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Minutes ExPO-r-Net Tumour Board Workshop

Venue: Hospital Universitari i Politècnic La Fe, Torre A
Avinguda de Fernando Abril Martorell, nº 106. 46026. Valencia, Spain

Session 1 VIRTUAL TUMOUR BOARDS

15:20-17:00

Welcome by Adela Cañete Fundacion Para La Investigacion del Hospital Universitario la Fe de la Comunidad Valencia and **Ruth Ladenstein,** Children´s Cancer Research Institute	
How and where are virtual tumour boards functioning in America and Europe? **Adela Cañete,** Fundacion Para La Investigacion del Hospital Universitario la Fe de la Comunidad Valencia	15:30-15:50

At first, Adela Cañete introduces the La Fe University Hospital with emphasis on the completely paper-free environment. She explains their status in March 2014, when ExPO-r-Net started, with standard in-house tumour boards for adults and children, 2-3 standard tumour boards with H. G. Alicante (200km away) including image transfer to PACS, and videoconferences. She then mentions that there are already severalvirtual tumour boards in Europe (e.g. France, Institute Gustave Roussy (IGR) and Germany, University of Münster) and the goal of La Fe is to establish a virtual tumour board as well.
She presents the Adobe Connect web conferencing platform as a potential website for conference participants. It is currently in use by La Fe and ensures confidentiality because it can only be viewed through a secure website by invited guests. The URL for the meeting is sent to participants through secure e-mail. It requires, however, the following software: i) Adobe Flash Player, ii) Adobe Connect Meeting Add-in. Once this software is downloaded, a clicking of the URL link provides immediate access to the conference. It can also be used via telephone. The disadvantage of this platform is that the data protection is not completely clarified. Some countries may have legal regulations that do not allow data flow via such platforms.
Consequently, Adela presents paediatric virtual tumour boards La Fe is in contact with:

- France: CanPedif
- USA: i) St. Jude Children´s Hospital (http://www.stjude.org), ii) Cure4Kids
- Australia: Dr. Michael Sullivan
- Canada (Toronto): Dr. Eric Bouffet

Once a month La Fe has provincial rounds with Toronto, Ottawa, Kingston, London and Hamilton for neuro-oncology patients (1h) with PPT presentations and the use of PACS for scans. Then there are monthly videoconferences with Amman (Jordan) and Karachi (Pakistan). Cure4Kids is used with Morocco and Columbia, cases are presented in PPT. There are also occasional requests for videoconferences from other hospitals. In some cases approval and a temporary license may be needed before videoconferencing.
The Münster University uses another system which was developed by themselves: Vidyo. The system will be discussed via videoconference with Stephanie Klco-Brosius later.

See presentation ExPO-r-Net TB-Workshop_Canyete

Discussion:
Adela wonders, how often and how long virtual tumour boards meet in IGR. Dominique Valteau-Couanet explains that the virtual tumour board in France consists of 4 centres and the frequency of meetings depends on the tumour type (mostly 1x/month, e.g. lymphoma, neuronal tumour, head and neck…). According to Dominique a meeting lasts around 2h or longer (3h for neurology). Data are entered before

and looked at by the radiologist and surgeon. The summary of the decision is sent to each reference centre. There are about 1.000 cases per year but one patient may be discussed repeatedly.
Dominique also points out that the centres tended to resist the installation of virtual tumour boards at the beginning because the time expenditure is high (cases have to be prepared, followed by the group discussion) and the expected benefit seemed to be low, since physicians were convinced that a virtual tumour board would not alter or improve their treatment decisions. However, several years of practice showed that virtual tumour boards definitely improve patient care.
Riccardo Riccardi asks if such tumour boards could also be used for training activities, e.g. for Eastern European countries. Dominique explains that this could be done easily, for example by presenting a clinical case which has to be worked on. In this context Adela mentions that Cure4Kids has a specified platform with training programs.
Ruth Ladenstein informs that New Zealand (Christchurch) is another well-connected country, but La Fe has not yet established any contact with them.

