



European Reference Network

for rare or low prevalence
complex diseases

⚙️ **Network**
Paediatric Cancer
(ERN PaedCan)

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Dissemination and Communication Strategy Plan

Submission: 30.10.2017



Co-funded by
the Health Programme
of the European Union

*This Dissemination Plan was funded by the European Union's Health Programme (2014-2020).
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Abbreviations

AACR – American Association for Cancer Research

ASCO – American Society of Clinical Oncology

CCI-E – Childhood Cancer International Europe

ECCO – European Cancer Congress

ECPC – European Cancer Patient Coalition

ENCCA - The European network for cancer research in children and adolescents

EORTC - European Organisation for Research and Treatment of Cancer

EPAAC - European Partnership for Action Against Cancer

ERN PaedCan – European Reference Network in Paediatric Cancer

ESTRO – European Society for Radiotherapy and Oncology

ESMO – European Society for Medical Oncology

ExPO-r-Net – European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment

NMT – Network Management Team

SIOPE – SIOP (Europe) the European Society for Paediatric Oncology

SIOPE CRC – SIOPE Clinical Research Council

TYA – Teenage and Young Adults

Introduction

The European Society for Paediatric Oncology (SIOPE) is the only pan-European organisation representing all professionals working in the field of childhood cancers. With more than 1,600 members across 34 European countries, SIOPE is leading the way to ensure the best possible care and outcomes for all children and adolescents with cancer in Europe.

SIOPE has extensive experience and expertise in several successful EU projects (e.g., ENCCA, PanCareSurFup, ExPO-r-Net, EuroCancerComs, EPAAC, Oncovideo Project), and some of its activities include dissemination and coordination, newsletters, websites, e-blasts, workshops, exhibitions, events in the Parliament, as well as public affairs and policy activities such as formulating responses to policy papers, directives and regulations. SIOPE also has close ties to patients and patient advocates.

SIOPE's network and experience make it uniquely positioned to carry out the ERN PaedCan's dissemination and communication strategy.

This Dissemination and Communication Strategy Plan will outline the proposed strategy and plan to meet the expectations and needs of the project. 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.

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 PaedCan will be based on the defined internal management rules, methodologies and work plan specified in the Grant Agreement.

1.1 Objectives

The major purpose of the Dissemination and Communication Strategy Plan is to provide a broad overall framework and guideline for disseminating and communicating about the activities of the ERN PaedCan and to ensure that the desired impact of the ERN PaedCan is achieved.

Specifically, the objectives are to:

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

2 Dissemination procedures

In order to ensure a highly efficient dissemination of scientific information at the European level, the ERN PaedCan consortium will create and carry out key communication actions addressed in WP6 in order to implement the best way to promote the project's results. To raise scientific and public awareness on ERN PaedCan's progress on building a roadmap to approved expert referral sites and tumour advisory boards for healthcare providers, systematic public information will be disseminated through internal and external dissemination routes as detailed in the key sections below.

2.1 Key actions

SIOPE will carry out the dissemination activities and will have the following tasks:

- Development of a strategy for internal and external dissemination;
- Publicize the project to all relevant network stakeholders;
- Identify the most appropriate results to be announced to relevant target audiences by means of publications and information outlets/tools;
- Proactively identify and maintain a database of the most efficient opportunities to reach these target audiences;
- More detailed tasks are described in the respective WP-Description in the Grant Agreement.

2.2 Target audiences

SIOPE, together with the Network Manager and the Network Coordinator will organise actions to increase the visibility of ERN PaedCan for respective project partners and other communities. The target groups are identified as follows:

- ERN PaedCan members and partners
- Previous ExPO-r-Net partners
- SIOPE, SIOP International, PanCare,
- SIOPE member community (SIOPE CRC, etc.); Healthcare and research professionals
- Interest groups such as partners in the Joint Action on Rare Cancers, ECPC, EURORDIS, Rare Cancers Europe, and other relevant European Projects
- CCI Europe, Patients, families and advisory groups (including teenagers and young adults)
- Policy makers: EU institutions and (sub)national authorities
- Industry: pharmaceutical and medical device organisations
- Regulatory agencies
- General public
- New Member States and European countries outside the EU. Translations will be encouraged.

2.3 Internal dissemination

The ERN PaedCan infrastructure aims to guarantee that all partners are informed about the progress and activity outcomes, network-planning and all other issues which ensure well-informed and well-briefed partners. This ensures the maximum efficiency of resources, consistency of results, and increases the synergy and integration of the partners. The management meetings and coordination of meetings will play an important role in this task. All information generated within the project will be communicated to the NMT who will be in charge of channelling this information to the other contractors, where appropriate.

2.4 External dissemination

ERN PaedCan aims at communicating effectively with parties outside of the consortium, in particular other healthcare providers (members and non-members), as well as with other European consortia, policy makers, and more generally with the scientific community and its citizens at large. We will pro-actively reach out to the

communities that we anticipate will be most interested in and benefit from the outputs of ERN PaedCan, through participation in key meetings and organising dissemination events with relevant groups (e.g. parents and survivor associations).

Since the European Commission is also providing communication material about ERNs, the ERN PaedCan Dissemination Partner will liaise with the European Commission to harmonize complementary material.

In line with the obligations regarding dissemination of results and achievements, the NM and the SIOPE office will ensure continuous, complete and highly visible public relations activities to the various target audiences identified. This includes the provision of all public documents, materials and tools described in the next section.

