

ERN eUROGEN

Communication & Dissemination Strategy Plan

v.01.19.2020 JT

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Abbreviations:

CIRCABC – Communication and Information Resource Centre for Administrations, Businesses and Citizens

EAU – European Association of Urology

EC – European Commission

ECP – ERN Collaborative Platform

ePAG – ERN Patient Advisory Group

ERN – European Reference Network

EU – European Union

HCP – Healthcare Provider

WP – Work Package

1. INTRODUCTION

1.1. ERNs and ERN eUROGEN

[European Reference Networks](#) (ERNs) are virtual networks gathering doctors and researchers with high expertise in the fields of rare or low-prevalence and complex diseases, transforming the care of patients from all over Europe. Approximately 6-8,000 rare diseases affect 30 million EU citizens, and no country alone has the knowledge and capacity to provide access to diagnosis and high-quality treatment for all of these. In 2017, the European Commission (EC) launched 24 ERNs involving over 900 highly specialized healthcare teams, located in over 300 hospitals in 26 European countries. In 2019 Affiliated Partners (Associated National Centers and National Coordination Hubs) were added to the networks, representing health care providers in Member States where a network had no existing full member. In addition, in 2019, the EC launched a call for applications for new full members, who will join the ERNs in 2021.

[ERN eUROGEN](#) is the ERN for rare and complex urorectogenital diseases and conditions. Our network comprises currently 29 full member healthcare providers, 12 associated national centers and 4 national coordination hubs across 19 countries. We are currently assessing applications from 31 new healthcare providers to join our network as full members in response to the 2019 EU call.

1.2. 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.

This Communication & Dissemination Strategy Plan will outline ERN eUROGEN's proposed strategy and plan to meet the expectations and needs of the project¹. It outlines the procedures and key actions ensuring they are implemented and followed. In addition, the Dissemination and Communication Strategy Plan lists the tools to be used and target groups to be reached.

1.3. Aims & Objectives

The major purpose of the Communication & Dissemination Strategy 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.

¹ The Dissemination and Communication Strategy Plan corresponds to WP6 on knowledge sharing and dissemination and specifically deliverable 2 as outlined in Annex I (Part A) of the Specific Grant Agreement and Annex I of the Framework Partnership agreement. The overall Dissemination and Communication Strategy Plan for ERN eUROGEN will be based on the defined internal management rules, methodologies and work plan specified in the Grant Agreement.

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. DISSEMINATION PROCEDURES

2.1. Target Audiences

In line with the obligations regarding dissemination of results and achievements, ERN eUROGEN will ensure continuous, complete and highly visible communications activities to the various target audiences identified.

2.1.1 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, 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 channeling this information to the other parties, where appropriate, either through the newsletter or targeted emails.

2.1.2 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 current 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 is 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 national level;
- Local HCPs can ask their national authorities for more cooperation at 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.

The EU ERN Communication Office and other ERNs

Objectives:

- Provide a two-way channel for the EU ERN Communication Office and officers to the participants of ERN eUROGEN relating to communications;
- Provide a two-way channel for other ERN Communication officers and for ERN Cross-Actions relating to communications.

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

2.2. Tools

2.2.1 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 the European Association of Urology (EAU) by 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.
- [EC e-newsletter](#) – a bi/tri-annual highlight of activities and programmes of interest within the ERNS. ERN eUROGEN is responsible for suggesting and providing content relating to the network.
- [Network e-newsletter](#) – a monthly newsletter, published on the first Tuesday of the month, facilitated using the EAU’s [MailChimp](#) account. ERN eUROGEN is responsible for writing and curating content, compiling the newsletter, sending it out, and maintaining the database of recipients.

2.2.2 Social Media

Social media channels offer a way of establishing a direct connection with a large audience, and to provide 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 all over Europe or abroad. 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 in the field by 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 responsible for writing and curating content and responding to any contact made to the network.

