

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



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Work Package 5:

- ✓ Establishment of a Paediatric Oncology tumour board ERN working to common standards and using IT tools based on Ehealth concepts for sharing and providing expertise and advise.

Sharing expertise through a tumour board among clinicians in local/expert centers requires **common standards** and an **ICT System**, that warrants data interoperability, efficient data management and confidentiality.

To achieve this in a crossborder setting we will explore an ICT strategy with the aim of connecting the existing elements with an interoperability architecture within the framework given by Article 14 and eHealth Action Plan 2012-2020.

Our vision:



The implementation of modern IT tools across borders will allow tumour boards to share expert opinions for European children with cancer in need of special cross-border settings. This will foster also knowledge transfer and expertise and integrate local care teams lacking expertise or tools for specific therapeutic elements.

EXPECTED OUTCOME



- ExPO-R-NET will identify, connect and encourage to establish Tumour Boards as hubs of expertise embedded in the pre-existing expertise of CTG across Europe thus creating a virtual ExPO-R-NET tumour board platform.
- A routing contact point will be established to guide requests of all stakeholders to the right forum.
- E-health based IT tools will allow interacting more easily and safely, thus providing timely advice and answers with respect to the requested information.

Clinicians
(information providers)

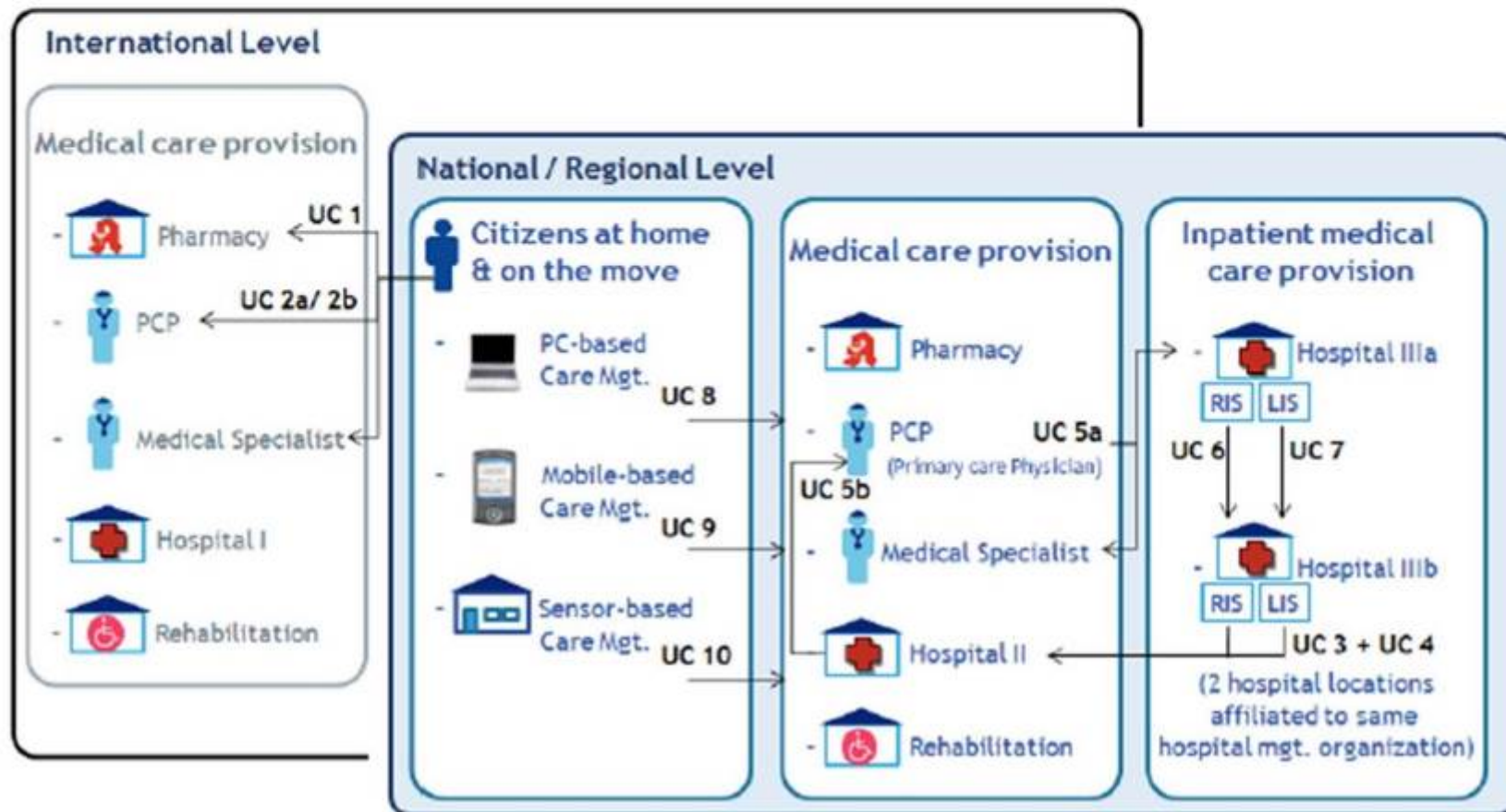
IT Experts
(know-how)



