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Consumers, Health and Food
Executive Agency

European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment

2013 12 07 ExPO-r-Net

- Call: 4.2.2.7. Pilot networks of cooperation under Directive 2011/24/EU

ExPO-r-Net 6 Month Project Update

Project goals

- **The ExPO-r-NeT project will build a Paediatric Oncology (PO) European Reference Network (ERN) providing paramount requirements for 'Cross-border healthcare'**
  - **Provision of healthcare** to children and young people with cancer in a Member State other than the Member State of affiliation.
  - Identification of the target groups , i.e. children with special diagnostic and therapeutic needs with conditions requiring a particular concentration of resources or expertise, especially when the expertise with certain cancer conditions is rare and case volume low.
  - **Reduction of current inequalities** in childhood cancer survival and healthcare capabilities in different member states.
  - Establish a PO-ERN **linking pre-existing reference centres with tumour boards** to provide cross border expertise. The latter is inherent to the Cooperative PO- Clinical Trial tumour and Leukaemia Groups which may contribute high-level diagnostic and medical expertise to rare childhood cancer populations.
  - Improving access to high-quality health care for children with cancer whose conditions require specialised resources or expertise not widely available due to low case volumes and lack of local resource.

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Project expected impact

The strategic relevance

- Generation of information and provision of a framework for the PO-ERN to improve standards of care for children and young people with cancer.
- Incorporate the expertise from right across Europe and collate existing information to help patients get access to the best possible information, treatment and care.

The innovative contribution

- A clear roadmap to approved expert referral sites and tumour advisory boards for healthcare providers.
- Fostering eHealth solutions based on interoperability and standardisation: this will help professionals work more efficiently and exchange information and data that are essential for tumour boards providing advice and expertise beyond local institutional borders.

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ExPO-r-Net Consortium

18 Associated Partners	Name	Country
CCRI (***Coordinator***)	St. Anna Kinderkrebsforschung e.V.	Austria
SIOPE	European Society of Paediatric Oncology	Belgium
IGR	Institut Gustave-Roussy	France
MUL	Medical University of Lublin	Poland
HULAFE	Fundación para la Investigación Hospital Universitario La Fe	Spain
ULUND	Lund University	Sweden
AOPD	Azienda Ospedaliera di Padova	Italy
IGG	Istituto Giannina Gaslini	Italy
CAU	Christian-Albrechts-Universitaet zu Kiel	Germany
AIT	Austrian Institute of Technology	Austria
CINECA	Consorzio Interuniversitario	Italy
INT	Istituto Nazionale dei Tumori	Italy
KlinikumDo	Klinikum Dortmund GmbH	Germany
UCL	University College London	United Kingdom
UOB	Lund University	United Kingdom
ECRMF	European Cancer Research Managers Foundation	United Kingdom
Charité	Universitätsmedizin Berlin: Charité	Germany
ÖKKH	Österreichische Kinder-Krebs-Hilfe	Austria

Collaborating partners	
Number	42
Eastern European	17%
Western European	83%

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WP1

- **Coordination of the project**
  - Actions undertaken to manage the project and to make sure that it is implemented as planned

WP leader: Ruth Ladenstein

WP1 Management Milestones

- **Milestone 1**
  - Name: Kick off meeting in the Executive Agency's premises in Luxembourg
  - Expected date: 21.03.2014
  - Progress: finalized √
  - Open tasks/next steps: none
- **Milestone 2**
  - Name: Quality Assurance Plan (QUAP)
  - Expected date: 31.05.2014
  - Progress: finalized √
  - Open tasks/next steps: none
- **Milestone 3**
  - Name: Biannual Consortium Meetings (every 6 months)
  - Expected date: 28.02.2017
  - Progress: ongoing
  - Open tasks/next steps: 3rd biannual meeting 6th March 2015, Padova, Italy

