



EUROPEAN PAEDIATRIC TRANSLATIONAL RESEARCH INFRASTRUCTURE

# EPTRI Communication and Advocacy

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EPTRI OPEN MEETING — April 2<sup>nd</sup>-3<sup>rd</sup> 2020



This project has received funding from the European Union's Horizon 2020 research and innovation programme under Grant Agreement No 777554

# OVERVIEW

## 1. EPTRI Communication Activities

- Internal
  - Communication and dissemination plan
  - Communication toolkit
- External
  - Social media
  - Website
  - Newsletters
  - Brochure
  - Webinars
  - Events

## 2. Communication and dissemination plan to be included in the Conceptual Design Report (CDR)

## 3. Patient involvement

# INTERNAL COMMUNICATION


## 1. EPTRI COMMUNICATION AND DISSEMINATION PLAN


## 2. COMMUNICATION TOOLKIT — group of resources including:


- Presentation template (ppt)
- Abstract template
- Roll-up
- Infography
- Other similar resources aimed at aligning EPTRI communication strategy


## 3. MAILING LIST — all@eptri.eu


**What is EPTRI?**  
EPTRI stands for European Paediatric Translational Research Infrastructure

 **20%** European population are children


 **30%** Marketed drugs have paediatric authorization


 **MINORS ARE NOT SMALL ADULTS**

 Create a framework for a future basic research infrastructure (RI) focused on **PAEDIATRIC MEDICINES**, including the most relevant technological innovations in paediatric research




- **Conceptual Design Report** describing scientific/technical requirements + key components of the new RI
- **11 WPs**, 4 thematic platforms and **1** scientific domain
- **2-year** project






- **26** partners from **19** EU /non EU countries
- Coordinated by 

[www.eptri.eu](http://www.eptri.eu)

**EPTRI**  
EUROPEAN PAEDIATRIC TRANSLATIONAL RESEARCH INFRASTRUCTURE

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# EXTERNAL COMMUNICATION

## FACEBOOK PROFILE

- Lay audience (non-professional)
- **13/15 posts** published each month
- Total page likes: **178**
- Audience:
  - Mostly **women**
  - **25-34** years old
  - Followers
    - ✓ **Italian** (CVBF, PENTA)
    - ✓ **Albanian** (UHCT)
    - ✓ **Spanish** (FSJD, SERMAS)



# EXTERNAL COMMUNICATION

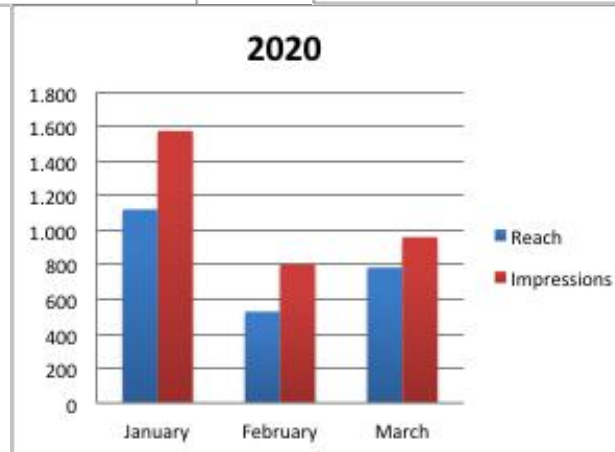
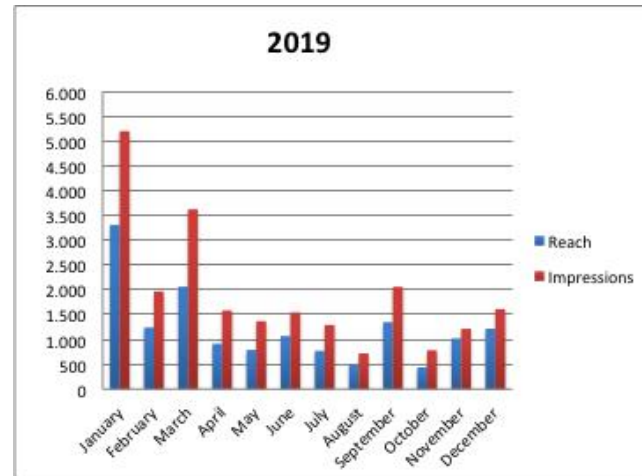
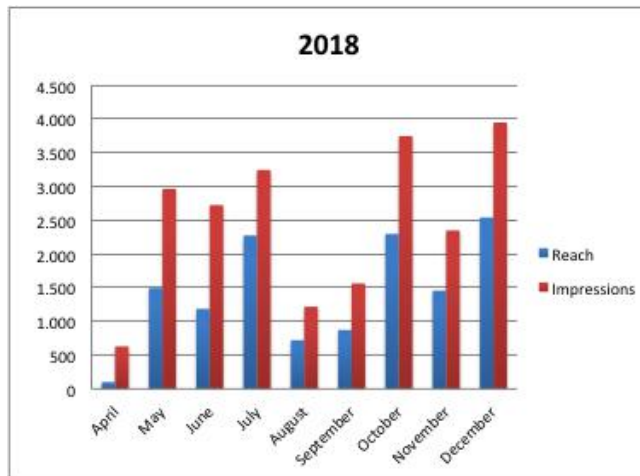
## FACEBOOK PROFILE

- Content: EPTRI presentations in events, activities with YPAGs, documents, webinars, **scientific thematic campaigns** (banners, infographics or explainer videos)
  - Biobanking
  - Paediatric Pharmacology
  - Paediatric Formulation
  - Women in science
  - Science in films
  - Science books
  - Research models (pre-clinical)
  - Genetics
  - Rare Diseases
  - Sample donation



