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Paediatric Cancer European Reference Network Y3-5

JA2015 - GPSD [705038]

START DATE: 01/03/2019

END DATE: 28/02/2022

DURATION: 36 month(s)

CURRENT STATUS: Finalised

PROGRAMME TITLE: 3rd Health Programme (2014-2020)

PROGRAMME PRIORITY: -

CALL: Multiannual Grant Agreements for European Reference Networks

TOPIC: ERN Specific Grant Agreements 2019 - 2021

EC CONTRIBUTION: 600000 EUR

KEYWORDS: Cross-Border Healthcare, Paediatric Oncology, Tumour Boards

Project abstract

The mission of ERN-PAEDCAN is to improve outcomes of childhood cancer and malignant haematological diseases by reducing the current inequalities in different member states. Comparative population-based cancer registry research has provided robust evidence for significant inequalities in survival from childhood cancer across Europe: the difference may be as much as 30% units, with worse outcomes in Eastern Europe. Despite a reduction in the geographical differences in the period 2005–09, the former socialist economies still have roughly 20% excess mortality from cancer in children compared with the rest of Europe. In its second year ERN-PAEDCAN aims to continue to provide paramount requirements for 'Cross-border healthcare' allowing the provision of healthcare to children with cancer in a Member State other than the Member State of affiliation. We identify target groups with conditions requiring a particular concentration of resources or expertise, especially when the expertise with certain cancer conditions is rare and case volume low. Taking into account the potential burden on families seeking cross border health care ERN-PAEDCAN intends to establish mechanisms to facilitate movement of information and knowledge rather than patients. We aim to extend local and national 'tumour board' culture to the cross border level with identified and required ICT tools and eHealth networks. High-quality, accessible and cost-effective healthcare for childhood cancer are achieved by strengthening the integration of pre-existing knowledge and expertise, and fostering stronger cooperation between patients, professionals and healthcare authorities. The innovative contribution of ERN-PAEDCAN is a clear roadmap to approved expert referral sites and tumour advisory boards for healthcare providers fulfilling our vision of a more supportive environment for children with cancer with special needs by integrating pre-existing networks and knowledge across borders.

Work package

Work Package 1: Coordination of the action

Start month: 1

End month: 36

Work Package Leader: CCRI

Task 1.1 Day-to-day management and implementation of the ERN-PAEDCAN activities.

Task 1.2 Facilitate and support the communication among ERN members.

Task 1.3 Support the dissemination and evaluation activities.

Task 1.4 Preparation and submission of technical and financial reports.

Work Package 2: Dissemination

Start month: 1

End month: 36

Work Package Leader: CCRI

Task 2.1 ERN PaedCan will disseminate access points through the RoadMap for HCPs looking for advice and highly skilled treatment interventions making Guidance within the RoadMap easily accessible via relevant WEB pages (SIOPE/European Commission).

Task 2.2 ERN PaedCan will disseminate the potential of the CPMS and foster structured advice by reaching out to HCP in Europe creating awareness of this option in close collaboration with clinical trial groups.

Task 2.3 These activities will receive strong support through SIOPE by distributing these activities in addition actively to its members and capitalising also on the CRC community and its potential to inform national paediatric national societies and tumour groups.

Task 2.4 With the active support of SIOPE, Coordinator's team will create/update the dissemination plan of activities for years 3 to 5 to make sure information may reach a maximum of interest groups within the communities.

Task 2.5 Two GA meetings per year, including all relevant stakeholders (ERN-PAEDCAN members, PO experts, patient and parents' organisations, policy-makers) will be used to foster dissemination about the new opportunities to improve patients' pathways across Europe as needed and relevant.

Task 2.6 Stakeholder meetings and meetings with other ERNs, meetings of adult cancer groups and parents'/patients' survivor organisations will further help to inform the wider communities. This also includes creation of dissemination materials (e.g. brochures, banners, etc.) and promotion of ERN-PAEDCAN in external meetings.

Work Package 3: Evaluation of the action implementation

Start month: 1

End month: 36

Work Package Leader: CCRI

Task 3.1 Implementation of the Quality Assurance Plan (QAP).

Task 3.2 Outline the quality control, quality assurance and present the various roles and responsibilities of the team in managing the project's quality processes.

Task 3.3 Assess and evaluate the impact and quality of the activities proposed under ERN-PAEDCAN through a mid-term and a final evaluation report.

Work Package 4: Roadmap development

Start month: 1

End month: 36

Work Package Leader: CCRI

Task 4.1 Assess the status of the roadmaps initiated in years 1 and 2 of ERN-PAEDCAN.

Task 4.2 Identify the interested trial groups to embark in the bottom up process to outline their standards of care and to identify the respective highly skilled interventions likely to require CBHC settings within their respective clinical trial group.

Task 4.3 As a next step identification of respective HoCs by the CTG engaged with treatment across Europe. HoCs need to provide advisory boards/tumour boards and need to be willing to engage in advisory function and be ready to receive CBHC patients.