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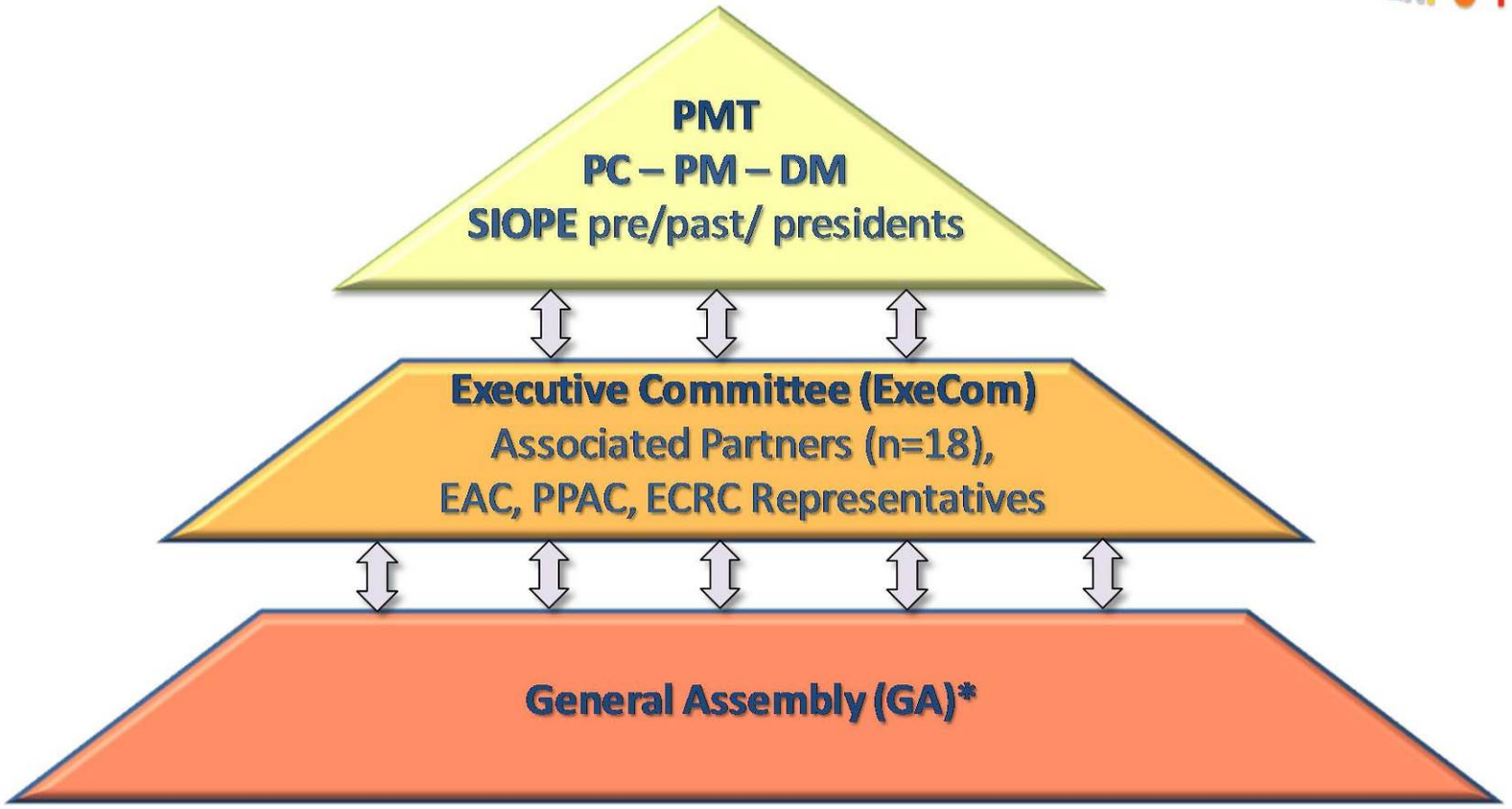
Quality Assurance Plan (QUAP) – Organisational Structure of ExPO-r-Net



***General Assembly:** *ExeCom, Collaborating Partners, ECRC chairs, SIOPE Board, PPAC, EAC, PanCare, ITCC, ENCCA TYA Leaders*

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Meetings

Meetings /Conferences	Project Body	No. of meetings	No. of representatives
Major Meetings *SIOP congress, Oct. 22.-25.10., Toronto* *ExPO-r-Net session: 24.10., 12-14 pm (Huron Room)*	General Assembly	1x / year	50-100
Medium Meetings *Valencia*	Executive Committee	2x / year	18 + (up to 30 collaborating partners of LTG, ITCC or TYA according to topic addressed)
Small Meetings *Face to face meetings embedded in ENCCA or SIOPE*	PMT	2-4x / year as needed	6
Working meetings/dissemination activities *Wroclav (Wilms tumor group), TYA, ENCCA long term sustainability meeting*	PMT integrating with Leukemia and Tumor groups ITCC, TYA	To be agreed with respective LTG, ITCC and TYA	2-3 PMT representatives to join with respective LTG, ITCC or TYA committees
Small meetings and teleconferences *Project updates Jul. 2014*	PMT only or with WP leaders	2-6x / year as needed	6

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WP2

- **Project dissemination, progress update and action points**

WP leader: Samira Essiaf/ SIOPE

ExPO-r-Net Brochure

European Expert Paediatric Oncology Reference Nerw()f1(*toe* Diagnostics and Treatment

Because Children & Adolescents with Cancer deserve the best possible Treatment - no matter where they live !

Tilos _____Oie_ErJ'O.t...._hls.-..d--OieE\ro.

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WHAT IS ExPO-r-Net?

ExPQ.r-Net is a 3-year project that wdlbUild a European Reference Network (ERN) or Paedi atric Oncol ogy

Goals:

- Link pr!H!xisting centres or excellence in paediatnc onCOlogy
- Enable treatment of Children and young people with cancer in a Member State other than the Member State of affiliation
- Improve access to h191Hlualrty healthcare lor allyoung people and children With cancer
- Reduce Inequalities in ChildhoOd cancer SUlVIVal and heahhcare capabilties in dllferent EU Member States
- Empower patients affected by complex or rare diSeases to Choose and be reimbursed by public and private heahhcare proVIders across the EU

Stakeholders

More than 60 Partners from 17 Countnes .

- 18 Associated Partners
- More than SO Collaborating Partners
- 8 Work Packages

WHY ExPO-r-Net?

Because 6.000 children and yow19 peopledie *ol* C3lC8r Wop& eadlye;.

Because 10% to 20% *ol* l1emdie from Clr.lble forms *ol* cn:erwherequality en IS notatC8llSible

BecauHaccess to quality care saves children's lives

Because together, we are stronger!

