ERN-PAEDCAN Partner - Paediatric Rare Tumours Network - European Registry
(N°777336)

Interim Evaluation Report – PARTNER project

D3.2 – Preparation of the Interim report

This report is a part of the project 777336 PARTNER which has received funding from the European Union's Health Programme (2014-2020)

(Version 30.06.2019)

PARTNER (777336) – 2nd Periodic report (1 January 2019 to 31 December 2019)	DELIVERABLES

Deliverable Title -

WP no.	Del. no.	Lead beneficiary	Nature	Dissemination level	Delivery date from Annex I (project month)	Delivered Yes/No	Actual / Forecast delivery date
3	3.2	CCRI	Report	Public	30.06.2019	Yes	30.06.2019

Comments

CCRI has completed the interim evaluation of the project at M18 of the project – as foreseen by the Annex I of the contract.

Interim Evaluation Report – PARTNER project

The interim evaluation carried out by CCRI was completed based on the QAP and the Annex I of the contract.

The Evaluation of the project had three objectives:

- O3.1 Ensure that deliverables are achieved within the project´s timeframe and in line with progress towards the strategic objective
- O3.2 Enhance internal project management and internal processes through evaluation of the project management and feedback loops to partners
- O3.3 Maximise the impact of outcomes and increase utility of the project

The WP3 - Evaluation work package has three tasks during the project's implementation:

- Task 3.1 - Creation of the Quality Assurance Plan
- Task 3.2 - Undertake the continuous evaluation of the project management and internal processes
- Task 3.3 - Systematic appraisal of the quality of the project
- Task 3.4 – Systematic appraisal of the effects of the project
- Task 3.5 – External evaluation

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Task 3.1 - Creation of the Quality Assurance Plan

PARTNER has developed a **Quality Assurance Plan** (QAP) (D3.1 Quality Assurance Plan (QUAP) in RP1 which **outlines the quality control (QC) and quality assurance (QA)** of the project's work plan and the continuous process for improvement of the implementation of the project.

The QAP was inspired in the Grant Agreement and Consortium Agreement of project PARTNER but it is not a repetition of these documents. The major purpose of the QAP was to provide a broad overall framework and guidelines for implementing quality management on the project to ensure a successful execution of PARTNER.

Task 3.2 - Continuous evaluation of the project management and internal processes

Project management:
CCRI has been working closely with AOPD and supported the coordinator and project manager to help the implementation and reporting activities of the project, and the management of the consortium.
Work packages, deliverables, milestones, risks and specific objectives have been carefully evaluated based on the indicators of the QAP. CCRI joined meetings and telephone conferences; supervised project targets and was available for providing help for the resolution of possible problems. The management team of partner has applied the management model described in the Annex I and QAP of the contract.

Meetings:
A kick-off meeting and 4 consortium meetings took place until 30.06.2019 as planned in the Annex I, and also other important working meetings and teleconferences were organised as described in Table 1, Table 2 and Table 3 of the 1st periodic report of the project.

Financial management:
The financial report has been submitted on time including the incurred costs of the 1st reporting period. The coordinator has distributed the pre-financing as per contract, and monitored the budget consumed by the members of the consortium. Apart from minor budget shifts justified in the report no relevant budget changes took place which would have needed a contract amendment request.

Work packages:

WP Number	WP Title	Lead beneficiary	Start month	End month	Status[1]
WP1	Coordination of the project	1 - AOPD	1	36	On time
WP2	Dissemination of the project	2 - CCRI	1	36	On time
WP3	Evaluation of the project	2 - CCRI	1	36	On time

[1] Status can be indicated as: ***on time, delayed, achieved, or partly achieved***.

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WP4	Analysis and harmonization of data acquisition of the existing national VRT registries	4 - EKUT	1	18	On time
WP5	Creation of a European registry for paediatric patients with very rare tumours	1 - AOPD	1	36	On time
WP6	Standard of care recommendations for children with VRT	5 - CURIE	1	36	On time
WP7	Integration of LHEAR countries in an EU platform dedicated to VRT in paediatric age	6 - GUMed	1	36	On time

The workplan has been implemented with minor delays and without major deviations - as reported in the 1st technical report of the project. All partners have confirmed that in general activities were going according to plan in the first 18 months of the project.

