

Project name:
ERN eUROGEN

**European Reference Network for rare urogenital
diseases and complex conditions**

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ERN eUROGEN is a European Reference Network (ERN) approved by the ERN Board of Member States (BoMS). For more information about the ERNs and the EU health strategy, please [click here](#). The ERNs are funded by the European Union. The views and opinions expressed are those of the author(s) only and do not necessarily reflect those of the European Union or HaDEA. Neither the European Union nor HaDEA can be held responsible for them.

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1. INTRODUCTION

This Dissemination Plan outlines ERN eUROGEN’s proposed strategy to meet the expectations and needs of the programme. It outlines the procedures and key actions ensuring they are implemented and followed. In addition, the Dissemination Plan lists the tools to be used and target groups to be reached.

1.1. Definitions: Communication & Dissemination

- **Communication** covers the whole of a project, including results, and starts at the outset of the project. It is directed towards multiple audiences, within and also beyond the project’s own community, including the media and general public. The aim is to inform and engage with society to show how it can benefit from clinical care, education and training, research, and new innovations and to highlight the impact on health care for rare and complex diseases.
- **Dissemination** covers project results only and happens only once results are available. It is directed towards specialist audiences, groups that may use the results in their own work, including peer groups, industry, professional organizations and policymakers. The aim is to enable the take-up and use of results and make a significant impact on health care.

Both are essential to the achievement and success of the ERNs.

2. AIMS & OBJECTIVES

The major purpose of the Dissemination Plan is to provide a broad overall framework and guideline for communicating the activities and disseminating the results of ERN eUROGEN and to ensure that the desired impact of ERN eUROGEN is achieved. A clear, strategic plan will improve and enhance our reputation and build trust, demonstrate the value of the network to our stakeholders, and help to deliver the network’s priorities.

Specifically, the aims are to:

- Raise awareness – let others know what we are doing
- Inform – educate the community
- Promote – disseminate our outputs and results
- Engage – get input and feedback from the community

To achieve these, our objectives are to:

- Identify our audiences (internal and external)
- Target communications and information to the appropriate audiences
- Focus on delivering clear, understandable, successful, proactive, high quality communications
- Ensure we are using the full range of communications tools and channels
- Evaluate to measure the impact of communications and dissemination activity

2.1. Strategic Objective during the Bridging Grant

To disseminate knowledge across the enlarged network and beyond through active cross-ERN, EU, and international collaborations, providing updates of public and network information through the ERN eUROGEN website, YouTube channel and additional social media platforms

2.2. Indicators during the Bridging Grant

Impact/Outcome Indicator No	Impact/Outcome Indicator Name	Target Value	Due Date
WP2.PI1	Dissemination activities further developed	Increased website hits, newsletter, and YouTube/social media subscribers, sending out at least 10 -newsletters	M18
WP2.PI2	Global collaboration	Two additional signed global collaboration agreements when applicable	M18
WP2.011	Dissemination activities for webinar programme increased with Supporting Partners	Increase registrations to webinars by 20%	M18
WP2.012	Prepare representation at Annual European Association of Urology (EAU) Congress (planned 1-4 July 2022 Amsterdam)	Potential to reach audience of 18,000 urologists. Preparation of one ERN EUROGEN Special Session. Preparation of one PMS helpdesk at the congress	M7
WP2.013	Number of congresses / conferences / meetings at which the ERN activities and results are presented	At least 5 new events at which ERN activities & results are presented by M18	M18
WP2.014	Dissemination Plan updated	Document updated	M8
WP2.015	Dissemination Report produced	Document produced	M10
WP2.111	Increased awareness of ERN eUROGEN	5 new publications from the network	M18
WP2.112	Number of individual ERN website hits	40,000 page views	M18

WP2.113	Updated Dissemination Strategy agreed by Strategic Board	Dissemination Plan agreed by Strategic Board	M8
WP2.114	Dissemination Report agreed by Strategic Board	Dissemination Plan agreed by Strategic Board	M10
WP2.115	Knowledge dissemination of healthcare professionals and patients	Increased knowledge of rare urogenital diseases and complex conditions	M18

3. DISSEMINATION PROCEDURES

3.1. Target Audiences

3.1.1 Internal

- Full HCP Members
- Affiliated Partners (Associated National Centers and National Coordination Hubs)
- Supporting Partners
- ERN Patient Advisory Group (ePAG) Representatives

ERN eUROGEN aims to guarantee that all parties are well-informed and well-briefed about activities, progress, outcomes, network planning and all other issues. This ensures the maximum efficiency of resources and consistency of results and increases the synergy and integration of the members and partners.

Coordination Team meetings, Workstream meetings and the annual Strategic Board Meeting will play an important role in this task. All information generated within the project will be communicated to the Coordination Team, who will be in charge of channelling this information to the other parties, where appropriate, either through the newsletter or targeted emails.

3.1.2 External

ERN eUROGEN aims to communicate effectively with parties outside of the network, in particular non-member HCPs as well as with other European consortia, policy makers, and more generally with the clinical and scientific community, and its citizens and patients at large. We will proactively reach out to the communities that we anticipate will be most interested in, and benefit from, the outputs of ERN eUROGEN.