HOW ExPO-r-Net Works

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3 Activity Areas:

- Identifying health inequalities between Member States
- Supporting cooperation on cross-border heahhcare and mobility or patients. heahh-care prolssoonals and information
- Innovating healthcare deliVery

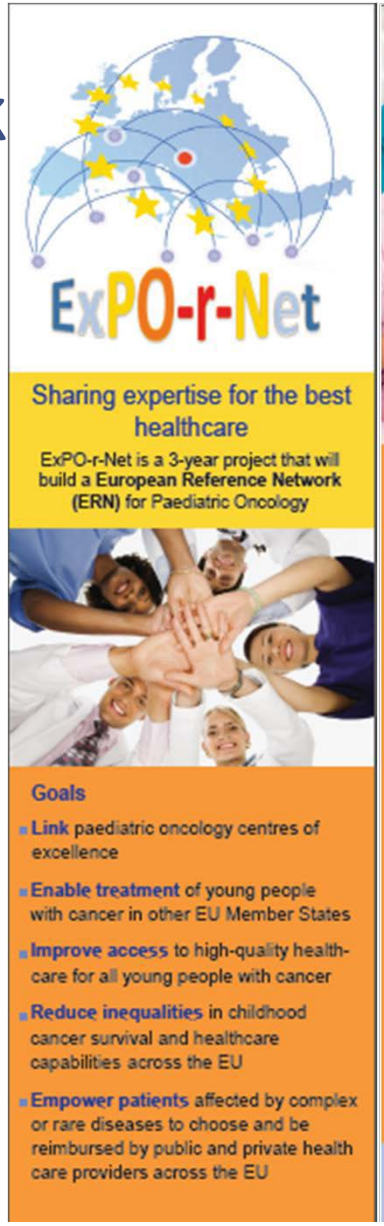
Key concepts and ooliverables:

- Centre or excellence: proVIding highly speaalISed heahhcare
- Paediatric oncol ogy reference roadmap: contalf'Ing approved expert referral sdes & tumour adVisory boards
- ICT tools and e-Health: to laethtate movement or information and krlow1edge rather than pabents, Whenever posSible, keeping the pabent WIthm the supporbVe family and langUaQe enVIronment
- Survivorship Passport: al ready enVISaQed as part Of several previous or Ofl90ing J)rojects, this instnrment will be develOped further ror long-tenn follOw-up or ChildhoOd cancer SUVIVors across Europe.

In cooperation with ENCCA (www.encca.eu) and PanCareSurfup (wwwpancaresurtup.eu).

ExPO-r-Net Bookmark

- **New Bookmark**
  - To be printed
  - Small format
  - Easy to use and
  - distribute



