



## Paediatric Clinical Research Infrastructure Network (PedCRIN)

CSA\_ H2020-INFRADEV-2016-2017/H2020-INFRADEV-2016-1 (Individual support to ESFRI and other world-class research infrastructures)

Grant Agreement # 731046

### Deliverable D5.10 Newsletter 7

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**Contact:** Jacques Demotes  
ECRIN-ERIC Director General  
European Clinical Research Infrastructure Network  
BioPark, 5-7 rue Watt  
75013 Paris, France  
Tel: +33 180058646  
[jacques.demotes@ecrin.org](mailto:jacques.demotes@ecrin.org)  
[www.ecrin.org](http://www.ecrin.org)



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## PedCRIN supported multinational clinical studies



The **WE Study** (Walking Easier with cerebral palsy) has enrolled 57 children in three European countries: Norway, France and Poland. More information about the [WE-study](#) can be found on the PedCRIN website.



The **POPART** (Prophylactic Oropharyngeal Surfactant for Preterm infant: A Randomised Trial) has enrolled 228 babies in Ireland, Belgium, Sweden, Norway, the Czech Republic and Portugal. Read more about the [POPART-study](#) on the PedCRIN website.

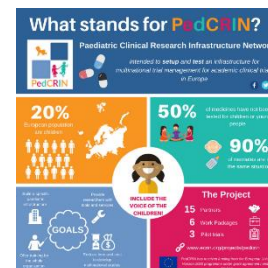
The **OTBB3 Trial** (Oxytocin Treatment in Neonates and Infants With Prader-Willi Syndrome) has recruited 13 children in two European countries (France and Belgium). Regulatory submission is going on in Germany, Italy and the Netherlands

## PedCRIN Sustainability Board meeting

The **PedCRIN Sustainability Board Meeting** was held on **26th June 2020** via videoconference. Members of the consortium and the government representatives (ECRIN assembly of members) participated in the meeting. The purpose of the meeting was to elicit the perspective of the members on the sustainability of PedCRIN project. Next meeting with the Board Members will be organized in September 2020 to follow-up on the progress.

## PedCRIN Communication and Consultation Toolkits

Work Package 5 of the PedCRIN project developed a Communication and a Consultation Toolkit. All project partners can implement these toolkits in all their communication activities. Those partners able to perform a consultation with children and/or parents can use the Consultation Toolkit, which will help them organize such consultations.



## Interviews

The partner Fundació Sant Joan de Déu Barcelona (FSJD) has performed a series of interviews to PedCRIN partners and sponsors to disseminate their tasks and roles in the project:

Interview with **Tessa van der Geest**, PedCRIN consortium member (RadboudUMC, The Netherlands)

Interview with **Dr. Donato Bonifazi**, PedCRIN consortium member (CVBF, Italy)

Interview with **Dr. Pirkko Lepola**, PedCRIN consortium member (HUS, Finland)

Interview with the **POPART Trial Sponsor**: University College Dublin (Ireland)

Interview with the **WE-Study Trial Sponsor**: St. Olavs University Hospital (Norway)

Interview with **Joana Claverol Torres** (FSJD, Spain)

Interview with **Dr. Eric Vermeulen** (VSOP, Netherlands)

You can access to the different interviews in the News section of PedCRIN website:

<https://ecrin.org/projects/pedcrin/news>

## YPAG activities

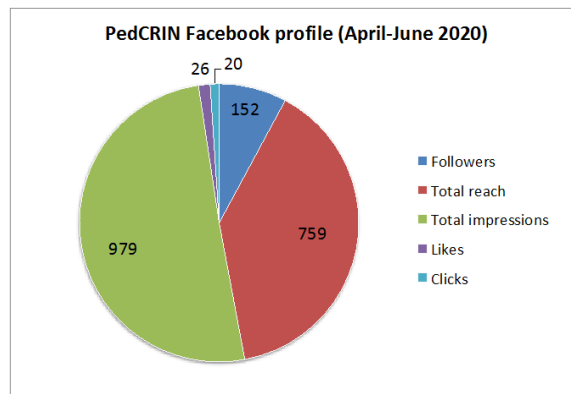
Several European YPAGs (Young Persons Advisory Groups) have participated along with PedCRIN in diverse activities aimed at engaging young patients to participate in clinical research. YPAGs from Italy, Spain, Scotland and other European territories have reviewed some of the patients' materials for the PedCRIN's pilot trial "The WE-Study".