HCPs and health researchers (non-ERN members)

Objectives:

- Raise awareness of the existence, the potential and the possibilities offered by ERN eUROGEN to provide expert advice addressing rare and complex urorectogenital cases;
- Explain the benefits of virtual advice given in a safe, secure IT environment;
- Provide guidance on how to access ERN eUROGEN for cases needing further multi-disciplinary and surgical expertise;
- Provide clinical practice guidelines and/or consensus documents; and
- Encourage expert centres to apply for membership to ERN eUROGEN in any new calls as they arise.

Key messages:

- The ERNs have the combined knowledge of the experts in several HCPs and therefore, can address patient care, from research to diagnosis, treatment, and hopefully, cure, based on the currently available scientific knowledge.
- ERNs benefit from high-level capacity building: network support; training (eLearning, access to complex cases), development of clinical decision-making tools, clinical and interdisciplinary research;
- Healthcare professionals can access ERN advice on concrete clinical cases where the knowledge and expertise at their disposal are not sufficient; they can share their own expertise and experience on rare and complex cases; they can have access to advanced resources in research, clinical trials, European registries etc.;

- ERNs are not directly accessible by individual patients: HCPs connect patients with the relevant patient organisations at the national level;
- Local HCPs can ask their national authorities for more cooperation at the European level through a bottom-up approach.

Patient, family and advisory organisations

Objectives:

- Raise patients' awareness about the potential benefits offered to them by the European coordination of knowledge and expertise through the ERNs;
- Clarify whom they have to contact/how it concretely works and manage expectations.

Key messages:

- Europe is broadening the field of possibilities to find solutions and support for their disease;
- Show short-term results (and limitations) of active ERNs;
- The patient's first contact point remains the clinician treating them in the HCP in the country where they live.

The media

Objectives:

- Raise awareness about the existence of ERN eUROGEN and the general objective of all 24 ERNs to improve quality and safety and access to highly specialised healthcare across the EU for patients affected by rare or low prevalence and complex diseases;
- Highlight the EU added value in this innovative form of cross-border healthcare and how it's having an impact on citizens' lives.

Key messages:

- Show the concrete results of ERN eUROGEN actions, by using the data collected by the ERN Monitoring system at a European level, as well as within each HCP (incl. figures, e.g. on the number of potential patients and surgical procedures performed, the cost of rare diseases in Europe, etc);
- The European action can support national efforts and provide added value by pooling resources to address isolated cases through an economy of scale; knowledge is traveling, not patients.

Other audiences

- Academic and professional societies
- Policy makers: EU institutions and (sub)national authorities
- New Member States and European countries outside the EU
- Industry: pharmaceutical and medical device organisations
- Regulatory agencies
- The general public and patients

3.2. Tools

3.2.1 Websites

- [EC website](#) – a centralised webpage with information about all the ERNs. ERN eUROGEN is responsible for keeping the EC updated so that information is current.
- [Network website](#) – an interactive website has been established, hosted by our [Supporting Partner](#), the [European Association of Urology](#) (EAU), through their WordPress account, which serves as the main contact point for external users. ERN eUROGEN is responsible for administering the website in accordance with the EC's guidelines.

- [ERN Collaborative Platform \(ECP\)](#) – an EC-hosted intranet accessible by ERN eUROGEN partners to gather and share documents and to communicate via forums. ERN eUROGEN is responsible for keeping this site organised and updated.

3.2.2 Newsletters & Social Media

The [network e-newsletter](#) is a monthly newsletter facilitated using the EAU's [MailChimp](#) account. Newsletters are also sent out before each ERN eUROGEN [webinar](#), alerting subscribers that registration is open. ERN eUROGEN is responsible for writing and curating content, compiling the newsletters, sending them out, and maintaining the database of recipients.

Social media channels offer a way of establishing a direct connection with a large audience and providing organic content to them in order to build a brand, raise awareness, drive traffic to our website, and recruit new members or clinical and research partners to access additional expertise from Europe and globally. Social media also allows the management of reputation and the wielding of influence in debates on science and innovation. They are also a valuable way of gaining insight into the field through social listening. It is easy to gather analytic data to evaluate performance. A benefit of social media channels is that they are a no-cost means of dissemination and communication, although there is the ability to use funds to boost reach.

ERN eUROGEN is active on the following platforms and is responsible for writing and curating content and responding to any contact made to the network:

- [Facebook](#)
- [Instagram](#)
- [LinkedIn](#)
- [X](#) (formerly known as Twitter)
- [YouTube](#)

At this time, we do not see any advantage to using Pinterest, Snapchat or TikTok, but will continue to keep aware of these and any newly developing platforms.

We use the below tools relating to newsletters and social media:

- [Canva](#) – an easy-to-use to use design tool for web graphics with preset sizes and templates for social media, and the ability to create a 'brand kit' to ensure a consistent identity across channels.