Channel	Type	Posts	Times	Analyze
Facebook	Business page, events and potentially groups	Once per day, over 40 characters	Wed, Thu & Fri, 12-4pm	Followers, reach & engagement.
Instagram	Business profile	Once per day, increased visibility using stories, handles (@) and 5-10 hashtags under 24 characters (#)	Mon, Wed, Thu, Fri & Sat, 11am, 3pm, 7pm & 9pm.	Followers, likes, comments & mentions. Stories views & engagements.

LinkedIn	Company page, business/commercial networking	When relevant/appropriate, longform content embeds (e.g., linking to website, blog, presentation or video)	Tue, Wed, Thu & Sat, 8am, 12pm, 6pm & 8pm	Clicks, impressions & interactions
Twitter	Business profile, lists of contacts and influencers	2-3 x per day, 71-100 characters + reactive tweets and retweets. Increased visibility using handles (@) and 2-3 hashtags (#).	Tue, Wed, Thu & Sun, 7am, 12pm, 4pm & 9pm.	Followes, impressions, retweets & mentions.
WordPress	Website & blog	Longform content, search optimized	When appropriate/relevant	Page views, users
YouTube	Brand channel	Video content/vlogs, titled and tagged carefully	When appropriate/relevant	Subscribers, views, comments, shares.

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 will use the below tools relating to social media:

- [AnswerThePublic](#) – an app which monitors autocomplete data from search engines like Google and shows what people are asking around your keyword. This can then be used to create fresh, useful content.
- [Canva](#) – a easy 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.
- [Hemingway](#) – an app which highlights lengthy, complex sentences and common errors in order to make posts shorter and more readable
- [Hootsuite](#) – a social media management platform which allows the monitoring of multiple social media streams in one place, scheduling of posts in advance, easy access to analytics data, as well as social listening and engagement.

Content ideas:

A Month of Tweets				
Monday	Tuesday	Wednesday	Thursday	Friday
FAQ	Retweet	Pro-tip	Retweet with comment	Behind-the-scenes pic
# MotivationMonday	Key piece of content	GIF	Statistic	Meme
Twitter poll	Ask a question	WednesdayWisdom	Successful past Tweet	Shout out
Positive brand news	UGC	Video	Go live!	One-liner

2.2.3 Mobile App

ERN eUROGEN will be developing a mobile app for smartphones and tablets. This will allow increased communication and dissemination, and interaction with partners and the public, with users receiving notifications when there are updates. In addition to links to our website and newsletters, we will also be able to include important information which we have developed, such as patient pathways, clinical guidelines, and clinical decision support tools, to help both patients and clinicians.

2.2.4 Promotional Materials

- Logos – (see Appendix 1)
- EC
- [EC Communication Toolkit for ERN Members](#) – including press materials, ERN visuals, flyers, brochures, website guidance, social media visuals, and videos. In addition, there are separate webpages for:
 - [Overview](#) – including communication materials
 - [Videos](#) – collating the official videos made by the EC
 - [Publications](#) – collating press releases, factsheets, brochures from the EC
 - [Interactive Map](#) – showing ERN members
- [CIRCABC](#) – an EC hosted intranet accessible by ERN eUROGEN partners which 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 will provide 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.

2.2.5 Media and Scientific Publications

- Articles for [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."
- Scientific Abstracts/Presentations for academic meetings
- Press releases
- Advertisements
- [Interviews](#)
- Encouraging other types of coverage (e.g., TV or radio)
- Patient stories - encourage patients to share their stories

2.2.6 Working with Other Organizations

When working with other organizations, we will support our aims and objectives, we will develop joint approaches to events, publications, education and training, promotional materials, and so on. We have connections to several other external organizations (professional bodies, member organizations, advocacy groups, etc.) as Supporting Partners:

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

or as collaborators:

- [EURORDIS](#) Rare Diseases Europe
- [European Joint Programme on Rare Diseases](#) (EJP RD)

as well as having links with the other 23 ERNs, particularly those with which we have cross-ERN actions.

