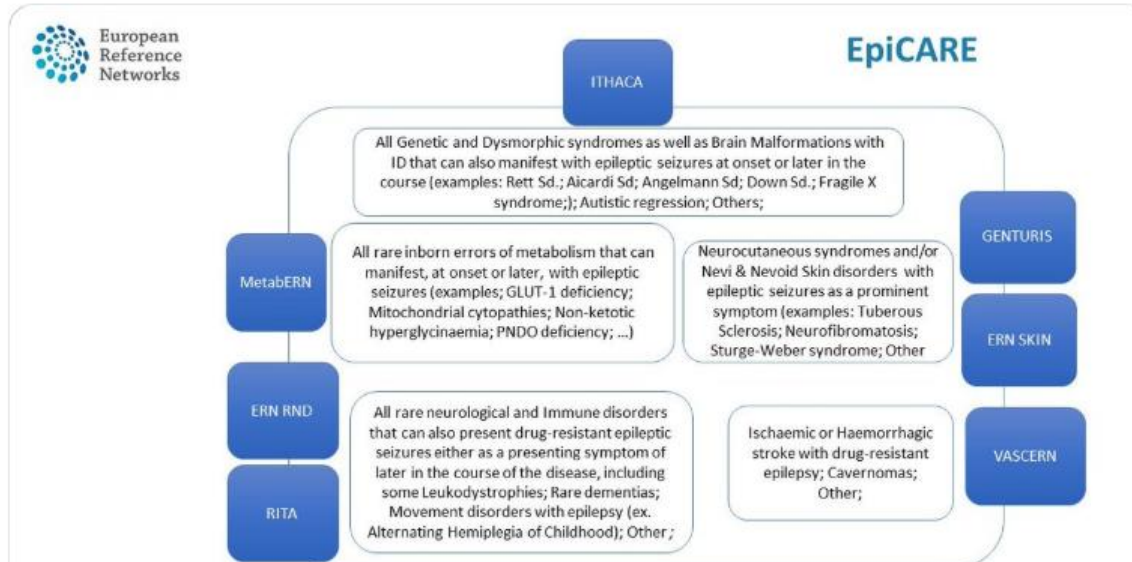
Following



Epileptic #seizures are the symptom (sometimes the first manifestation) of at least 150 #rarediseases. Therefore #ERN #EpiCARE's work overlaps with a numerous other European Reference Networks. Collaboration is essential.

#epilepsy #ERNEu #ShareCareCure

- ERN Coordinators are committed to address overlaps.
- 1 Workshop on liver tumors – Rare Liver with PaedCan and EURACAN
- eUROGEN/ERNICA ongoing discussions on a joint working group on anorectal malformation
- eUROGEN/ITHACA/ErkNet on a joint working group for Spina Bifida



Thank You