# EXTERNAL COMMUNICATION

## FACEBOOK KPIs: Page Reach and Impressions



# EXTERNAL COMMUNICATION

## FACEBOOK KPIs (April 2018-March 2020)

- Engagement rate (mean): **32%**
- Total likes: **734**
- Total loves: **21**
- Total comments: **6**
- Total shares: **105**
- Post clicks: **1,802**
- Post reach: **29,371**
- Posts published: **341**



# EXTERNAL COMMUNICATION

## LINKEDIN PROFILE

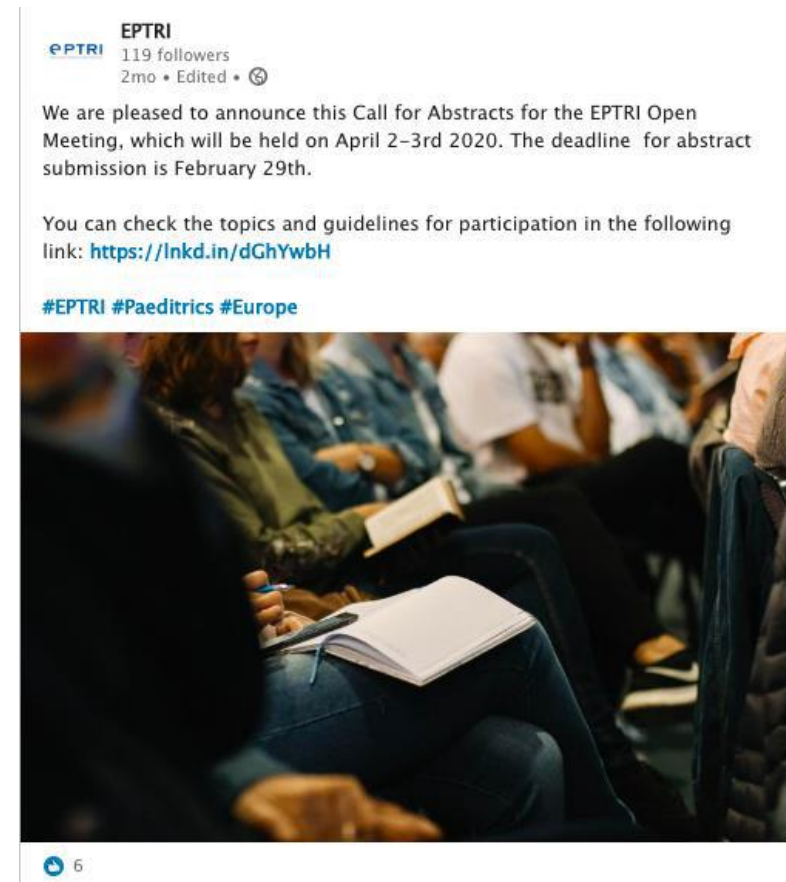
- Specialized audience: researchers, clinicians, institutions, policy-makers...
- Around **12 posts** per month
- Total page followers: **118**
- Audience mainly **Italian** and **Spanish**. They work on **research, health-care, pharma**, education and biotechnology
- General contents:
  - Scientific papers
  - Biomedical and RI events, meetings, workshops
  - Webinars
  - Newsletter subscription
  - Articles on biobanks, pharmacology, etc.
  - EPTRI presentations and activities



# EXTERNAL COMMUNICATION

## LINKEDIN KPIs (April 2018-March 2020)

- Engagement rate (mean): **96%**
- Page views: **1,077**
- Visitors
  - Mobile: **121**
  - Desktop: **292**
- Total reactions: **493**
- Total post comments: **21**
- Total shares: **73**
- Post clicks: **583**
- Posts published: **296**
- Viewing impressions: **21,835**