Task 4.4 Initiate at least 3 tumour entity sub-network for the ERN PaedCan roadmap.

Work Package 5: Tumour Board development

Start month: 1
End month: 36
Work Package Leader: CCRI

Task 5.1 Continue to identify centres that have a VTB in place and CBHC established that are willing to implement the CPMS.

Task 5.2 Progress report on pitfalls and user friendliness of the CPMS.

Work Package 6: Twinning and e-Training Programmes

Start month: 1
End month: 36
Work Package Leader: CCRI

Task 6.1 Identification of LHEAR country-twinning partners and their needs.

Task 6.2 Identification of individuals willing to participate in educational programmes and educational programmes and opportunities are identified.

Task 6.3 Establish a memorandum of understanding with twinning partner centres.

Task 6.4 Identify the needs of the community and particularly the rare tumour community that would most benefit from the development of the e-learning tools.

Task 6.5 Develop and produce a movie per year on a specific tumour entity.

Task 6.6 Liaise with different stakeholders to produce a webinar on a prior identified topic and tumour entity.

Work Package 7: Best practice sharing

Start month: 1
End month: 36
Work Package Leader: CCRI

Task 7.1 Organise a best practice meeting per year on a tumour entity that is represented in the roadmap development.

Task 7.2 Liaison with representatives of the CRC, chairs of the NAPHOS, other experts and representatives of parents/patients' organisation.

Task 7.3 Establishment of best practice guidelines.

Work Package 8: Survivorship Passport (SURPASS)

Start month: 1

End month: 36

Work Package Leader: CCRI

Task 8.1 Continuous support to the paediatric oncology community, parents, patients and survivors to implement the SURPASS across Europe.

Task 8.2 Setting up a stakeholder meeting per year of the SURPASS community to support the implementation of the SURPASS on the national level.

COORDINATOR

ST. ANNA KINDERKREBSFORSCHUNG GMBH (CCRI GmbH)

Zimmermannplatz 10
1090 Vienna

Austria

WEBSITE: <http://https://www.ccri.at>

PARTNERS

No partners related to the current project

Dissemination report.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

Continuous dissemination activities. (Banner, Leaflets, roll ups, etc.)

Final evaluation report.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

A final evaluation report will be produced to assess the quality of the project implementation.

Roadmap contribution 1.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

Roadmap sub-networks establishment in one specific Tumour Entity.

Roadmap contribution 2.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

Roadmap sub-networks establishment in one specific Tumour Entity.

Roadmap contribution 3.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

Roadmap sub-networks establishment in one specific Tumour Entity.

Final report on the CPMS and Virtual Tumour

Board integration.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

Promotion of the CPMS system in HCP centres. Report on the Virtual Tumour Board integration and updated user community.

Twining fellowship/observership agreements.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

Up to 6 oncologists from LHEAR-country centres will participate in an exchange programme for 1-2 months.

Twining training programme.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

Up to 24 healthcare professionals from LHEAR countries should participate in different educational events (e.g. ESO, ESTRO courses etc.). Attendance reports will be produced.

Dedicated tumour entity webinars.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

3 specialty training webinars on specific tumour entities will be organised. Training programme reports will be produced.

Educational movie 2.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

1 movie dedicated to parents' and patients' or to a tumour entity. Flyer (or leaflet) with link to movie will be delivered.

Educational movie 3.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

1 movie dedicated to parents' and patients' or to a tumour entity. Flyer (or leaflet) with link to movie will be delivered.

Best practice meeting.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

3 best practice meetings on specific tumour entities. Refers to tumour group(s) actively participating in the Roadmap contribution of Objective 1. Meeting outcomes on best practice guidelines will be documented.

SURPASS meeting.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

Foster implementation and integration of SURPASS. Meeting outcomes will be documented in the final report.

ESCP Registry development

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

Development of an European Standard Clinical Practice (ESCP)-specific registry An ESCP-specific slim but enhanced registry beyond pure epidemiological registry ambition performed in a number but not all member states, and prepare for the integration of the European Patient Identity Management (EUPID). The registry will allow to measure paediatric cancer entity-specific outcomes, and will contribute to close the current gaps in paediatric outcome registration in Europe.

SURPASS Bioregistry

CCRI GmbH

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 04/07/2022

Implementation of the SURPASS Bioregistry

Mid-term evaluation report.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 03/12/2020

A mid-term evaluation report will be produced to assess the quality of the project implementation.

Mid-term report on the CPMS and Virtual Tumour Board integration.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 03/12/2020

Promotion of the CPMS system in HCP centres. Report on the Virtual Tumour Board integration and updated user community.

Educational movie 1.

CCRI

Paediatric Cancer European Reference Network Y3-5 (ERN-PAEDCAN-Y3-5)

Published on: 01/12/2020

1 movie dedicated to parents' and patients' or to a tumour entity. Flyer (or leaflet) with link to movie will be delivered.