Deliverables:

Up-to-date overview of deliverables in the EC Funding and Tenders portal:

WP No	Del Rel.	Del No	Title	Description	Lead	Nature	Dissemir	Est. Del. Date (ar	Receipt Da	Approval Date	Status
WP2	D2.1	D1	Dissemination & Commun	Dissemination & Communication plan are establis...	CCRI	Report	Public	31 Mar 2018	20 Apr 20	23 Apr 2018	Approved
WP2	D2.2	D2	Leaflet.	Numbered in the proposal as (MD.3). A leaflet t...	CCRI	Other	Public	31 Mar 2018	05 Jun 20	05 Jun 2018	Approved
WP2	D2.3	D3	Project website launched	Numbered in the proposal as (MD.5). Each projec...	CCRI	Websit	Public	31 Mar 2018	20 Apr 20	23 Apr 2018	Approved
WP2	D2.4	D4	Layman version of the fin	Numbered in the proposal as (MD.5).This is a sh...	CCRI	Report	Public	31 Dec 2020			Pending
WP3	D3.1	D5	Quality Assurance Plan (Q	Quality Assurance Plan (QUAP) is completed.	CCRI	Report	Public	31 Mar 2018	16 May 2(	17 May 201	Approved
WP3	D3.2	D6	Preparation of the Interin	Preparation of the Interim Report.	CCRI	Report	Public	30 Jun 2019			Pending
WP3	D3.3	D7	Preparation of the final E	Preparation of the final Evaluation Report.	CCRI	Report	Public	31 Dec 2020			Pending
WP4	D4.1	D8	Gathering of VRT entities	Gathering of VRT entities and variables of nati...	EKUT	Other	Public	31 Dec 2018	31 Dec 2(	13 Mar 2019	Approved
WP4	D4.2	D9	Report and recommendat	Report and recommendations on harmonized proced...	EKUT	Report	Public	30 Jun 2019			Pending
WP4	D4.3	D10	List of variables that will	List of variables that will be selected to link...	EKUT	Other	Public	30 Jun 2019			Pending
WP5	D5.1	D11	Report on the operative s	The registry structure is expected to be fully ...	AOPI	Other	Public	31 Oct 2020			Pending
WP6	D6.1	D12	List of VRT that need star	List of VRT that need standard of care elaborat...	CURI	Other	Public	30 Jun 2018	29 Jun 20	19 Jul 2018	Approved
WP6	D6.2	D13	Development of standard	Development of standard of care recommendations...	CURI	Other	Public	31 Dec 2020			Pending
WP7	D7.1	D14	Report describing the resi	Report describing the results of the EU survey.	GUM	Report	Public	30 Apr 2019	30 Apr 20		Submitted
WP7	D7.2	D15	Creation of a manual (in E	Creation of a manual (in English and local lang...	GUM	Other	Public	31 Oct 2020			Pending

Deliverables of the 1st reporting period - overview as per Evaluation template:

Deliv. N°	Deliverable Title	WP N°	Lead beneficiary	Type	Due date	Status[2]	Justification of delay(s) and Corrective measure(s) (if applicable)
D2.1	Dissemination & Communication plan	WP2	2 - CCRI	Report	3	Achieved	The establishment of the Dissemination and Communication plan took a little longer, but it is much

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	established.						better balanced than expected.
D2.2	Leaflet.	WP2	2 – CCRI	Other	3	Achieved	The realisation of the Leaflet took a little longer than expected for technical reason, but it is much better representative of the project PARTNER.
D2.3	Project website launched.	WP2	2 – CCRI	Websites, patents filling, etc.	3	Achieved	The integration of website took a little longer than expected for technical reason.
D3.1	Quality Assurance Plan (QUAP) is completed.	WP3	2 – CCRI	Report	3	Achieved	The review of the QUAP took a little longer than expected.
D4.1	Gathering of VRT entities and variables of national registries and preparation of consensus core data sheet for with entities and variables for European data base.	WP4	4 - EKUT	Other	12	Achieved	
D6.1	List of VRT that need standard of care elaboration.	WP6	5 - CURIE	Other	6	Achieved	

All deliverables of the 1st reporting period have been achieved with minor delays. These delays have been explained and justified above and also in the technical report of the project.