From our IT- partner



European Interoperability framework: use cases:





From our IT- partner



4 levels of interoperability :

- Technical Interoperability:Need trust from the source systems (IT Administrators)
- Semantic Interoperability we need a common language – dataset standardisation
- Pragmatic Interoperability We need shared processes (workflow support)
- Juristic Interoperability Need common rules (roles and rights)

Tasks.



1. Knowing the state of the art: identify currently functioning TB in Europe and abroad.
2. Analyse the methodology used through a questionnaire (clinical and IT elements).
3. Specify conceptual models and standardize IT languages.
4. Define Standard Operating Procedures (SOPs) and roadmaps to implement ExPO-r-Net TB as soon as e-Health IT platforms currently in development in Europe are launched.
5. Develop a coherent ICT strategy and devise interoperability architecture for the ExPO-r-Net.

MILESTONES

1. Evaluation of CURRENT EXISTING tumour boards THROUGH A QUESTIONNAIRE (SWOT analysis). **Month: 12**
2. Definition of Standard Operating Procedures (SOPs) and road-maps on ExPO-r-Net Tumour Boards. **Month : 24**
3. Development of ICT strategy and interoperability architecture for the ExPO-r-Net. **Month : 36**

Tasks.



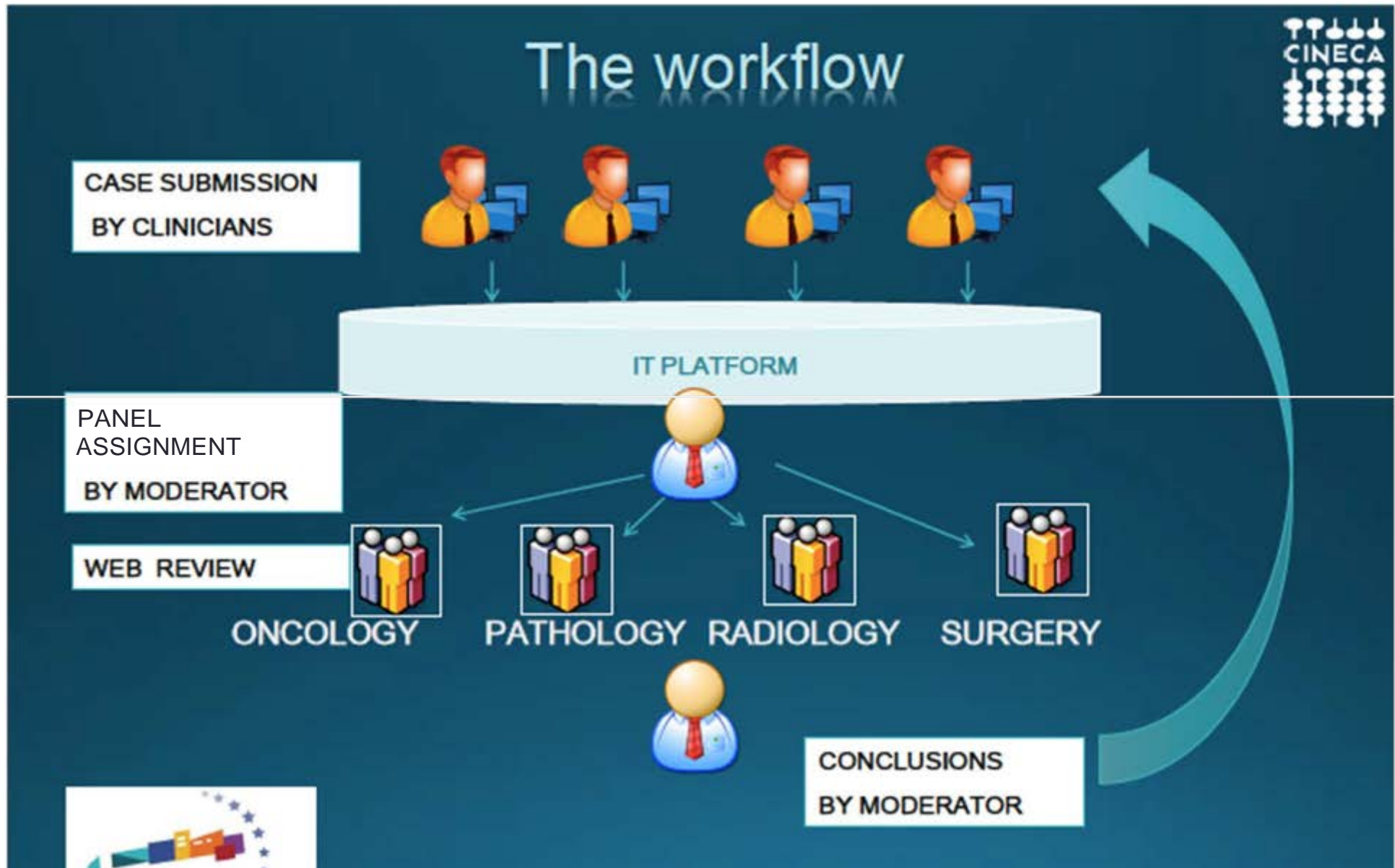
1. Knowing the state of the art: identify currently functioning TB in Europe and abroad.
2. Analyse the methodology used through a questionnaire (clinical and IT elements).

Current existing TB/ platforms 1

- Web base conference:
 - Adobe-connect (France, Cure-kids).
 - Vidyo (Munster)
- Adults:
 - Breast/ Scotland: Tandberg 2500 videoconferencing
 - USA (California): Adobe-connect
 - USA (N. Carolina): Adobe-connect.



Expert advice : radiology/ pathology



Tasks.



1. Knowing the state of the art: identify currently functioning TB in Europe and abroad.
2. Analyse the methodology used through a questionnaire (clinical and IT elements).

Questionnaire to centers

Questionnaire

Do you have a Pediatric Multidisciplinary Tumor Board?

How often do you meet? _____

Usual length? _____

Number of cases/meeting? _____

There is a designated coordinator? _____

There is a designated data manager? _____

There is a core member group? _____

Pediatric Tumor Board Meeting Room: Do you have...?