ExPO-r-Net E-Blast

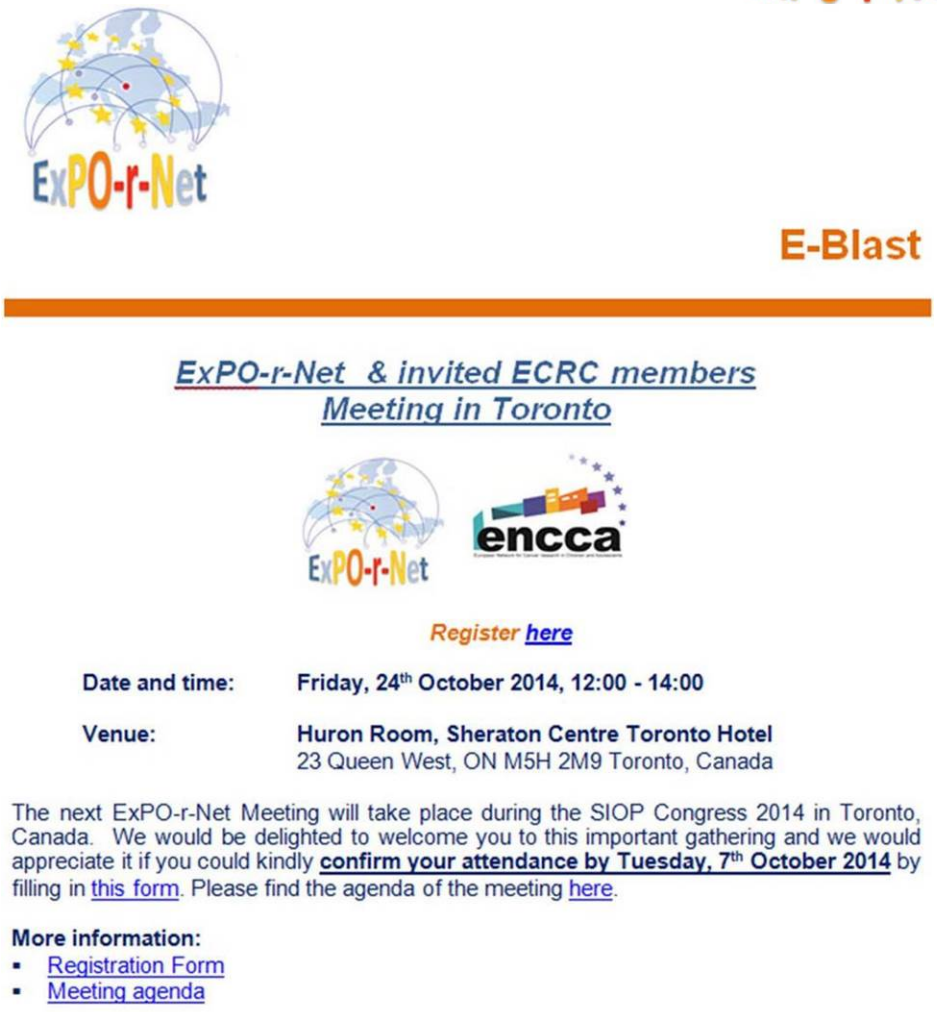
❑ Dedicated E-Blast

Important news for all partners

- Internal deadlines
- Meetings & Events
- Publications
- Cross-communication

Ensures coherence with all SIOPE-related communication Outlets

❑ Dedicated Section in the SIOPE Newsletter



E-Blast

ExPO-r-Net & invited ECRC members Meeting in Toronto

Register here

Date and time: **Friday, 24th October 2014, 12:00 - 14:00**

Venue: **Huron Room, Sheraton Centre Toronto Hotel**
23 Queen West, ON M5H 2M9 Toronto, Canada

The next ExPO-r-Net Meeting will take place during the SIOP Congress 2014 in Toronto, Canada. We would be delighted to welcome you to this important gathering and we would appreciate it if you could kindly **confirm your attendance by Tuesday, 7th October 2014** by filling in this form. Please find the agenda of the meeting here.

More information:

- Registration Form
- Meeting agenda

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ExPO-r-Net Online Tools

Extranet

- A first version of the ExPO-r-Net webpage is online at the address:

www.expornet.eu

- Provides key information about the project

Intranet

- Office 365 as collaboration platform for ExPO-r-Net

Structure of the intranet

ExPO-r-Net Dissemination at Events

- ExPO-r-Net Kick-Off meeting
- ExPO-r-Net at the ERN Conference 2014
- ExPO-r-Net at the SIOPE-ENCCA Conference 2014
- ExPO-r-Net at the SIOP Congress Toronto 2014

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WP3

❑ Evaluation of the project

- Actions undertaken to verify if the project is being implemented as planned and reaches the objectives

WP leader: Pam Kearns / University of Birmingham, UOB

WP3 Milestones

Commence Internal Evaluation Plan

- September 2014
- **Review of WP documents and Feedback by WP leads**
  - Interim review of WP 4 questionnaire to identify the needs of rare childhood and young people cancer types and entity subgroups
  - Minutes of WP TCs plus TC with Enrique Terol comprising funding opportunities (received 26/09/2014…on-going review)

- ICPRB review
  - WP6
    - 1st draft of principles of accreditation process for paediatric oncology/haematology

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WP3 Milestones

- **Determine External evaluation plan**
  - March 2015
  - Initial plan under development; anticipated draft end of November 2014

- **External evaluation Report on ExPO-r-Net project**
  - December 2016

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WP4

- **Addressing needs and challenges of cross-border healthcare co-operations and current expert fragmentation**

WP leader: Ruth Ladenstein / CCRI

WP4 Milestones

- **M1 – month 36**
  - **Biannual Meeting of ExPO-r-Net Exe Com**
  - **Annual meeting of the ECRC (Toronto, October 2014)** to identify and to agree on potential cross border needs and challenges within ECTG.
- **M2 – month 12**
  - **A questionnaire within the respective ECTG committees has been developed and circulated: Responses have already been achieved and analysis will be done**
    - https://www.surveymonkey.com/s/ExPO-r-Net_FrontLine
    - https://www.surveymonkey.com/s/ExPO-r-Net_Relapse
- **M3 – month 24**
  - Identification of reference sites eligible and willing to be part of **ExPO-r-Net via the ECRC (first review on associated and collaborative partners of ExPO-r-Net.**
- **M4 – month 36**
  - Bechmarking report on reference sites.

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WP4 Expected results

- **Phase 2 : Roll – out of the identification process for PO-ERN throughout Europe**

- **Result for the End of project:**
  Roadmap for public health care providers and patients

  - Development of quality and safety benchmarks to establish best practice within and outside the network
  - Identification of reference sites based on bench-marking, helping to justify the need for cross border health care
  - Enhancement of European cooperation for highly specialized healthcare for patients with special needs

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WP5

- **Paediatric Oncology tumour board ERN based on E-Health/ICT concepts for sharing and providing expert advice.**

WP leaders: Adela Canete / H. U. P. La Fe. IIS La Fe
Günter Schreier / Austrian Institute of Technology, AIT

WP5 Milestones

- **Evaluation of CURRENT existing tumor boards through a questionnaire (SWOT ANALYSIS).**
  - Expected date: month 12.
  - Descriptive work= Snap/shot picture of current TBs.
  - Design a questionnaire to be distributed among partners in national groups, clinical trial groups, other institutions.
  - Questionnaire:
    - Clinical
    - IT

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Virtual Tumor Boards in Europe

1-France: Institute Gustave Rossy:

Adobe connect.

2- Germany: Münster.: Vidyo.

3- Curekids: a platform used by many centers. (Adobe connect).