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Milestones:

Mile. N°	Milestone Title	WP N°	Lead beneficiary	Due date	Means of verification	Status[3]	Justification of delay(s) and Corrective measure(s) *(if applicable)*
MS1	Kick-off meeting will be organized.	WP1	1 - AOPD	1	Organisation of kick-off meeting with all stakeholders.	Achieved	
MS2	Consortium meetings.	WP1	1 - AOPD	36	Every 6 months Consortium meetings are organised to address the progress of the project.	Achieved	The organization of the biannual consortium meetings is an ongoing process that will last until the project ends in December 2020
MS3	PARTNER logo available.	WP2	2 - CCRI	3	PARTNER logo available.	Achieved	
MS4	PARTNER communication tools available.	WP2	2 - CCRI	6	PARTNER communication tools available.	Achieved	
MS5	Quality Assurance Plan (QUAP).	WP3	2 – CCRI	3	Quality Assurance Plan (QUAP).	Achieved	
MS6	Evaluation Plan template is ready.	WP3	2 - CCRI	6	Evaluation Plan template is ready.	Achieved	

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MS7	Consensus meeting on entities and variables to be collected within PARTNER.	WP4	4 - EKUT	12	Consensus meeting on entities and variables to be collected within PARTNER.	Achieved	
MS9	Development of the International Registry structure	WP5	1 - AOPD	12	Development of the International Registry structure.	Achieved	
MS14	Creation of a VRT Working Group for LHEAR countries.	WP7	6 - GUMed	3	Creation of a VRT Working Group for LHEAR countries.	Achieved	
MS15	Elaboration and circulation of a VRT questionnaire for LHEAR countries.	WP7	6 - GUMed	10	Elaboration and circulation of a VRT questionnaire for LHEAR countries.	Achieved	
MS16	Full Integration of PARTNER in the SIOPE communication plan and tools.	WP2	2 - CCRI	6	In order to achieve maximum reach, full integration of PARTNER in the SIOPE communication plan and tools is expected.	Achieved	

All the milestones of the 1st reporting period have been achieved.

Implementation risks and mitigation actions:

Risk N°	Description of risk	WP N°	Proposed risk-mitigation measures	Did risk materialize?	Mitigation measures applied?
1	Management risk.	WP1	PMT will prepare a risk analysis and agree on contingency plan at the beginning of the project.	No	The QAP has outlined the quality control (QC) and quality assurance (QA) of the project's work plan and the continuous process for improvement of the implementation of the project. The QAP has also outlined the various activities, deliverables, milestones, roles and responsibilities of the project parties involved, to ensure the quality of the project's implementation processes and follow-up. The QAP refers to the contractual project documentation which outlines all rights and duties, commitments and agreed work plan to which all partners are legally bound. The QAP mentions and provides guidance for all documents and templates that support the implementation methodology of PARTNER. The QAP has listed the quality planning tools and metrics to be used on the project and the process for ensuring it adheres to the required standards and controls, risk management, reporting and amendment procedures.
2	Different opinion between national groups.	WP4, WP5, WP7	National groups will agree a decision-making process at the beginning of the project.	No	WP5 - The decision-making process was discussed in the Kick-off meeting (Brussels) and in the 1st Consortium meeting (Luxembourg). Different modalities have been proposed and applied in relation of the various tasks (of the different WP) to be