- A specific room?
- Access to retrospective images/reports during meeting?
- Video-conference: H.323 vs web based Video Conf Syst
- Equipment connected to PACS
- Equipment for projecting and viewing radiology images/specimen biopsies

Cases presentation:

- New cases at diagnosis
- Prior surgery/radiotherapy
- After surgery/radiotherapy
- Progression/relapse

Treatment decisions have to be reviewed and accepted by all members? Real time vs Postponed?

is there a Pediatric Tumor Board recommendation report?
In paper or electronic format? _____

Questionnaire

Pediatric Tumor Board development: Do you have...?

- Allocated protected time to attend the meeting?
- Patient's case is not discussed unless all specialists involved are present?
- Patient is informed that his/her case will be presented?
- If treatment recommendations are not followed, patient is informed?

Are difficult cases discussed with other Tumor Boards?

Pediatric Tumor Board attendance is: mandatory or optional?

Is there any official recognition to Pediatric Tumor Board attendance?

Do you have any standard operation procedures (SOPs)?

Do you have any technical/administrative support?

Is there an official Tumor Board report?

Pediatric Tumor Board recommendations: mand or opt?

Recommendations inclusion in med report: mand or opt?

Is there a monitoring report on recommendations?

Is there an evaluation of the quality of decision making?

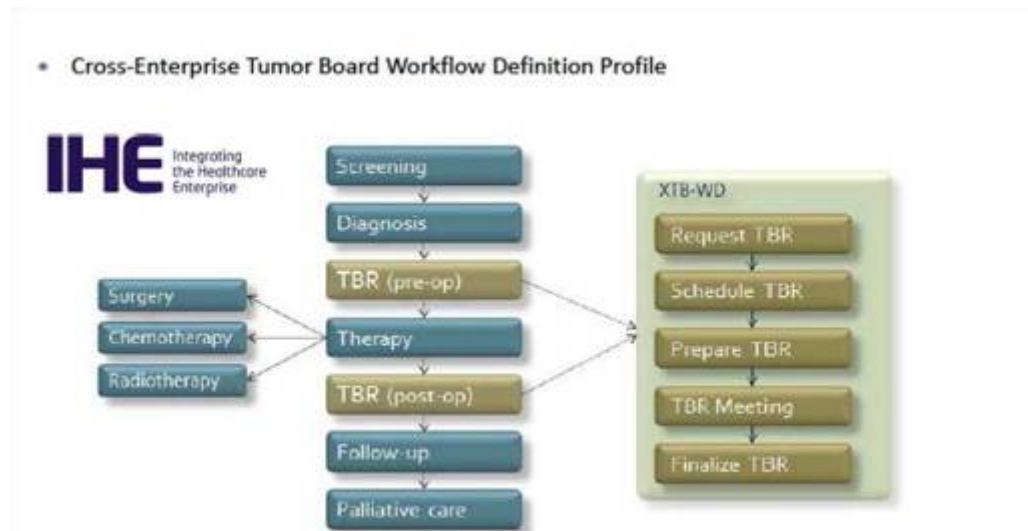
At the end, what have we found out about VTB and its implementation?.

- Problems :
 - Confidentiality
 - Security
 - Cost
- Informed consent ?
- Different levels of interoperability: 1/ Data transfer. 2/ Case presentation. 3/ Communication.
- Different complexity levels according to local /national development and regulations.



Upcoming months

- Questionnaire to be sent to CTG.
- Analysis of answers to carry on SWOT analysis.
- Work with IT partners: we don't have to re-invent the wheel.



□ Hospital Universitari i Politècnic La Fe. IIS La Fe. Valencia, Spain

- Main reference hospital in C. Valenciana, created in 1968 (980 beds, 170 pediat).
- Number of employees (hospital): 5910 (700 in pediatric hospital).
- Research Institute since 2009, turn over: 14.511.046 E (Public projects: 9.750.286)
- Main activities/competencies:
 - Integral and personalized health care for our population: Excellence.
 - Continuum in health care (prevention, diagnosis, therapy, rehabilitation).
 - Teaching hospital: pre, post, med+ nursing, patients, general population.
- Non-paper environment.