# EXTERNAL COMMUNICATION

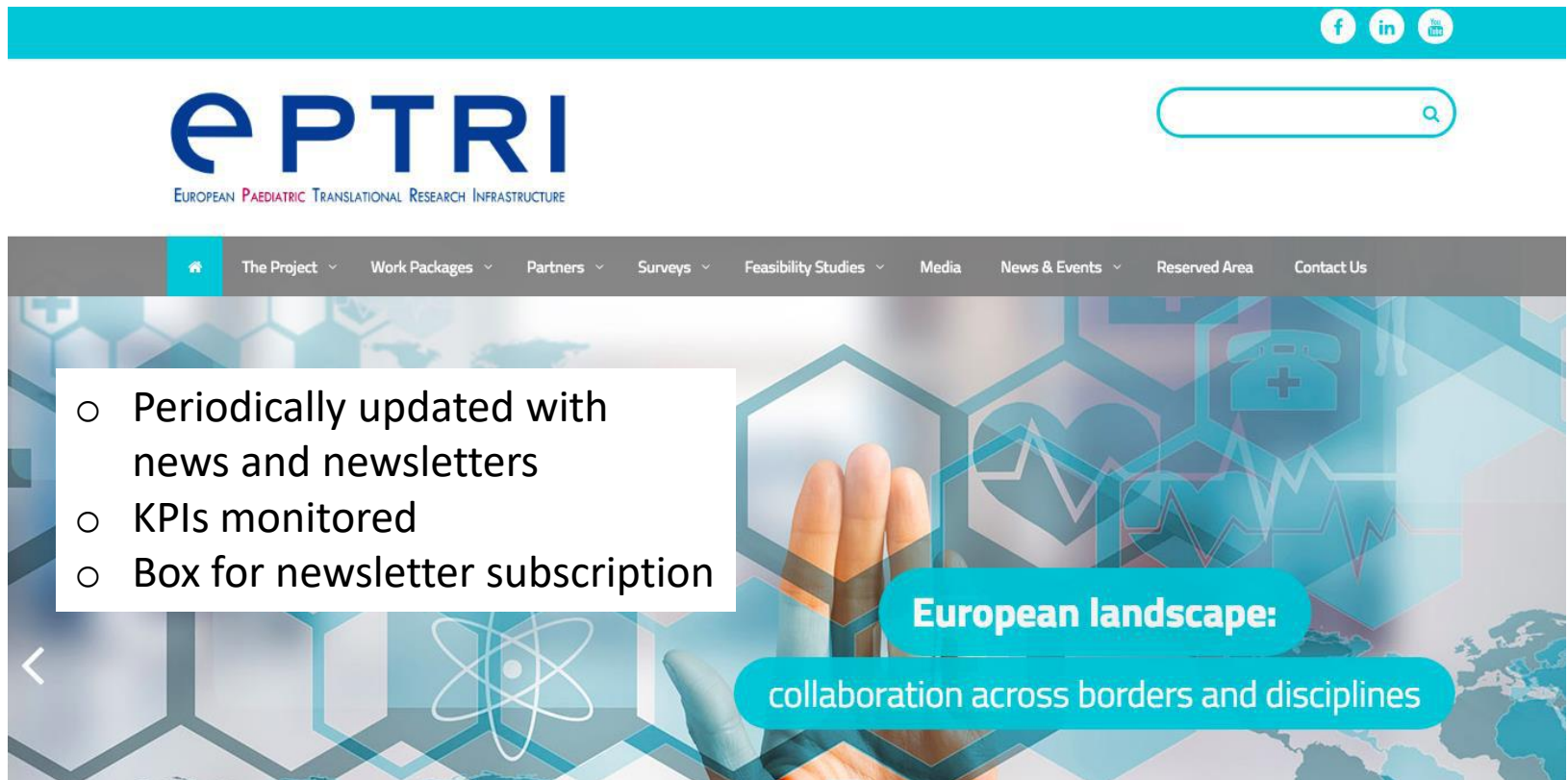
## YOUTUBE CHANNEL

The screenshot shows the EPTRI YouTube channel interface. At the top, there is a search bar with the text 'Buscar' and a magnifying glass icon. To the right of the search bar are icons for a grid, a bell, and a profile. Below this is the large EPTRI logo in blue, with the text 'EUROPEAN PAEDIATRIC TRANSLATIONAL RESEARCH INFRASTRUCTURE' underneath it. The channel name 'EPTRI' is displayed in blue, with '7 suscriptores' (7 subscribers) below it. To the right of the channel name is a 'SUSCRITO' (Subscribed) button and a bell icon. Below the channel name is a navigation bar with the following links: 'INICIO', 'VÍDEOS', 'LISTAS DE REPRODUCCIÓN', 'CANALES', 'COMENTARIOS', and 'MÁS INFORMACIÓN'. Below the navigation bar is a section titled 'Subidas' (Uploads) with a 'REPRODUCIR TODO' (Play All) button. Below this are five video thumbnails with their titles and view counts:

- ID-EPTRI Project (European Paediatric Translational...)**  
110 visualizaciones • Hace 9 meses
- Webinar on Social Media to communicate Science and...**  
35 visualizaciones • Hace 1 año
- ID-EPTRI Project - KOM - full video - part 2**  
12 visualizaciones • Hace 1 año
- ID-EPTRI Project - KOM - full video - part 1**  
15 visualizaciones • Hace 1 año
- ID-EPTRI Project - Kick-off Meeting**  
25 visualizaciones • Hace 1 año

# EXTERNAL COMMUNICATION

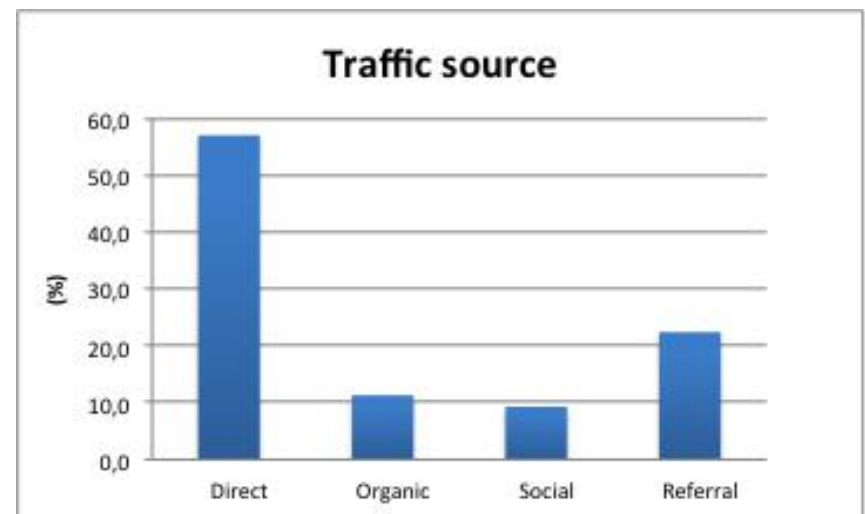
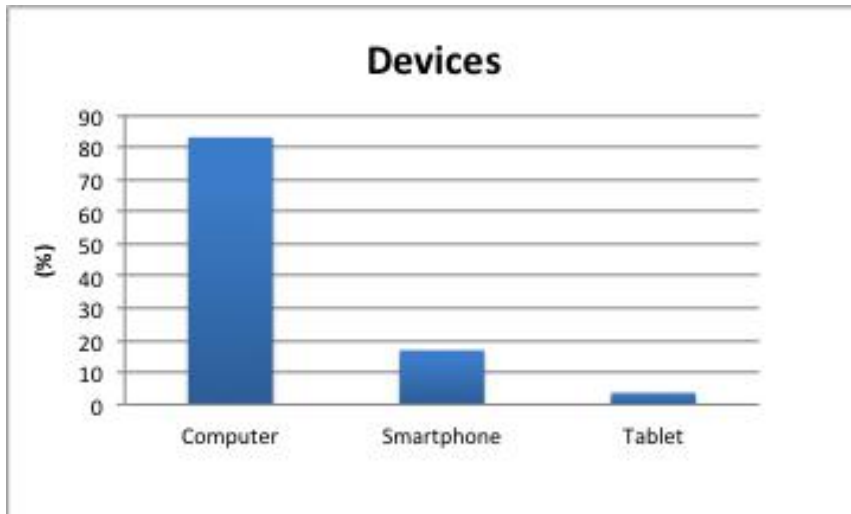
## EPTRI WEBSITE