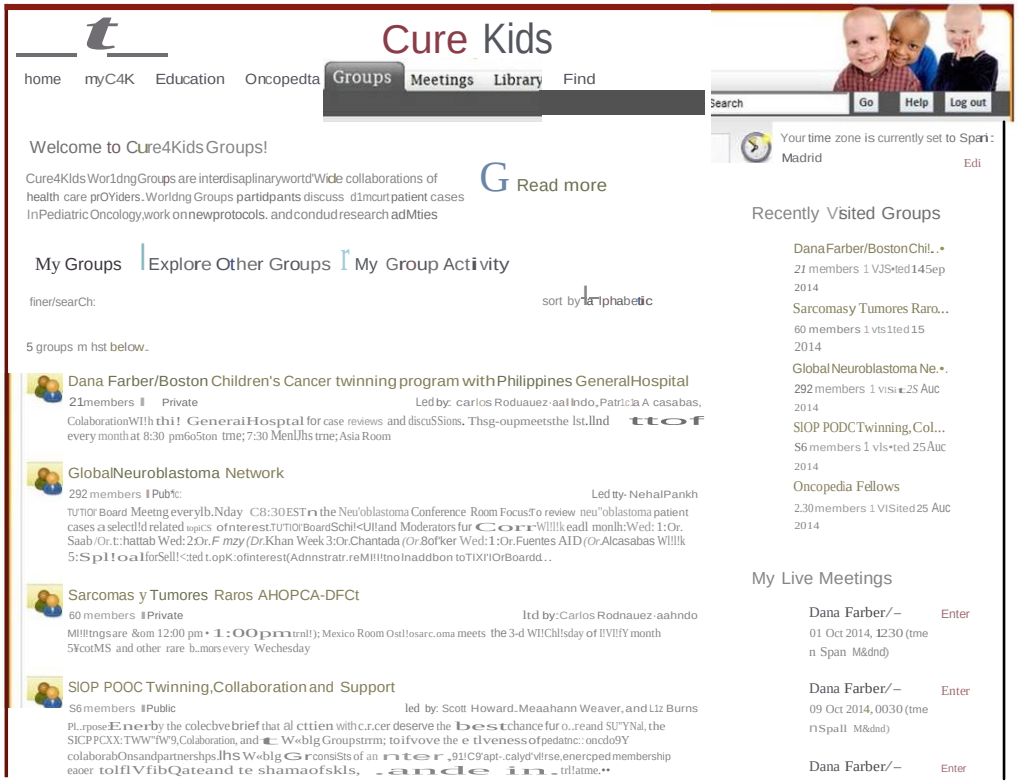
4- Other: skype.