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					performed. All different groups agreed on the need to establish a correct decision-making process before to commence the discussion on each specific task in order to avoid pauses in the workflow and to speed up the whole process. E.g.: writing of the guidelines through the creation of working groups with established duties and according a step by step plan of work. // identification of the 4 VRT needing standard of care elaboration: proposal gathered by TC and voting via email. WP4-PARTNER aims to harmonize data collection for the four-existing rare tumour data bases for the goal to build a common European registry. There is a critical risk of different opinions about the content of the registry and the structure. This registry will be built on a strong basis of European collaboration over several years. Already while preparation of the proposal there was an agreement on the future structure of the European data base. It was agreed on a federal structure where the strong basis is built by the (harmonized) existing national registries. The decision-making process for the entities and variables to be registered were discussed in the first consortium meetings in January and April 2018 (Bruxelles and Luxembourg). All different groups agreed on the proposed decision-making process. It was decided to share information on the existing national data bases

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					including entities and variables being collected. Available resources (data sheets, set of variables) from different countries were presented in the consortium meeting in Luxembourg. It was agreed to build working groups for different entities. A final decision on entities and working groups was made within the Consensus Meeting in Tuebingen (September 2018). Further discussion of the data set was done via Email and a consensus was reached. WP7 - Until now there was not any risk influencing the realisation of the project. The project task 7.1 and milestone MS14 were obtained without any problems and differences between the national groups represented by specialists from onco-haematology from LHEAR countries. However, the task 7.2) and MS15 - although reached on time – posed some difficulties. They resulted from our wish to send the surveys on the organization, registration and medical care over selected VRT in children should be sent not only to the LHEAR countries collaborating with PARTNER project, but also to the other LHEAR countries (i.e.: Slovakia, Hungary, Bosnia and Herzegovina, North Macedonia, Bulgaria, Latvia, Estonia, Romania (different centers) and Belarus). We received the contacts to the pediatricians/pediatric oncologists from these “other” LHEAR

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					countries from well-known representatives of LHEAR countries collaborating with PARTNER. However, we assumed that we will not receive responses from all of them. The mail contacts might not be precise, and/or the responders might not be interested in cooperation with our project. Nevertheless, we sent the surveys to these new LHEAR countries and since then received 4 answers. The responders seemed to be interested not only in filling in the surveys but also in further cooperation with PARTNER in terms of improving the medical care over VRT in children.
3	Presence of nonhomogeneous data in the national registries.	WP4	Data will be homogenised at a national level before they will be transferred to PARTNER.	No	Standards in the four countries of the existing rare tumour data bases: Poland, Italy, France and Germany are different. WP4 not only aims for a harmonization of the gathered VRT entities and variables of the national registries, but also for recommendations on harmonized procedures of primary source data verification, registration and documentation. Standards of good clinical practise and EU regulations will be applied. A consensus on recommendations and necessary requirements for registration in PARTNER is planned for the first half of 2019 (D4.2). An agreement on the decision-making process shall be reached within the Consensus Meeting in Brussels in January 2019.
4	Impossibility to reach consensus on standard of	WP6	A process to reach consensus will be defined. If consensus would be impossible this will be clearly	No	This potential risk would be discussed / analysed during the validation process of the standard of care guidelines, i.e. during 2019, but the WP6 should be on time with nothing excepted

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	treatment for certain VRTs.		reported in the final documents.		impossible until now.
5	Differences in the regulation of registries and data transferring in the different countries.	WP5, WP7	Data pseudonymization will allow overcoming these problems.	No	WP5 - Data pseudonymization through the EUPID system was discussed and approved since it could allow to overcome different regulations among associate and collaborative partners. Moreover, the adherence, of the EUPID tool, to the strict European regulation will be crucial to avoid any hurdle at the time other EU countries will start to register patients in the European registry, when actually in use. The linkage between the national registries preserving data privacy will be assured by the adoption of the EUPID system. On one hand, PARTNER will involve the VRT registries already existing in France, Germany, Italy and Poland. This first step is since these Groups are already collaborating and have taken first steps to harmonize their national registries. Soon, moreover, it will be investigated how to collaborate and share data with general paediatric oncology national registries like the ones existing in United Kingdom, Spain, The Netherlands and Hungary. On the other hand, for countries where a VRT registry has not yet been established, the possibility to use directly the EU Registry will be offered. For this last purpose, EUPID system will be integrated in the PARTNER registry, in order to allow direct registration of patients from the countries where a VRT registry is