# EXTERNAL COMMUNICATION

## EPTRI WEBSITE KPIs (Jan 2010 – March 2020)

- Total visitors: **6,273**
- Returning visitors: **2,624 (41.8%)**
- Age: **25-44**
- Country: mostly from **Italy, USA, Spain, France, Albania** and **UK**
- Page views: **25,212**



# EXTERNAL COMMUNICATION

## EPTRI WEBSITE KPIS

### Top 10 most visited pages (Jan 2018 – March 2020)

Page	Page Views	Bounce Rate
Homepage	7574 (30,0%)	40,8%
About the project	1605 (6,4%)	68,3%
News	1553 (6,2%)	33,1%
Partners and collaborators map	1220 (4,8%)	54,1%
WP1	815 (3,2%)	29,4%
CVBF	545 (2,2%)	44,9%
EPTRI Open Meeting	500 (2,0%)	71,0%
Governance	494 (1,9%)	53,3%
Supporters	437 (1,7%)	53,8%
Newsletters	330 (1,3%)	40,0%
<b>Total views</b>	<b>25212</b>	

# EXTERNAL COMMUNICATION

## NEWSLETTERS



- **7 newsletters** since the launch of the project
- Published on the EPTRI **website** and disseminated through the **mailing list** and **social media**
- Newsletters include:
  - Short editorial from a partner of the consortium + picture and signature
  - Latest news related to the state of art of the project
  - Presentations at relevant events
  - Scientific publications related to the project
  - Events section



# EXTERNAL COMMUNICATION

## NEWSLETTERS



Title	Total Recipients	Successful Deliveries	Total Bounces	Open Rate	Total Opens	Click Rate
1st EPTRI Newsletter	1063	1045	18	27.94%	670	3.73%
2nd EPTRI Newsletter	1060	1042	18	19.10%	403	2.88%
3rd EPTRI Newsletter	1148	1127	21	19.52%	448	3.90%
4th EPTRI Newsletter	1144	1124	20	16.81%	392	2.14%
5th EPTRI Newsletter	1143	1121	22	20.87%	514	1.16%
6th EPTRI Newsletter	1159	1121	38	18.82%	469	0.62%
March 2020 - Special Issue	1140	1116	24	27.06%	633	1.97%



# EXTERNAL COMMUNICATION

## BROCHURE

- Detailed description of the RI **services**
- Audience: **academia, institutions** and **pharma**
- Format: **print** and **digital**
- Disseminated through social media, website and newsletter
- It can also be adapted into a poster or a roll-up
- Launched in **English** but can be translated to any language



# EXTERNAL COMMUNICATION

**ePTRI**  
EUROPEAN PAEDIATRIC TRANSLATIONAL RESEARCH INFRASTRUCTURE



The project has received funding from the European Union's Horizon 2020 research and innovation programme under Grant Agreement 101019786.



**ePTRI**  
EUROPEAN PAEDIATRIC TRANSLATIONAL RESEARCH INFRASTRUCTURE

## EPTRI AIMS AND CONTEXT

Minors represent 20% of the European population and their health protection is one of the most important priority and challenge for Europe. Nevertheless, children are often excluded from the advantages of the scientific innovation, such as new medicinal products, while around 50% of the medicines administered to young patients have been developed for adults and not even been tested specifically for paediatric use.

**Children cannot be compared to adults.** Considering the many biological and physiological changes occurring during human development, they represent a special population that is indeed made of several different age groups with variable pharmacokinetic-biological characteristics. For this reason, it is important to **develop new medicines and therapies for children and young patients by performing dedicated paediatric research** and implementing to this aim the many innovative technologies currently adopted in the drug development process.

EPTRI (European Paediatric Translational Research Infrastructure) is an EU funded project aimed to design the framework for a new infrastructure dedicated to paediatric research that will work to accelerate the **paediatric drug development processes from medicines discovery, preclinical research and developmental pharmacology to age tailored formulations and medical devices.** The final goal is to facilitate the translation of the acquired new knowledge and scientific innovation into paediatric clinical studies phases and medical use.

EPTRI will be an **open science space** allowing researchers to **work together** without geographical, institutional or financial barriers and a system of many interconnected research areas, which will contribute to bring new paediatric medicines on the market according to recognised medical priorities and innovation trends. EPTRI will also promote processes allowing **knowledge translation to the industrial sector** and supporting

'prioritisation' of paediatric drugs development within the existing industrial strategies.

EPTRI is also expected to **positively impact on the social and ethical aspects** since it will address the theme of research for a vulnerable and neglected population and will involve paediatric patients' representatives and Young Persons Advisory Groups (YPAGs) in its advisory bodies to include their point of view in the different activities planned by the future paediatric research infrastructure.