Coffee break

Case presentation (via videoconference, Adobe Connect) **Carlos Esquembre**, Hospital General de Alicante	15:50-16:10

Adela Cañete introduces her colleague Carlos Esquembre from the Alicante General Hospital, with which La Fe holds regular virtual tumour board meetings. Before the case presentation starts, she explains how to use Adobe connect, how images are entered and shared etc.. The presenter has to prepare a PPT presentation and confidential information has to be modified, if required.
Carlos presents the case of a 3 year old girl with a painless tumour in the right forearm (bone dysplasia). He explains the development of the case from 2008 until now including all treatment schemes, histology and radiology images. After such a presentation, a tumour board should be able to discuss and decide on the next treatment steps.
Remark: Pre-prepared ppt-slides may guide as specific request, but are not ideal to review image material (pathology/histology materials, read outs). Hence, a broader and technically more advanced solution is desirable.

Discussion:
The participants first focus on data protection. To properly discuss a case, sometimes images of the patient have to be shown and going through the medical history might require quoting a patient´s name. However, the discussion of a case in virtual tumour boards is in favour of the patient and according to good clinical practice. If the patient gives consent, legal requirements should be fulfilled.
The next point in the discussion is the transfer and sharing of images. Günter Schreier explains that a high-end broadband internet connection is not necessarily needed for the sharing of images in virtual tumour boards. The upload of pictures can take some time but this could be done upfront. As soon as the pictures are uploaded, a moderate connection is good enough to work with.
Dominique Valteau-Couanet adds that in the case of IGR the pictures are sent to the coordinator who shares them during the meeting. Ruth Ladenstein summarizes that the meeting coordinator, who prepares the images/presentation would then need an excellent internet connection whereas the others can get by with moderate connections.
Kathy Prichard-Jones observed that according to her experience many physicians are not happy with the images on the computer screen because they may miss small abnormalities. Dominique replies that in case that happens in IGR the images are sent directly to the inquiring persons to enable them a detailed look.
Eugenia Rinaldi explains that CINECA has a data centre with an image server that manages the transfer. Any radiology image goes to the server first and can then be moved wherever needed. The images do not display the patient´s name but are encoded. Only the clinician who provided the pictures can track the real patient.
Remark: We need to get clarity about the function of tumour boards; i.e. is it a public health component and which rules apply there or does it fall under research activity where the rules are more stringent!

Other approaches, the Münster experience (via videoconference) **Stephanie Klco-Brosius**, Universitätsklinikum Münster	16:10-16:30

While the connection with Stephanie Klco-Brosius is built, Pablo Berlanga explains that the University of Münster has developed its own connective system, Vidyo, because Adobe Connect is considered unsafe by the German legal authority*. While Stephanie is connected with Valencia, simultaneously a tumour conference takes place in Münster. Stephanie explains that Münster is having regular tumour conferences for radiology and weekly children´s oncology tumour conferences. They can choose more than one monitor and have the possibility to show images and life videos of meeting participants. She also explains the task bars of Vidyo. Up to 10 persons can attend a Vidyo conference.
The current running costs for the system are € 130,000.- with and add-on of 12,000.- to 26,000.- per new user when you expand the system**. And you need a dedicated router with the right proxy, otherwise the firewall of a system might block the connection. This would be an investment of approximately € 7,000.-. If you have problems with a hospital system´s firewall you may circumvent it by using a laptop with an external network. If your computer is well equipped, you will have good quality of image, voice and video broadcasting.
**It has to be specified why Adobe Connect is considered unsafe by the German authority. What are the running costs from Adobe Connect?*
***Specification: Start-up costs? Running costs? Who is the user, the hospital? Does this mean that in a CBMC setting we need to buy "user rights" for our partners – or eventually public health authorities?*

Discussion:
Pablo asks why Adobe Connect is considered unsafe by the German legal authority and Stephanie explains that in Germany you need an encrypted system and for this you need specific software which is not available in Adobe Connect. Kathy Prichard-Jones asks if parent´s consent was obtained for such conferences which Stephanie negates, since this is a consultation and therefore parent´s consent is not necessary. Stephanie cannot say if Adobe Connect would be allowed even in Germany if parent´s consent was obtained before a video conference about the respective child. The participants agree that this has to be clarified because, as Gianni Bisogno points out, there is no use in establishing a system like Adobe Connect if some countries are not allowed to use it. It has to be clarified if patient´s/parent´s consent would allow using Adobe Connect in countries like Germany, where it is currently forbidden.
Enrique Terol mentions that the EU is currently developing new regulations and Germany is trying to oppose them.
Another point for discussion is how the system will be financially supported after the ExPO-r-Net project and Stephanie hopes that until then new funding will arise.
Remark: The high running costs for the Münster system may create a sustainability problem.