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					not in use. WP7 - Differences in the regulation of registries and data transferring in the different countries have been identified through the analysis of the results of surveys (Task 7.2). However, the analysis is ongoing, so the risk-mitigation measures have not yet been applied.
6	Lack of effective IT system interoperability.	WP5, WP7	IT partners should demonstrate the effective interoperability of the systems before starting their work.	No	WP5 - In a period in which interoperability between systems in health care has become the real challenge, the system we are aiming to create (PARTNER registry) will be equipped with all the technological components that enable the exchange of data with external systems according to the main interoperability standards used in health care domain, such as HL7 and DICOM, both using dedicated channels and via web services exposure. On this basis, interoperability is possible in compliance with the standard frameworks IHE and CDISC. The adoption of these standards will guarantee the possibility to connect PARTNER with the European IT platform, with the Clinical Patients Management System (CPMS) and with the European Platform for Rare Disease Registration (ERDRi). The use of the EUPID system is another asset to guarantee the possibility to create links between different systems and ultimately ERN communities. WP7 - Lack of effective IT system interoperability has been discussed at the meetings related to the PARTNER project;

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					however, this topic has not been analysed yet by WP7 so the risk-mitigation measures have not been implemented.
7	Lack of resources for LHEAR to participate to PARTNER.	WP7	No or very low costs will be asked to LHEAR countries to access VRT platform and PARTNER LHEAR countries. In addition, involvement of LHEAR countries will be progressive according to their resources.	No	The activities led by WP7 to date did not require any financial resources and costs to the LHEAR countries invited to cooperate. Additionally, the costs of the 1st LHEAR countries PARTNERship Meeting organized by GUMed on 14th of September 2018 in Gdansk, Poland have been reimbursed to all participants from the EU LHEAR countries.

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Specific objectives of the project and performance metrics:

Specific Objective 1 Effective project coordination and management in order to timely achieve the project objectives		
Activities carried out	**Target**	**Achievement status**
• Regular teleconferences with the project management team (PMT) including the project coordinator, UPRC representative, project manager and WP leaders every other month or at least quarterly starting Month 1 • Creation of a meeting calendar by Months 2 • Organisation of regular working meetings • Organisation of biannual meetings including all relevant share and stakeholders • Preparation of Interim and Final reports for Months 12, 24, 36	- TCs of PMT scheduled	Achieved
	- Project meeting agenda agreed	Achieved
	- Meetings of network's partners - arranged and achievements documented (agenda, minutes, presentations).	Achieved
	- Respective reports available as scheduled	Achieved
Output Indicator(s)	**Target**	**Achievement status**
• Scheduled meetings • Preparation of Interim	- >90% achieved according to proposed schedules	Achieved
	- Successful report deliveries on target	Achieved
Outcome/Impact Indicator(s)	**Target**	**Achievement status**
• Consortium meetings	- 2 per year	Achieved

Specific Objective 3 Evaluation of the project		
Activities carried out	**Target**	**Achievement status**
• Creation of the Quality Assurance Plan outlining the activities and the organisational and management	- QAP developed and	Achieved

structure of PARTNER guiding the successful implementation of the project (Months 1-3)	implemented	
Output Indicator(s)	**Target**	**Achievement status**
• Surveillance of project management and internal processes – on target evaluation of Deliverables and Milestones. • Solution-based monitoring and evaluation processes via written feedback to project partners for corrective action, (monitor-review-remedy model). Indicators will include frequency of deadlines being met to deliver reports; participation in meetings and telephone conferences; and internal audit of project targets and resolution of problems. • Questionnaires to allow systematic appraisal of the quality of the project assessing the utility of project outcomes to meet user needs. (Questionnaires to healthcare professionals, patients and families, policy makers will be approached with questionnaires, to evaluate the utility and progress of the project outcomes • Systematic appraisal of the effects of the project. Here Measures will include assessment of public dissemination (on-line review of e-media), impact on public policy documents.	- >80% of Deliverables and MS on target	Achieved
	- >80% of actions on target	Achieved
	- >80% of questionnaires send returned within 3 months	Ongoing
	- At least 2x year documented dissemination activity	Ongoing
Outcome/Impact Indicator(s)	**Target**	**Achievement status**
• Quality Assurance Plan (QUAP) (preparation phase M1-3) • Interim Evaluation Report (preparation phase M12-17, delivered in M18) • Final evaluation report (preparation phase M30-35, delivered in M36)	- QAP and evaluation reports available at target times showing successful project implementation	Achieved (QAP + interim ev.)