EPTRI is a pan-European initiative, which involves 29 partners from 21 EU and non-EU countries, including non-profit research organisations, top-level universities, scientific and clinical centres of excellence. According to the survey conducted to map paediatric research facilities and competences, **more than 300 research units declared their availability to provide technologies, services and paediatric expertise** and have been grouped in the following Thematic Research Platform: Paediatric Medicines Discovery, Paediatric Biomarkers and Biomarkers, Developmental Pharmacology, Paediatric Medicines Formulations and Medical Devices.

Globally three types of services are foreseen in EPTRI: centralised services, integrated services, common services.

For more details please consult our web site where you will find all the information about the EPTRI project.

<https://eptri.eu/>



## EPTRI SINGLE ACCESS POINT AND CENTRALISED SERVICES

EPTRI operational activity will be based on a **HUB and Spoke model** with coordination and networking activities managed at Central HUB level. The central HUB will also act to **bridge EPTRI and the paediatric initiatives focused on clinical steps to make the whole paediatric drug developmental process more efficient and strategic.** IT technologies and tools will be used intensively to maintain a seamless communication and data sharing within the distributed research units.

In addition to the coordination and networking activities, the Central HUB will be in charge of:

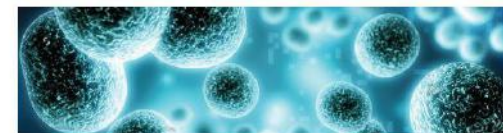
- **Single Access Point (SAP) management**, including provider identification and contract facilitation activities;
- **Management of the legal aspects** regarding **contracting and IP protection** between users and research units providing services;
- **Management of operational contacts** with the concerned paediatric initiatives to translate EPTRI capacities in **support to clinical paediatric studies.**



Requests for service will be received and managed through the Single Access Point that will distribute them according to their specificity.

At Central Hub level, some **'Centralised Services'** are foreseen. Those include services which for their own nature are best supplied in a centralised manner. Those are:

- Knowledge and technology transfer
- Document Repository and Libraries for scientific documents archiving and consultation
- Service to provide scientific advice on EPTRI specific issues (studies dedicated to human development, identification of new strategic lines of interventions, application of new technologies to drug development, etc.)
- Service for scouting of research funding opportunities in topics related to the activities of EPTRI
- Training and education, including staff exchanges and e-learning modules.



# EXTERNAL COMMUNICATION

## WEBINAR



- Overview of main **social media channels**. Different features/different targets
- How to choose the correct **channel** and create key **messages**
- **Tips** to reach a broader audience
- **Science communication** and **outreach** on social media

# EXTERNAL COMMUNICATION

## CREATE KEY MESSAGES ON SOCIAL MEDIA

### GENERAL TIPS


- Choose appropriate tone of voice
- Include key words, tags, hashtags
- Always use visual content, emojis, friendly links
- Be smartphone friendly
- Be appetitive: questions, polls, ask to share, etc.
- Publish at specific times (study audience)
- Interact with the audience
- Be concise and direct
- Create interesting content using a defined strategy




OPTRI

## CREATE KEY MESSAGES ON SOCIAL MEDIA


### SPECIFIC FEATURES



- Create communities using groups
- Donation button for nonprofits: patients
- Share infographics and videos
- Create thematic campaigns



- Lists of profiles of interest
- Create short tweets
- Create threads and polls
- Go for retweets and mentions



- Use a more formal tone
- Include tags and hashtags on the posts
- Publish scientific papers, conferences, professional outcomes
- Join professional groups with similar interests

OPTRI

## COMMUNICATE SCIENCE AND RESEARCH ON SOCIAL MEDIA

### IF YOU ARE A SCIENTIST OR AN ACADEMIC...


- Remember: these are social media, not scientific congresses. Avoid technical jargon and too much data. Humour
- Tell a story: people engage if they are moved or thrilled by an exciting story
- Use analogies and metaphors (i.e. "mitochondria are the powerhouses of the cell")
- Keep it very simple. Avoid giving too many details when explaining a paper: **three key points** are enough
- Try to bond your scientific work with popular culture. This will increase impact
- Images are your friends: use visuals in every post you publish, as well as emojis




OPTRI

## SCIENTIFIC POST EXAMPLES

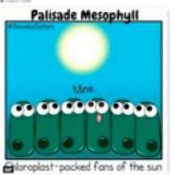
### TWITTER



Pictures of scientists, short-concise post, advertising the lab



Video, hot health topic, cutting-edge technology



Animation, humour, illustration

OPTRI

# EXTERNAL COMMUNICATION

## EVENTS

- EPTRI partners attended numerous events to present the project. Some of them were:
  - 2018:
    - ✓ Europe Biobank Week 2018 (Antwerp)
  - 2019:
    - ✓ 4<sup>th</sup> Health RI Conference (Utrecht)
    - ✓ 3<sup>rd</sup> European Conference of Pharmaceutics (Bologna)
    - ✓ 67<sup>th</sup> Meeting of Spanish Paediatric Association (Burgos)
    - ✓ 11<sup>th</sup> EuPFI Conference (Malmö)
    - ✓ 10<sup>th</sup> APS International PharmSci Conference (London)
    - ✓ Europe Biobank Week 2019 (Lubeck)
    - ✓ MIBio 2019 (Cambridge)
  - 2020:
    - ✓ Health RI Conference 2020 (Utrecht)

# EXTERNAL COMMUNICATION

## EVENTS



### EPTRI in Cyprus: participation of the Cyprus Institute of Neurology and Genetics in two events to present the Project

Members of the [Cyprus Institute of Neurology and Genetics](#), CING, participated in two scientific congresses where they are presenting the EPTRI project to an international audience.