Virtual Tumor Boards in USA

St. Jude Children's Research Hospital
ALSAC • Danny Thomas, Founder

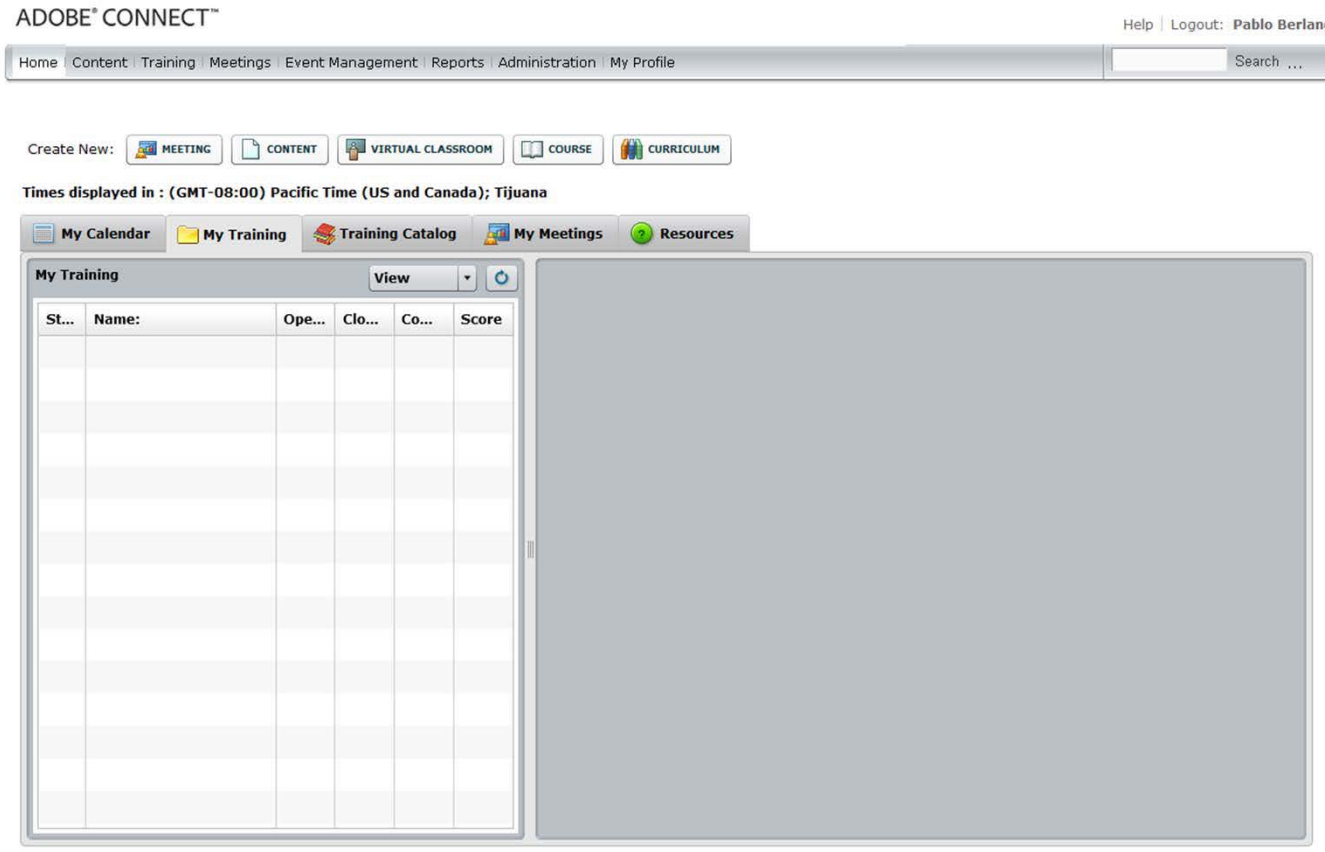
Cure4Kids™

Adobe® Connect™



Adobe Connect web conferencing platform

The Web conferencing software provides a secure website for conference participants in order to ensure patient confidentiality.



A Pediatric Tumor Board Questionnaire: Spanish results

30- question survey

Drive

Encuesta de manejo multidisciplinar de los tumores pediátricos en E

Descripción del formulario

1. Centro de trabajo*

2. ¿Cuál es aproximadamente el número medio de casos nuevos por año en tu Centro?*

- ○ a. < 10 casos/año
- ○ b. ≥10 casos/año y < 15 casos/año
- ○ c. ≥15 casos/año y < 25 casos/año
- ○ d. ≥25 casos/año y < 50 casos/año
- ○ e. ≥50 casos/año y < 75 casos/año
- ○ f. ≥75 casos/año

3. Especifica a continuación cuáles de las siguientes Unidades están disponibles en tu centro.

- ☐ a. Oncología Pediátrica

Pablo Berlanga and Adela Cañete

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Pediatric Oncology Units in Spain

27 Pediatric Oncology Units

27/43 Units = 63% response

Pablo Berlanga and Adela Cañete

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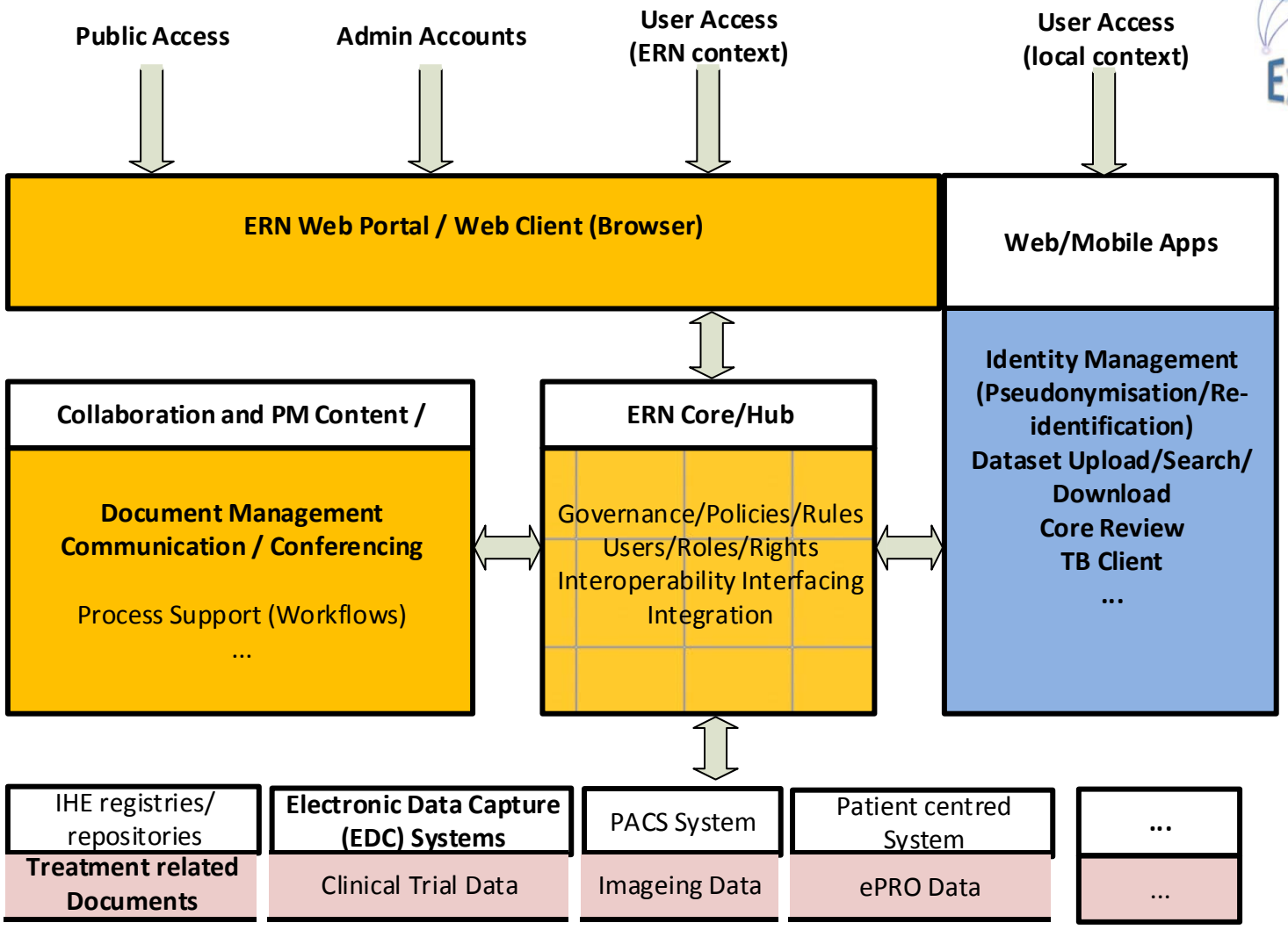
WP5 Milestones