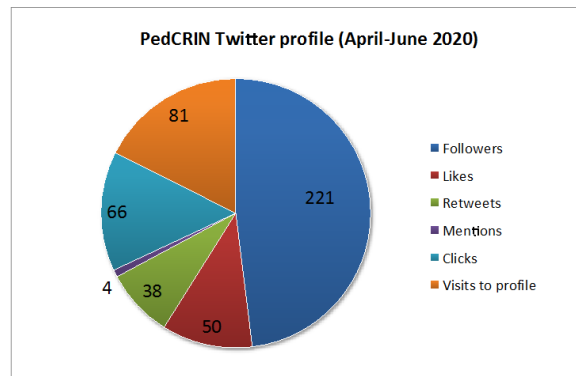
## PedCRIN social media

PedCRIN disseminates its outcomes and relevant information related to paediatric clinical trials and stays in touch with the audience through its social media profiles. You are invited to interact with us!

**Facebook:** The [Facebook profile](#) of the PedCRIN project has been active since January 2018 and currently has 152 followers. It is updated weekly with new contents and the most relevant KPIs are monitored every month.



**Twitter:** The [twitter profile the PedCRIN project](#) aims at reaching the general public but also professionals working on the healthcare field, researchers, sponsors of clinical trials and institutions. There are several tweets posted every week and the profile is dynamic, this is, there is an interaction with the followers. The KPIs are monitored every month.



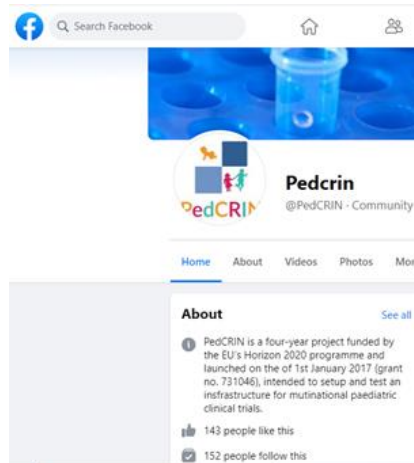
**LinkedIn:** The [LinkedIn profile of the PedCRIN project](#) currently has about **3,627 followers** and its aim is to increase the visibility of the project among professionals (researchers, scientific community, industry, institutions) outside the PedCRIN consortium).

## PedCRIN WP 3 Tools for Paediatric and Neonatal Clinical Trials

PedCRIN Work Package 3 has developed a series of tools addressed to help researchers and clinicians develop paediatric and neonatal clinical trials in an easier and more effective way. For instance, the document "**Procedures for management of paediatric clinical trials**" includes advice on relevant areas such as regulatory submissions, pharmacovigilance, monitoring or biosample management. All these tools are available at PedCRIN website in the ["Deliverables" section](#).

## What's PedCRIN?

The Paediatric Clinical Research Infrastructure Network (**PedCRIN**) **brings together** the European Clinical Research Infrastructure Network (**ECRIN**) and the founding partners of the European Paediatric Clinical Trial Research Infrastructure (**EPCT-RI**) to **develop capacity for the management of multinational paediatric non-commercial clinical trials**. **PedCRIN is a four-year project funded by the European Union's Horizon 2020 programme, launched on January 1<sup>st</sup> 2017 (grant agreement number 731046).**



The aim of PedCRIN is to develop the necessary tools and capacity to enhance the quality, safety, efficacy and ethical standards of multinational, non-commercial paediatric clinical trials. PedCRIN will effectively **bridge paediatricians and other partners across Europe** (and internationally) to combine resources and expertise to conduct and manage robust studies, while minimising risk and protecting the participants. **Continue reading about the PedCRIN project, the work packages it contains and the project partners on the [website](#).**



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**Our mailing address is:**

ECRIN (PedCRIN)  
5-7 Rue Watt  
75013 Paris, France

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