[Keep Reading](#)

### EPTRI at the 4th Health-RI Conference in Utrecht



EPTRI attended the 4th Health-RI Conference "*Opening Doors to P4 Health*", which took place in Utrecht (The Netherlands) last 17th of January.

[Keep Reading](#)

### EPTRI at the 3rd European Conference of Pharmaceutics in Bologna



This year EPTRI was invited to participate in the [3rd European Conference on Pharmaceutics](#), which was held in the city of Bologna (Italy) last March 26th. Nunzio Denora, from University of Bari and co-leader of the [WP8](#) on paediatric medicines formulations and medical devices, presented a poster entitled "*EPTRI: facilitating formulation science towards better medicines for children*" during the poster session of the conference.

[Keep Reading](#)

# COMMUNICATIONS PLAN FOR THE CDR

## OBJECTIVES



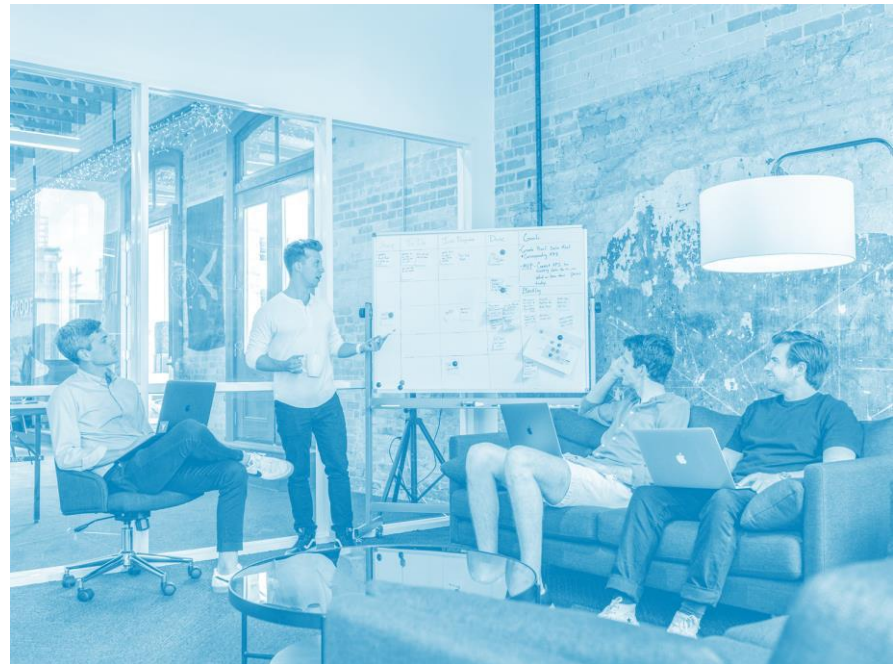
- **Define the dissemination strategy** of the future RI for the internal and external communication
- **Develop tools** to give visibility to EPTRI in the European and global scenarios
- Organize **networking activities** and sharing opportunities
- Promote **EPTRI services**
- Promote processes allowing **knowledge translation** in the paediatric research field



# COMMUNICATION PLAN FOR THE CDR

## EPTRI COMMUNICATION AND DISSEMINATION PLAN

- Audience
- Channels
  - Website
  - Social Media
- Tools
  - Newsletters
  - Brochure
  - Patients' toolkit
  - Webinars
  - Press releases
  - Participation in events
  - Others
- Resources
- Monitoring

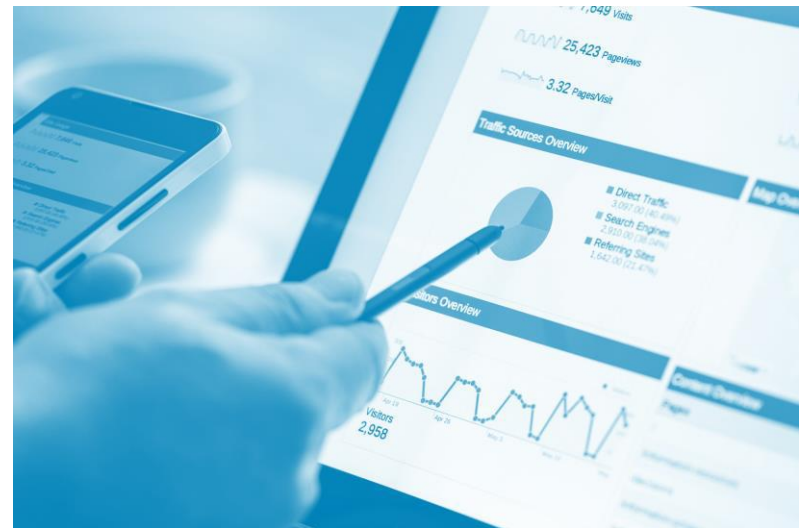


# COMMUNICATION PLAN FOR THE CDR

## DISSEMINATION CHANNELS

### EPTRI Website: promotional campaigns

- Choose key words to design the ads (Keyword Research): paediatric research, research network, medicines, biobanking...
- Decide budget
- Segmentation of the audience
- Design banners or artwork according to the ads
- Monitoring of the campaigns



# COMMUNICATION PLAN FOR THE CDR

## DISSEMINATION CHANNELS

### Social Media Channels



- Awareness
- Outcomes, activities, streaming of events, webinars...
- Thematic campaigns
- Twitter advertising campaigns



- Corporate channel, more focused on professional profiles
- Services, congresses, public calls, educational activities, job offers...
- LinkedIn advertising campaigns



- Videos about the RI: services, coverages, educational videos, etc
- YouTube advertising campaigns