- **For each milestone:**
  - Name: Development of ICT strategy and interoperability architecture for the ExPO-r-NeT.
  - Expected date: Month 36
  - Progress: under development
    - Participated in the European Reference Networks Expert Panel, Brussels, March 25, 2014
    - HL7 Austria / HL7 FHIR Workshop, March 19-20, Vienna
    - IHE Day 2014 / Connectathon, April 10th, 2014, Vienna
      - Liaised with IHE Europe
    - Two meetings with ITH icoserve technology for healthcare GmbH
    - Looked into synergies with ENCCA ICT Approach
  - Open tasks/next steps:
    - Negotiate a development partnership with ITH

See dedicated presentation on the Expo-R-Net Intranet concept

ERN proposed ICT Architecture



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WP6

- **Defining criteria for a common process for identification and certification of PO expert centres in Europe.**

WP leader: Jerzy R. Kowalczyk / Medical University of Lublin, MUL

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WP6 Milestones

- **Definition of terminology used for the certification process.**
- Expected date: **15.12.2014**

Document: **European Standards of Care for Children with Cancer**

ABBREVIATIONS,TERMINOLOGY AND DEFINITIONS

- **Abbreviations (34)**
- **The glossary of terminology and definitions used for a certification process is already structured**
- **Placed at** https://docs.google.com/spreadsheet
- **107 terms are defined but 27 still need to be discussed**
- **TC conferences is planned on October….**
- **Face to face meeting in November will conclude on glossary**

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WP6 Milestones

- **Description of quality evaluation (certification) system to ensure that procedures are being carried out in line with agreed standards**
- Expected date: **30.06.2015**

Principles of quality evaluation (certification) process

The full process contains 7 steps (plus the follow-up):

- Step 1: Application of a POH centre in the programme
- Step 2: Self-assessment
- Step 3: Go / no go decision
- Step 4: Peer review visit and designation check
- Step 5: Reporting
- Step 6: Formulate improvement plan
- Step 7: SIOPE Certificate –to be discussed with GA
- Follow-up

WP6 Milestones

Preparation of a checklist enabling self-assessment by treatment centres of their compliance with the European Standards.

- Expected date: **30.03.2016**

Checklist of compliance will be available for POH centres.

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WP6 Milestones

- **Self-assessment by treatment centres of their compliance with the European Standards.**
- Expected date: **15.03.2017**

Checlists filled-up by POH should be collected and reviewed.

On-site inspection of a sub-set of centres to fully review all aspects of the programme in accordance with the Certification Checklist will provide a verification of the self-assessment process

- Relation with ExPO-r-NeT overall objectives

WP 4 Addressing needs and challenges of cross-border healthcare co-operations and current expert fragmentation:

WP 5 Paediatric Oncology tumour board ERN based on EHealth/ICT concepts for sharing and providing expert advice

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WP7

- **Cross-border dimension of long-term follow-up: survivorship passport with crucial treatment & follow-up data.**

WP leader: Lars Hjort / Lund University, ULUND

WP 7 Milestones

- **Milestone 7.1 & 7.3:**
  - 7.1 Translation of the Survivorship Passport started
  - 7.3 Translations of the Survivorship Guidelines started
  - Expected date: M 6 & 30
  - Progress:
    - **Translation of the list of variables/items**: Italian almost done, other languages still to complete
    - **Translation of recommendations and of brochures**
      - From professional English to lay English
        - Virtual Expert Network at PanCare (PLAIN)
      - From lay English to other languages
        - Volunteers for German (Frey + Hennewig) and Spanish (Astigarraga + Marquez)
        - United Nations Volunteers (UNV). The system beneficiaries should be development NGOs

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WP 7 Milestones

❑ Milestone 7.1 & 7.3: continued

Application to the United Nations Volunteers (UNV):

- Mission, overall objectives and activities of the organization
- Three organization's projects or activities
- Two references external to the organization:
  - Eva Steliarova Foucher (IARC) or higher-level UN reference as a WHO/UN affiliated body.
  - Giorgio Perlilongo (SIOP) to vouch for the importance of the passport in all global regions.
- How the organization wishes to involve online volunteers in its activities
- Highlight the universal applicability of the Survivorship Passport and its vital relevance worldwide, including in particular developing countries.
- The UNV office is located in Bonn.
  - Gerlind Bode (ICCPO) has expressed the willingness to get in direct contact to support the application.