3.2.3 Promotional Materials

- [CIRCABC](#) – an EC-hosted intranet accessible by ERN eUROGEN partners that hosts standardised documents, templates, repositories, and a taxonomy in order to support the success of ERNs. Specifically, there are templates for clinical practice and guidelines documents, reporting documents, patient information materials, agendas, minutes, presentations, posters, flyers, and brochures.
- Dissemination Package – ERN eUROGEN provides each member of the network with a tailored Dissemination Package featuring the network logos and their HCP-specific logo, along with promotional materials and templates.
- [EC Communication Toolkit for ERN Members](#) – including press materials, ERN visuals, flyers, brochures, website guidance, social media visuals, and videos.
- Official ERN Logos

3.2.4 Media and Scientific Publications

- Articles in [external media sources](#)
- [Scientific publications](#) for peer-reviewed journals – if the paper is the result of work carried out by two or more ERN members working within the structure of the network this will be acknowledged by inclusion of the statement: "This work is generated within the European Reference Network for Urogenital Diseases, ERN eUROGEN."

3.2.5 Working with Other Organisations

When working with other organisations, we will support our aims and objectives, we develop joint approaches to events, publications, education and training, promotional materials, and so on.

We have connections to several other external organisations (professional bodies, member organisations, etc.) as [Supporting Partners](#):

- [ARM-Net](#) (Ano-rectal Malformations Network)
- [European Association of Urology](#) (EAU)
- [European Pediatric Surgeons' Association](#) (EUPSA)
- [European Society for Paediatric Urology](#) (ESPU)
- [International Society for the Study of BPS](#) (ESSIC)

Or as [Collaborative Partners](#):

- [Confederación Americana de Urología](#)
- [CureforU](#)
- [European Joint Programme on Rare Diseases](#) (EJP RD)
- [EURORDIS](#) Rare Diseases Europe
- [Rare Diseases International](#)
- The other 23 ERNs, particularly those with which we have cross-ERN actions

Or as [patient organisations endorsing our ePAGs](#):

- [AICI](#), Italy
- [AIMAR](#), Italy
- [ARM-Net](#)
- [Bladder Exstrophy Society](#), The Netherlands
- [Klinefelter's Syndrome Association](#), United Kingdom
- [Orchid](#), United Kingdom
- [SoMA eV](#), Germany
- [TOFS](#), United Kingdom

3.2.6 Events

Meetings, conferences, presentations, workshops, training sessions, seminars/webinars, and information booths are an effective way of disseminating information and communicating about the network. Below are some of the regular events that ERN eUROGEN is involved in:

- ERN eUROGEN Strategic Board Meeting – an annual meeting to communicate with and disseminate information to our internal audience
- [ERN eUROGEN Webinars](#) – monthly educational webinars featuring ERN eUROGEN experts on relevant topics
- [European Association of Urology Annual Congress](#) – our own thematic session, speakers at other plenary sessions, information booth in the exhibition center, articles in the congress newsletter
- Various scientific congresses – expert speaking contributions from project stakeholders, scientific abstracts and posters generated by the network

We are also active on social media relating to events in the field, seasonal events, and international awareness days (e.g., [Urology Week](#) and [Rare Disease Day](#))

4. FOLLOWING EC REGULATIONS

Confidentiality – ERN eUROGEN keeps confidential any data, documents or other material (in any form) that is identified as confidential at the time it is disclosed.

Disclaimer – ERN eUROGEN displays the following disclaimer on its website: “The views and opinions expressed on this website are those of the author(s) only and do not necessarily reflect those of the European Union or HaDEA. Neither the European Union nor HaDEA can be held responsible for them.”

Personal data – ERN eUROGEN processes any personal data (e.g., *name, address, identification number, e-mail, CV, bank account number, phone number*) gathered for communication and dissemination purposes according to the principles and conditions of the General Data Protection Regulation

Security – ERN eUROGEN requests written approval from the EC for security recommendations restricting disclosure or dissemination before disclosure or dissemination to a third party.

Use of Logos – In accordance with the implementing Decision 2014/287/EU for ERNs the EC has licensed the use of a unique graphic identifier ('logo'), which that Network and its Members shall use for the activities organised by the Network. The ERN logo constitutes the visual identity of the Networks and their members. It has been registered as a trademark by the European Union.



Only Coordinators and Members of the Networks approved by the Board of Member States are entitled to use the ERN logos; two basic logos (European Reference Network singular and European Reference Networks plural) and three types of extended logos (network name only, network + coordinator, network + member).

After signing an ERN eUROGEN Trademark Sublicensing Agreement (co-signed by the ERN eUROGEN HCP Network Coordinator Representative), ERN eUROGEN stakeholders can use

the logos according to the terms of the agreement.

Visibility of EU Funding – ERN eUROGEN ensures that any dissemination activity displays the following text and EU Emblem: “ERN eUROGEN is a European Reference Network (ERN) approved by the ERN Board of Member States (BoMS). For more information about the ERNs and the EU health strategy, please [click here](#). The ERNs are funded by the European Union.”