Specific Objective 4 Analysis and harmonization of data acquisition of the existing national VRT registries		
Activities carried out	**Target**	**Achievement status**
• Identification and agreements within project participants of VRT entities and variables to be included in PARTNER.	- 100% agreement within the partners by M12	Achieved

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• Harmonization of data definition and quality among the different national registries. • Definition of list of variables that will be selected for transfer from the Virtual Consultation system into the PARTNER database.		

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Output Indicator(s)	Target	Achievement status
• Preparation of a document containing the VRT candidates and variable included in the national registries during M2 to 6. • Preparation of core data sheet for with variables and entities to be transferred and prospectively registered by the PARTNER (preparation during M6 to12)	- List of VRT and variables documented by national registries by M6	Achieved
	- Agreed core data-sheet for PARTNER by M12	Achieved
Outcome/Impact Indicator(s)	**Target**	**Achievement status**
• Preparation of a report and recommendations for harmonization of data verification, registration and documentation during M12- 18	- Report on harmonization procedures between data registries by M18.	Ongoing

Specific Objective 5 Creation of a European registry for paediatric patients with very rare tumours		
Activities carried out	**Target**	**Achievement status**
• Create the registry infrastructure based on the core data set identified in WP4 (M12 to 18) with EUPID as an integral part • Integrate EUPID to respective national registries of France, Germany, Italy and Poland (M12-18) • Connect the virtual consultation system (VCS) to PARTNER using the EUPID system (M18- 24) • Define access modality to PARTNER for countries without national registries during above cited developments and time periods	- PARTNER infrastructure established	Achieved
	- EUPID applied retrospectively and for prospective use in respective registries	Ongoing
	- VCS and PARTNER connected by Month 24	Ongoing
	- LHEAR access modality to PARTNER defined	Ongoing
Output Indicator(s)	**Target**	**Achievement status**
• Development of the EUPID application to provide interoperability between national registries and PARTNER for data transfer and regular future	- Integration of all national registries achieved by M32 and PARTNER fully operable	Ongoing

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updates (M18- 24) followed by the implementation test phase (data transfers M24 – 30) and corrective measures M30 to 34)	and live by M36	
Outcome/Impact Indicator(s)	**Target**	**Achievement status**
• Final report by M36 describing the scope of PARTN-ER and data included in the newly established EU VRT – (PARTNER) registry with full interoperability and the potential to be linked with the EU proposed IT platform for ERNS as needed.	- Final Report ready on the successful PARTNER development	Ongoing

Specific Objective 6 Elaboration of Standard of care recommendations for children with VRT		
Activities carried out	**Target**	**Achievement status**
• Identification of VRT entities without standardized recommendations and evaluation of available evidence for harmonization of recommendations by M6	- VRT entities identified qualifying for standardized recommendations	Achieved
Output Indicator(s)	**Target**	**Achievement status**
• Preparation of harmonized recommendations and discussion with international external partners (e.g. ERN EUROCAN in Europe and Children's Oncology Group in USA) during M12 to 24.	- Consensus meeting on harmonized recommendations for selected VRT	Ongoing
Outcome/Impact Indicator(s)	**Target**	**Achievement status**
• Preparation of publication of consensus recommendations on 2 entities in peer reviewed journals and distribution through the project website (M25 to 35).	- Successful publication or at least acceptance of 2 new VRT consensus recommendations by M36	Ongoing