Discussion	16:30-17:00

Summary of the aforesaid and challenges.
Ruth Ladenstein summarizes that a system evaluation phase is needed to evaluate which tumour boards run smoothly. She also says that the problem of firewalls, overcoming of legal restrains and the need of remote routers should not be underestimated. If 60-70 clinics cannot afford the remote router, the system is a failure. How to deal with anonymization? Could anonymization be performed automatically as soon as a download of an image is started? How do images fly? Where do we need broadband internet connection?
Dominique Valteau-Couanet points out that anonymization implies the danger of mistakes, therefore a link with clinical data is important. Kathy agrees that you risk clinical error when you remove a patent´s name. She would rather suggest the patient´s consent over anonymization. However, she has no information if the discussion of a non-anonymized patient case cross border is allowed or not.
Enrique Terol answers that the EU has been able to include specific provision on informed consent in the legal framework. All information can be shared cross border, if the patient agrees.* This is currently in review and all member states agreed. Therefore, a frame is already available, however the ministry of justice can still decide for a no. What is missing yet is a clear informed consent process, which has to be

defined.

Remark: Important points to follow up are to clarify if tumour boards may operate with personal data based on their consultant function (as anonymization may create the hazards of error between patient cases).

**Trace legal document*

Technical aspects and disadvantage of Adobe Connect.

Günter Schreier recapitulates that the project ExPO-r-Net* has to define clearly the actual process it wants to accomplish including stakeholders and legal issues.

Virtual tumour boards need 3 software types:

- Software for data sharing, maybe even in real time and merging clinical documents with images
- Tumour board software, clearly better than PPT. This software shall store outcome documents, shall also have checkboxes for conclusions, possibilities to invite participants etc.
- Communication software for videoconferences, desktop sharing etc.

Günter sees the following problems with Adobe Connect:

It allows sharing documents but you are not in control of the server whereas with Vidyo you can control the whole chain of the information flow. There is danger that authorities would reject Adobe Connect because you lack full control of the communication. It has to be taken into consideration that the law in USA signifies full access to all Adobe data if needed. **He therefore thinks that European virtual tumour boards need their own server and not the Adobe cloud.**

This, however, associates with high costs for building the infrastructure and server maintenance**.

Remark: the high costs should be specified in a business plan.

**It has to be defined who within ExPO-r-Net will do this task. Probably Adela Cañete with support from experienced ones like Dominique Valteau-Couanet.*

**Cost effects and affordable solutions needed for the near future at least for the PO-ERN pilot phase.*

Responsibilities.

After an expert discussion follows a conclusion and the physician may follow the advice or not. You need a structured indication and conclusion. We have to think how this can be managed best. Gianni explains that his group gives advice for other centres which is then included in the patient note. Anybody can therefore ask why you decided in a certain way. Therefore one needs good, precise and well performed data for justification of the latter. We also have to consider that the system to be used should be as easy to use as possible. Maybe a basic version could be developed with more sophisticated functions for better developed countries.

Dominique and Gianni Bisogno raise the question of responsibilities. Could an expert giving advice be legally prosecuted? Kathy informs that the responsibility question is not new since for a long time expert advice is already given by email. As long as it is clearly stated as an advice and nothing more, legal requirements should be fulfilled.

Remark: Seek statement of Nikolaus Forgo or on national level about liabilities in advice situations. The solution is probably indeed an informed consent process explaining "non-liability". →Ask for formal written advice

CINECA case consultation forum (see also last chapter).