2.2.7 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 eUROGEN experts on relevant topics
- [European Association of Urology Annual Congress](#) – our own specialty session, speakers at other plenary sessions, information booth in the exhibition center, articles in the congress newspaper
- Various scientific congresses – expert speaking contributions from project stakeholders, scientific abstracts and posters generated by the network
- [Rare Disease Day](#) – active on social media
- [Urology Week](#) – active on social media
- Policy events
- European Commission events

We are also active on social media relating to events in the field, seasonal events, and international awareness days (2020/2021 schedule below):

<p>July</p> <p>Sarcoma Awareness Month</p> <p>17 – World Emoji Day</p> <p>30 – World Friendship Day</p>	<p>August</p> <p>12 – International Youth Day</p> <p>23 – Hashtag Day</p>	<p>September</p> <p>Childhood Cancer Awareness Month</p> <p>Urology Awareness Month</p> <p>5 – International Day of Charity</p> <p>11 – Stand Up to Cancer Day</p> <p>17 – World Patient Safety Day</p> <p>21-25 – Urology Week</p>	<p>October</p> <p>Spina Bifida Month</p> <p>10 – World Mental Health Day</p> <p>19-23 – Health Education Week</p>
<p>November</p> <p>Bladder Health Month</p> <p>13 – World Kindness Day</p>	<p>December</p> <p>25 – Christmas</p>	<p>January</p>	<p>February</p> <p>4 – World Cancer Day</p> <p>6 – Time to Talk Day</p> <p>28 – Rare Disease Day</p>
<p>March</p> <p>Kidney Month</p> <p>12 – World Kidney Day</p>	<p>April</p> <p>Stress Awareness Month</p>	<p>May</p> <p>10-14 – Women’s Health Week</p>	<p>June</p> <p>ERN eUROGEN Strategic Board Meeting (date TBC)</p> <p>Men’s Health Month</p>

15 – World Sleep Day 20 – Day of Happiness	7 – World Mental Health Day 19-23 – Every Kid Healthy Week	17-21 – Mental Health Awareness Week	14-18 – Men’s Health Week 14 – World Blood Donor Day
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3. EVALUATION

The communication and dissemination activities will be evaluated continuously to measure the success of the strategies outlined. Evaluation will involve:

- Monitoring the content of the websites, newsletters, and other websites talking about ERN eUROGEN;
- Using questionnaires following events;
- Discussions about the use of dissemination channels and materials amongst network members;
- Measuring the number of citations of publications, and using analytics systems on websites, newsletters and social media.

4. APPENDIX 1 – FOLLOWING EC REGULATIONS

Communication – ERN eUROGEN will promote the action and its results, by providing targeted information to multiple audiences (including the media and the public) in a strategic and effective manner.

Dissemination – ERN eUROGEN will, as soon as possible, disseminate its results by disclosing them to the public by appropriate means, including in scientific publications (in any medium).

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

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

Personal data – ERN eUROGEN will process 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

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 organized 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).

Visibility of EU Funding – ERN eUROGEN will ensure that any dissemination activity displays the EU Emblem and includes following text: "ERN eUROGEN is one of the 24 European Reference Networks (ERNs) approved by the ERN Board of Member States. The ERNs are co-funded by the European Commission. For more information about the ERNs and the EU health strategy, please visit <http://ec.europa.eu/health/ern>"

Co-funded by the European Union



ERN eUROGEN respects the EC rules as outlined in Article 27. 1.2 Information on EU funding of the Framework Partnership Agreement. ERN eUROGEN will ensure that any dissemination activity related to actions funded by the specific grants displays the EU Emblem and includes following text: "This [insert appropriate description, e.g. report, publication, conference, infrastructure equipment, insert type of result, etc.] was funded by the European Union's Health Programme (2014-2020).





Network
Urogenital Diseases
(ERN eUROGEN)

<http://eurogen-ern.eu/>

Co-funded by the European Union



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