# COMMUNICATION PLAN FOR THE CDR

## COMMUNICATION TOOLS

### Press department and press releases

- First press release: when the RI begins to function
- Centralized point to standardize communication with the press and other media
- Person expert in science communication to address issues related with biomedical research and general science topics



# COMMUNICATION PLAN FOR THE CDR

## OTHER COMMUNICATION AND DISSEMINATION STRATEGIES

- **Annual report:** digital format, disseminated through mailing lists and published on the website
- **Merchandising:** to distribute during events, congresses, etc. i.e. pens, notebooks, tote bags, USB sticks, calendars
- **Publication policy:** an annual plan must be defined

# COMMUNICATION PLAN FOR THE CDR

## RESOURCES

### 1. Human resources:

- *Graphic designer*: reformulation of the brand, corporate image, etc
- *Communications manager*: press, internal and external communication, social media
- *Science communicator*: lay summaries, patient participation activities, science dissemination contents, etc.

### 2. Financial resources:

- A specific budget must be defined to hire the personnel mentioned above

# PATIENT INVOLVEMENT

## **FOCUS GROUP** (March 2019)

- **Goal:** definition of guidelines to increase the interaction between researchers and patients
- **Partners involved:** WP5, WP6, WP7, WP8 and WP9
- **Methodology:**
  - Standard introduction
  - Analysis of the 10 areas of PPI in basic research
  - Analysis of the obstacles and solutions
- **Output:**

Guidance to incorporate the voice of the patients in basic research

# PATIENT INVOLVEMENT

## ORAL FORMULATIONS SURVEY

- Developed by WP8 and WP11
- Content: country and age-adapted questions to quantify **children's experience** with taking pharmaceutical **oral formulations**
- **Reviewed** and **translated** by **YPAGs** of Albania, Barcelona and Bari to make the language and layout more child-friendly
- Audience: boys and girls up to **18 years of age** (patients or healthy)
- Still open and available in **9 languages**

### Preliminary results of the survey about oral formulations

The EPTRI project developed a survey utilising country and age-adapted questions to quantify children's experience with taking various pharmaceutical formulations.

[Keep Reading](#)



# PATIENT INVOLVEMENT

## FORMULATIONS SURVEY: Preliminary results

- Important **similarities/differences** in preference for formulations across different **countries**
- **Health status** of a child influences the preference of certain formulations with variations across the different populations
- Results also highlight the **importance of children's involvement** as active stakeholders, as well as the importance to study preferences for kinds of oral formulations in developing tools to facilitate paediatric medicines formulation



# PATIENT INVOLVEMENT

## EPTRI PATIENTS' TOOLKIT: Objectives

- **Educate** patients and families about paediatric research, with a special focus in EPTRI's thematic platforms
- **Inform the general population** about basic research and paediatric medicines development
- Create a **general and interactive collection of reliable resources**, with lay content and flexible navigation to the users accordingly with their needs
- Design a **general video** to explain in lay language the basic research process in drug development and the opportunities for patient involvement
- Offer a **guidance** to incorporate the **voice of the patients** in basic research

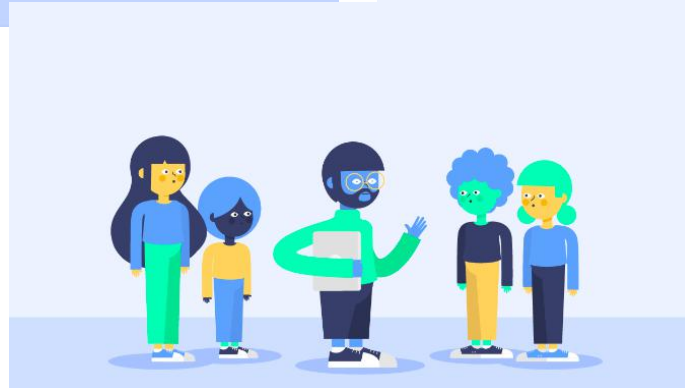
# PATIENT INVOLVEMENT

## EPTRI PATIENTS' TOOLKIT: Features

- **Video** in English subtitled in the main European languages, with interactive navigation
- **Curated resources** about different topics related to basic and translational research (reviewed by YPAGs):
  - Sample donation for research
  - Science for non-scientists
  - Patient and public involvement
  - Fundraising
  - Ethics
- **Integration the EPTRI website** and linkable from other sites
- Option of **sharing** in social media channels