Eugenia Rinaldi explains the CINECA system which is used by SIOPEL. Clinical data are linked to the images and the reviewers have forms to be answered, which means the information remains structured for analysis. The consultation system is not part of the protocol but has to be entered extra. Gender and age have to be stated and the patient receives a number. It is also indicated if the patient participates in a trial. Details will be presented at the SIOP congress in Toronto. Anybody from all over the world can make a request. One may participate via any hospital email address. The platform is multilingual. As soon as a new case arrives, a moderator decides about the group that should discuss it and the experts have to make reviews about the case within a certain time limit (with automatic reminders). The case is then discussed by the group and a final review is provided to the clinic which made the original request. The

system will start in October 2014 and after several years it will have accumulated a high amount of very informative data which are a great resource e.g. for training.
Remark: Are we sure that we are allowed to use these data for research purposes (is there an informed consent process in place in the CINECA system?).-->Y/N?

Recognition as an expert.
According to Kathy many request go to very few specialists indicating a need for new young experts. To become recognized as an expert the younger specialists should learn as fast as possible, e.g. by participation in difficult case discussions.

Patient requests.
Ruth says that with the help of specific organisations some parents make the same request to several hospitals in Europe which means several tumour boards discuss the same case individually wasting a lot of time. The medical information given by the patients/parents themselves is usually poor. To avoid this, a well-defined structure for tumour boards including a compensation system is needed.

Conclusions.
Günter summarizes that a well-structured process including an IT-strategy is needed to define how to proceed. The system should be as simple as possible and data protection systems have to be considered. Such systems may be expensive but the lack of them also produces costs. Open source is cheaper but the amount of pseudonymization/anonymization deepness or obtaining patient´s consent has to be clearly defined. Instead of developing new methods commercial tools may suffice. In this context Enrique explains that in the case of transplantation there is already a well-functioning system with pseudonymization by code in place, but access to clinical data to avoid patient safety issues.
Enrique reminds that ExPO-r-Net has to define what it is going to offer:

- Which services will be provided?
- What would be the tariff for that?
- Which questions have to be answered by ExPO-r-Net?
- Which tools do we need?
- How can hospital managers be convinced to commitment?

So far there is no benchmark, telemedicine is not yet conceptualized.
Remark: Costs for tumour board activities: Definition of the average expert salary per hour for this special service, →calculation of person months; DVC? How many people? How much time spent on the board? How does it work for local patients like in CBMC

Coffee break

Session 2 PEDIATRIC TUMOR BOARDS

17:30-19:00

A Paediatric Tumour Board Questionnaire: Spanish results **Pablo Berlanga,** Fundacion Para La Investigacion del Hospital Universitario la Fe de la Communidad Valencia	17:30-17:55

Adela Cañete and Pablo Berlanga sent out a questionnaire (Milestone for WP5) within Spain to analyse how paediatric tumour boards function. An adapted form of the questionnaire may also be applied in other countries. It was developed according to earlier surveys. Pablo presents the results:
The questionnaire contained 30 questions and was sent to 43 Spanish paediatric oncology units, 27 responded giving a response rate of 63%. Spain has 47 Mio inhabitants, 17 healthcare regions and 52 provinces. For those with more than 25 cases per year the response rate was much higher (88%). Most

units do have a paediatric multidisciplinary tumour board, especially those with more than 25 cases per year. The response rate was low from centres with less than 10 patients per year, where a multidisciplinary tumour board is not feasible. The questionnaire also requested information about the number of meetings (mostly weekly or monthly), the number of cases per meeting (mostly 3-4) and the usual meeting length (mostly up to 2h). Almost all units have established a designated meeting coordinator and a data manager (often identical with the coordinator).
Whereas the tumour boards usually consist of a core member group of paediatric oncologists, other experts may vary, in particular the radiotherapists.
Most multidisciplinary paediatric tumour board meetings are usually equipped with:

- access to retrospective images/reports
- connection to PACS (Picture Archiving and Communication System)
- projecting and viewing radiology images/specimen biopsies facilities
- a specific room for this purpose