2.5 Tools

- Use of online tools provided by the EU and through already existing platforms of SIOPE:
 - Project website (including detailed statistics)
 - An interactive ERN PaedCan website linked with the SIOPE website and hosted by the European Commission will be established. SIOPE is responsible for administering the website and will serve as the main contact point for external users. The website will include general information and updates on the progress, and will provide direct access to the intranet section.
 - Project intranet
 - The ERN PaedCan intranet, as part of the ERN Collaborative platform, will be accessible by ERN PaedCan partners to gather and share documents and to communicate online on special topics.
 - Project electronic newsletter/bulletin
 - Social media: Twitter, LinkedIn, YouTube (including hashtag #ERNPaedCan and detailed statistics),
- Promotional Materials:
 - Dissemination package including logo, PowerPoint presentation, and acknowledgement statement to the EU
 - Information brochure
 - Flyers, bookmark, roll-up banner and any other relevant promotional material
- Media and Scientific Publications:
 - Press releases
 - Articles
 - Abstracts
 - Scientific Articles/Papers
 - Advertisements
 - Interviews
 - Encouraging other types of coverage (e.g., TV or radio)

2.6 Information gathering on the ERN PaedCan progress

The partnership between SIOPE office team and the NMT, gives a strong added value to ERN PaedCan. Since SIOPE interacts closely with the National Paediatric Haematology Oncology Societies (NaPHOS) and the European

Clinical Trial Groups, which are all represented in the SIOPE Clinical Research Council (CRC), it will enable enhanced communication, coordination and dissemination of information to the whole paediatric oncology community in a very effective manner. SIOPE is an established voice of the paediatric oncology community and drives respective oncopolicy actions.

2.7 Attendance at Events

Some of the most effective possibilities for disseminating knowledge are based on the participants' own initiatives, for example, in the course of attending meetings, self-organized conferences, workshops, training sessions, seminars and self-published websites, publications, press releases, multimedia CD-ROMs, TV etc.

The benefits of disseminating knowledge on the consortium's own initiatives are evident: The participants are free to decide on the framework, matters and ways of presenting the knowledge, and can additionally systematically advertise within the target group, always within the rules established by the Grant Agreement.

Dissemination will also take place within third party activities, e.g. in speeches, presentations and information booths within conferences, exhibitions, training sessions organised by third parties (conferences organised by IRCs or by national or regional governments etc.).

ERN PaedCan project material will be distributed and the project will be presented at events such as:

- The annual International Childhood Cancer Day (ICC, 15 February) and annual Childhood Cancer Awareness Month (September)
- SIOPE Clinical Research Council (CRC) meetings
- Scientific Congresses (e.g., ESMO Congress, ASCO, AACR, EORTC Survivors Summit, ECCO Summit, SIOP International Congress, ESTRO Congress, TYA Internal Congress, ACCELERATE Congress, CCI Europe Annual Congress)
 - Expert speaking contributions from project stakeholders
 - Scientific abstracts and posters generated by the network
- Policy events (ICC event at the Parliament, MEPs Against Cancer (MAC) events, and others)
- European Commission events
- SIOPE and other member-led events (annual national meetings)

2.8 Evaluation

The dissemination activities will be evaluated continuously to measure the success of the strategies outlined in the Dissemination Plan. The evaluation method will involve:

- Monitoring the content of the websites, newsletters, and other websites talking about ERN PaedCan;
- Using questionnaires following workshops and conferences;
- Discussions about the use of dissemination channels and materials amongst partners;
- Measuring the number of citations of publications, and using measuring systems on websites, newsletters and social media.

2.9 The EU Emblem (ERN PaedCan Logo)

As dissemination partner SIOPE will *survey and respect the EU rules with regards to the ERN and ERN PaedCan logo* as outlined in Article 27. 1.2 Information on EU funding of the Framework Partnership Agreement. *SIOPE office will respect the Information and right to use the EU Emblem* and ensure unless CHAFEA requests otherwise, that any dissemination activity related to the specific actions (including at conferences, seminars, in information material, such as brochures, leaflets, posters, presentations, etc., in electronic form, via social media, etc.) and any infrastructure, equipment or major result funded by the specific grants displays the EU Emblem and include 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).”

Furthermore, SIOPE office as dissemination partner takes care that the EU Emblem has prominence when displaying with another logo and give guidance to ERN PaedCan partners on the use of the logo (which can be used by the partner without first obtaining permission from the Agency, however, solely for the purpose above). They will also survey, that any communication activity with respect to the specific action, in whatever form and or by whatever medium, must specify that it reflects only the author’s views and that CHAFEA/European Commission is not liable for any use that may be made of the information contained therein.

2.10 Publications

Dissemination activities including but not restricted to publications and presentations are governed by the provisions outlined below.

Prior notice of any planned publication/dissemination activity, with a copy of it, shall be made 30 days before the publication/dissemination activity to the NMT. Any objection to the planned publication shall be made in accordance with the NMT in writing to the NMT and to any Party concerned within 10 days after receipt of the notice. If not resolved through discussion with the NMT, the Executive Committee will ultimately be involved in the decision making process. If no objection is made within the time limit stated above, the publication is permitted.

If foreground Information / Intellectual Property or Background Information / Intellectual Property of another Party is needed for publication of a student degree thesis, approval for use shall be obtained from the appropriate Party owing such rights or affected by the use. The approval of the relevant parties shall be sought at least 30 days before the latest date of which the contents of the planned publication can be altered. For the avoidance of doubt, no such publication will be made without such approval of a party who would be adversely affected by that publication. Approval shall not be unreasonably delayed or withheld.

SIOPE office will respect the above mentioned established rules and contribute to their proper implementation.