# PATIENT INVOLVEMENT

## EPTRI PATIENTS' TOOLKIT: Look & Feel



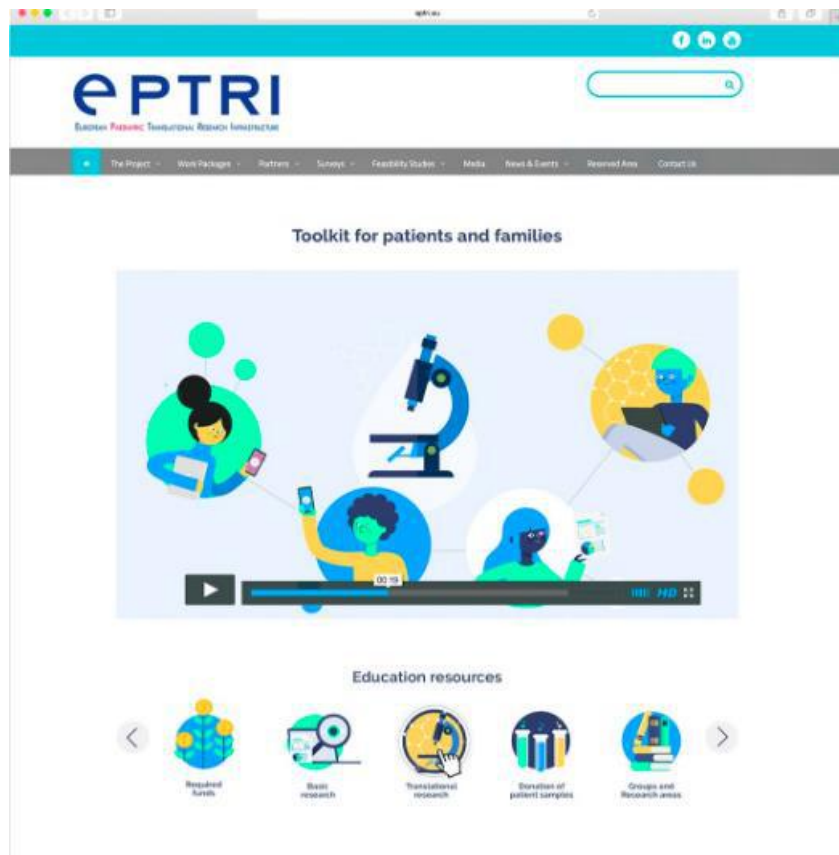
# PATIENT INVOLVEMENT

## EPTRI PATIENTS' TOOLKIT: Look & Feel



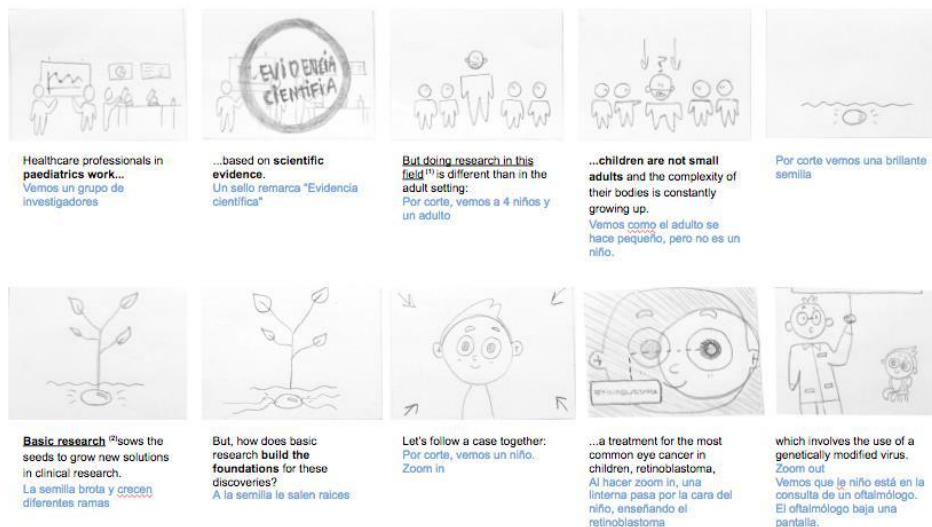
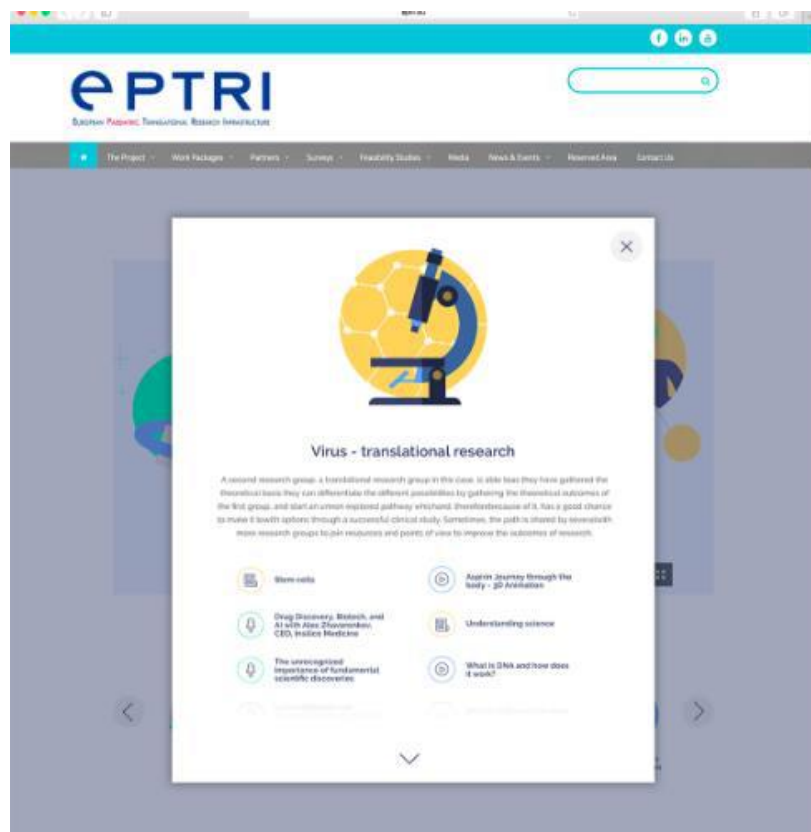
# PATIENT INVOLVEMENT

## EPTRI PATIENTS' TOOLKIT: Interface



# PATIENT INVOLVEMENT

## EPTRI PATIENTS' TOOLKIT: Clips with resources and storyboard



# EPTRI IN THE FUTURE

## INFRAIA

- Next step: implementation of the **framework** developed during the ID-EPTRI project
- **Work Package** - Communication, Dissemination and Patients Involvement
  - Development of a communications and dissemination plan for the RI
  - Development of the communication channels
  - Development of the communications tools and targeted actions
  - Patients Public Involvement (PPI)
  - Publication Policy