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WP 7 Milestones

❑ Milestone 7.1 & 7.3: continued

- **Languages "priority list"**
  - The "big" ones: French, Spanish, German, Polish, Italian
  - The "less spoken" ones: Hungarian, Portuguese, Greek

- **Selection of Network partners:**
  - Those who have supported translations of the European Standards of Care.
  - Patient organizations in:
    - Greece (SIOPE contact)
    - Romania (Little People, local media contact of SIOPE)
    - Austria (ICCPO, OK)

Key Persons:

- Lars Hjorth (ExPo-r-Net WP leader, PanCare chairman)
- Rod Skinner (PanCareSurFup guidelines chairman)
- Olga Kozhaeva (SIOPE)
- Riccardo Haupt (Survivorship Passport coordinator)

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WP7 Milestones

Milestone 7.2:

- Identification of experts for the Virtual late effects centre
- Expected date: M 12
- Progress
  - A pragmatic approach will be used in collaboration with WP 3 & 6
  - At the next PanCare meeting in Lucerne (October 8-10, 2014) a preliminary list of names will obtained.
  - As many countries as possible should be represented since local knowledge is extremely important when giving advice on e.g. follow-up.

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WP8

- **Integrating children with very rare tumours in a European Reference Network.**

WP leader: Gianni Bisogno / Azienda Ospedaliera di Padova, AOPD

WP8 Milestones

- **Establishment of VRT network tumor board and working group on rare STS in collaboration with EpSSG**
  - Expected date: November 2014 (8 months)

The Board has been established (EXPOrNeT WP8 Meeting, Milan 29/9/2014)

A document describing the working procedure has been written

An Advisory Desk has been opened (1st of October)

This will be a flexible and always ongoing process

Very rare tumors – European tumor board

- Need of a legal advice

- The effectiveness and the quality of the system is strictly ralated with the availble resources

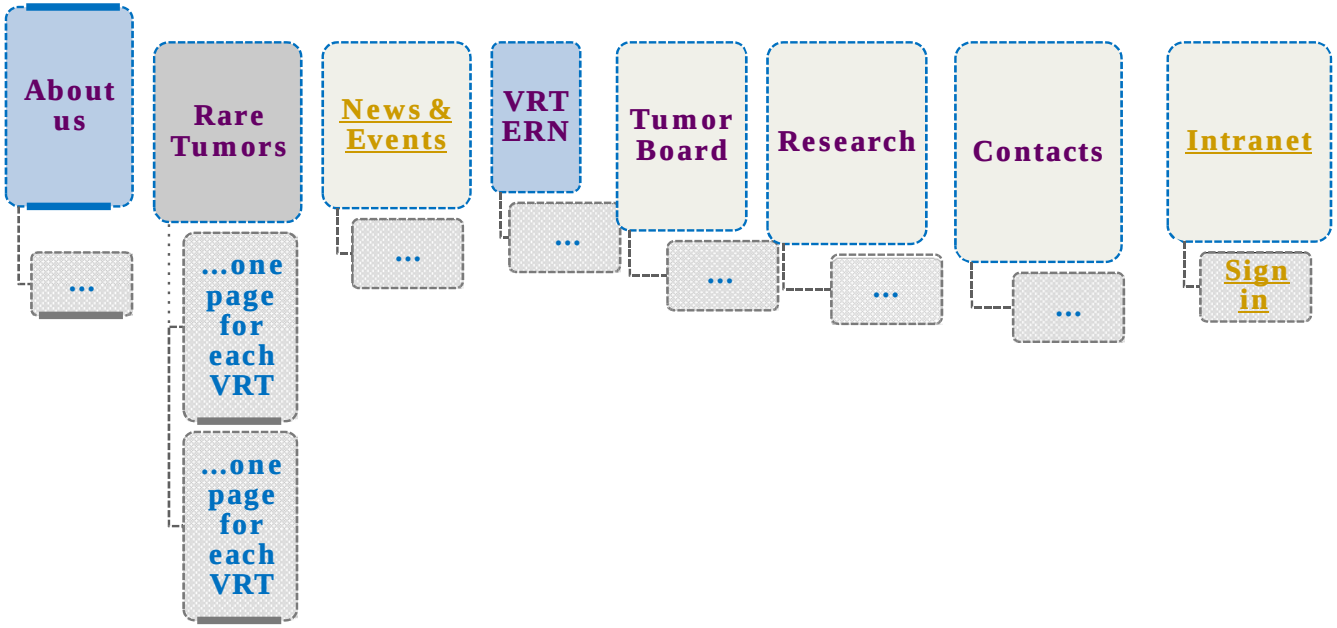
WP8 Milestones

- **Establishment of a website dedicated to inform families and the public**
  - Expected date : March 2015 (12 months)

SIOPE (partner in EXPO-r-Net: WP Dissemination)

- to launch a website page as part of the SIOPE website

- to distribute the VRT questionnaire (surveymonkey)



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Next EXPO-r-Net ExeCom Meeting

Padova, 5th-6th March 2015

- *5th March: 20.30 pm: networking dinner*
- *6th March: 8.30 am -16.30 pm: Meeting*

Piazza Cavour, 27
Via VIII Febbraio, 20/24
35122 Padova

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