However, equipment for videoconferencing is not standard yet (30-40%) and of those who work with it only 2/3rd have web based video conference systems (Adobe Connect, Skype…).
Pablo also showed an analysis of the rationale for chosen cases. 60% of the centres always discussed cases i) after progression/relapse, ii) prior to surgery/radiotherapy and iii) new cases at diagnosis. If a case is discussed or not often depends on the treating physician.
For case preparation the patient list is always circulated prior to the meeting (100%) but case summaries (30%), a specified reason for consultation (40%) and the recognition of the preparation time in the job time schedule (30%) are less common.
After the meeting, in 75-80% of the units a paediatric tumour board recommendation report is compiled, either in paper form or in an electronic database. About 60% of difficult cases are also discussed with other tumour boards (with med. Oncology and/or other paediatric centres).
Paediatric tumour board development:

- 20% have an allocated protected time to attend the meeting
- 50% discuss a case only, when ALL specialists involved are present
- 80% of the patients are informed that their case will be presented
- If treatment recommendations are not followed, in 40% the patient is informed

Insight in status quo and conclusions.
In only half of the units the paediatric tumour board recommendations are mandatory. This is important because it has to be evaluated how often the recommendations are followed or not. If they are rarely ever followed, a tumour board is a waste of time. Only 20-25% of the units give official recognition for the attendance. Only very few have standard operating procedures (SOPs, 20-25%) and technical/administrative support (20-25%), reflecting a low rate of official tumour board reports (25%). However, the inclusion of the recommendation in the medical report is mostly mandatory (60-70%).
None of the units have a monitoring report on the recommendations and a quality of decision making evaluation and none of the units participate in virtual tumour boards. Some are interested to participate in virtual tumour boards but they fear complex and elaborate discussions. They want quick second opinions instead.
Remark: Tumour board request advisory in a voluntary process and not binding to be considered.
Future: benchmarking process necessary if there is compensation in place via member states.

See presentation ExPO-r-Net TB-Workshop_Berlanga

Discussion:
Tumour board recommendations.
Kathy Prichard-Jones is surprised that only about 50% of the units have to follow the tumour board recommendations and wonders about the rate of recommendations NOT followed. Pablo replies that the rate of recommendation denial is unknown. The questionnaire could also not evaluate, WHY recommendations were not followed. The respondents could have given explanations why but this was

optional and most refrained from doing so.
Kathy informs about a survey on how often board decisions are followed with the result that decisions are followed most often in cancer and least often in mental disease. Another result of this survey was that the more people are in the board the less the advice is followed*.
Ruth Ladenstein mentions that the St. Anna Hospital follows 90% of the recommendations because the St. Anna Hospital is a study recommendation centre for all paediatric tumours except brain tumour. This means that practically all St. Anna patients are in a trial. The board decisions are only rejected when parents disagree.
**The reason behind should be explored.*

Education.
Ruth suggests also that credit points according to the ECTS system should be given to stimulate young physicians to participate in a tumour board.
Remark: To be explored: national recognition criteria for ECTS

Action points on questionnaire.

- The questionnaire should be made more precise and Europeanized
- It is concordantly decided that the rate of recommendation acceptance has to be evaluated.
- The adapted questionnaire should be sent to other European countries
- For legal reasons recommendations from external virtual tumour boards have to be optional and not mandatory.

According to Kathy it can be expected that different countries are in different stages to work with small units and networks. Some countries may not have national organisations for protocols. This will be clarified by Jerzy Kowalczyk.
Remark: Requests to tumour boards should be qualified, i.e. made by the treating physician. ExPO-r-Net needs to define the communication process (request/answer templates etc.). Probably to be done by Adela Cañete with support of experienced experts like Dominique Valteau-Couanet.