Specific Objective 7 Integration of LHEAR countries in a EU platform dedicated to VRT in paediatric age		
Activities carried out	**Target**	**Achievement status**
• Development and circulation of a dedicated questionnaire to identify LHEAR	- 80% of LHEAR	Achieved

countries with and without pre-existing national institutional VRT data collection or registries to understand their special needs for support given their less favourable economic situation during M2 to 10.	questionnaires received back by Month 10	
Output Indicator(s)	**Target**	**Achievement status**
• Letters of commitment of LHEAR countries with and without pre-existing structures to feed or use the PARTNER received by M12	- 80% of LHEAR countries committed by M12	Achieved
Outcome/Impact Indicator(s)	**Target**	**Achievement status**
• Preparation of report describing the results of the LHEAR countries' questionnaires during M10 to 14. • Creation of a manual in different languages explaining how to use the virtual consultation system and how to access and use the new VRT PARTNER platform starting M12 for VCS and for registry in M30. • Translations in LHEAR language of standard of care recommendations for VRT during M30 - 36 to inform also the wider non- expert audience (patients and families) • Creation and implementation of a dedicated access to the newly established PARTNER VRT registry for selected LHEAR countries by M28- 32	- LHEAR questionnaire report completed by M16	Ongoing
	- Manual translated in at least 3 different languages by M34	Ongoing
	- At least 2 standard of care recommendations translated in at least 3 languages by M36	Ongoing
	- At least 2 LHEAR countries operative and successfully accessing the PARTNER platform by M34	Ongoing

Task 3.3 - Systematic appraisal of the quality of the project

In the second half of the project, a cohort of healthcare professionals, patients and families, policy makers will be approached with questionnaires, to evaluate the utility and progress of the project outcomes. Examples include the utility of the planned deliverables, i.e., establishment and activation of the PARTNER registry, the integration of the EUPID system for initial and continued data linkage via the EUPID App respecting all data protection rules, etc.

Task 3.4 – Systematic appraisal of the effects of the project

This task aimed to assess public dissemination, and its impact.

Dissemination of the project:

SIOPE has carried out the planned dissemination activities as foreseen by the Annex I and by the Dissemination and Communication Plan. The technical report describes in great detail the variety of tools and channels SIOPE has utilised. SIOPE has created an interactive project website integrated within the EXPERT website, and disseminated the aims, efforts and results of the project at conferences, on social media and via promotional materials (bookmarks, flyers, brochures, etc.). Thanks to the dissemination activities, the PARTNER project's activities and aims are visible to all stakeholders: healthcare and research professionals, Parents and Patients, Policy makers, as well as industry and general public.

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Specific Objective 2 Dissemination of the project		
Activities carried out	**Target**	**Achievement status**
• Definition of a dissemination and communication plan to promote PARTNER and facilitate communication towards all target groups in collaboration with National Paediatric Haematology – Oncology Societies (NAPHOs) during months 1 to 3	- Dissemination &communication plan established by Month 3	Achieved
Output Indicator(s)	**Target**	**Achievement status**
• Creation of the project kit including logo, dedicated brochure, templates, 1-page factsheet and presentation for project partners during Months 1 to 6. • Integration of PARTNER in the EXPeRT public website & SIOPE Intranet	- Complete project kit available by Month 6	Achieved
	- Project website integration by Month 8	Achieve
Outcome/Impact Indicator(s)	**Target**	**Achievement status**
• PARTNER newsletter disseminated via emails and integrated in the SIOPE newsletter	- 2 newsletters per year	Achieved

Task 3.5 – External evaluation

This task includes a small board of external reviewers who will assess the quality of the registry's implementation according to JRC registry platform guidelines, by the end of the project. In the meantime, these external reviewers will be invited to participate in PARTNER consortium meetings. The task is only due by December 31, 2020.

Conclusion

The Interim Evaluation concluded, that the PARTNER project has complied with the QAP, followed the workplan laid down in Annex I, and is expected to achieve its objectives, complete its deliverables and milestones until the end of the project. During the first 18 months, no major deviations took place, only minor delays happened which are completely normal during such a project. These delays have been appropriately taken care of and have been justified and explained in the first technical report. Technical and financial reports of the first period were submitted on time to the EC and have already been approved.