The different ExPO-r-Net Partners experience and discussion	17:55-19:00

The situation in different countries is discussed. Enrique Terol informs that probably due to insufficient planning some countries have too many units. Some centres are too small and are not allowed to treat specific patients. This is an issue which as to be addressed by healthcare decision makers. A standard of care has to be established. There are no clear rules/criteria in most EU member states.
Dominique Valteau-Couanet suggests establishing criteria for small centres* to be allowed to treat patients with the help of reference centres.
Ruth Ladenstein makes aware of the problem that cross border questions are often asked inadequately. We should then suggest that the questioner should connect with a local centre from which is known that they are well trained and capable for the respective case. The goal would be to go from your small hospital to the closest reference centre. Ruth thinks that the motivation why this is not yet done is the fear to lose your face if contacting a so-called competitor. If you contact a centre abroad your neighbour will not become aware of it. A compensation scheme for cross border healthcare would be public and therefore counteract this.
Günter Schreier points out that very few have experience with virtual tumour boards. He suggests a pop-up questionnaire in the current version in case somebody clicks “yes” for details on the experience with virtual tumour boards. He will prepare the respective questions to be sent to Pablo Berlanga**.
Eventually, Ruth announces positive news that the Austrian Cancer plan was published today including the survivorship passport as part of it.
**To be done by Jerzy Kowalczyk*
***To be done by AIT*

CINECA case consultation forum (see also above).
Within ENCCA, CINECA in collaboration with SIOPEL and CHIC, has developed a specific platform for

reviewing cases on paediatric liver tumours and sharing large diagnostic image files via web, certified for quality and security. Eugenia shows, how this tool looks like and functions for a clinician, how he is supposed to enter a case, how to upload images via a dedicated image upload client etc.. Each case receives its own number. As soon as a case is uploaded it becomes visible on the dashboard of the moderator who then takes action. He can accept or reject the case. If accepted it is assigned to one or more specific panels of reviewers. They can review the structured information independently. Each review is then available to everybody and a discussion is started via web-chat/videoconference. The workflow is clearly defined.
Usually there are 4 reviewers and the moderator/leader. The diagnoses may agree or differ. The final diagnosis is decided in the videoconference and announced by the moderator/discussion leader. The whole process is supposed to last 7 days maximum. You may want to discuss at the beginning of the review and at the end. The final decision is made available to the initial clinician. To access the platform the only requirement is a computer with internet connection and a standard internet browser. Every user has a personal account (username and password) from the SIOPEL website using encrypted connection.
Eugenia shows a test example of a processed pathology image which can be zoomed, moved and focussed as needed. This functions via the Big File Client.
Eugenia informs that the workflow for this platform was demanding and complicated. CINECA started in march and it is now ready to be launched.
Gianni asks how long it takes to upload the images and Davide Sarazeno gives an estimate of approximately 1h. Kathy Prichard-Jones asks how this platform will be financed in the future. Eugenia answers that in the moment it is funded by ENCCA but CINECA is looking for further funding and they take USA as example where such platforms are often run with external funding.
Remark: The upload time for images is very long. Who will cope with this? Are there alternative solutions?

See presentation ExPO-r-Net TB-Workshop_Rinaldi

End of Tumour Board Workshop

Action points for WP5

- **Gather information on details of the IGR virtual tumor boards**: track keeping, organizational structures, registration, communication with client, data saving and protection
- **Gather information on details of the Münster tumor board tool:** running costs, starting costs, definition of user, user rights etc.
- **Gather information on the costs for the CINECA case consultation forum**
- **Business plan for a European virtual tumour board with own server, as the Adobe cloud is considered unsafe by some EU-countries.**
- **Liabilities in advice situations:** Informed consent process explaining “non-liability”?
- **Definition of processes for tumour boards including, communication between client and tumour board, stakeholders and legal issues**: →Probably to be done by Adela Cañete with the help of experienced experts like Dominique Valteau-Couanet.
- **Definition of the compensation system**: Costs for tumour board activities expert salary per hour for special service, person months; average number of persons and time spent per tumour board etc.). → Probably to be done by Adela Cañete with the help of experienced experts like Dominique Valteau-Couanet.
- **Pop-up questionnaire in the adapted tumour board questionnaire for details on experience with virtual tumour boards**. The respective questions will be prepared by Günter Schreier and sent to Pablo Berlanga.

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- **Trace legal document that allows all information to be shared cross border**, if the patient agrees.
- **Contact Nikolaus Forgo for a template formal written advice**
- To be explored for tumour boards: **national recognition criteria for ECTS**