

Introduction

This is an invitation for your child's diagnosis and treatment to be discussed in a virtual tumor board of the ExPO-r-Net. This can only happen if you give your informed consent.

Your child has been diagnosed of a particular type of cancer. Cancer in children is a rare disease and because of the low number of cases per year, extensive experience is difficult to acquire in any one hospital treating children's cancer. Many of the cases are complex and challenging and require a detailed consideration of the different therapeutic options available. There is less experience than in other types of common diseases where a standard treatment is officially established.

Due to the specific nature of your child's tumor, the decision on the best treatment for your child may benefit from discussion at an international multidisciplinary virtual meeting to exchange opinions from established experts in this type of tumor. If you agree to this discussion, your informed consent is required for your doctor to participate in a virtual tumor board of the ExPO-r-Net and share information about your child's case

What is ExPO-r-Net?

ExPO-r-Net (European Expert Paediatric Oncology Reference Network of Diagnosis and Treatment) is a project funded by CHAFEA (Consumers, Health, Agriculture and Food Executive Agency) of the European Union (EU) that aims to build a Pediatric Oncology European Reference Network. This network aims to facilitate for "Cross-border healthcare" to allow children and young people with cancer access to expertise and specialist healthcare in a Member State other than the Member State of affiliation.

The mission of ExPO-r-Net is to reduce current inequalities in childhood cancer survival and healthcare capabilities in different EU Member States by building a European Reference Network for Paediatric Oncology (ERN-PO).

European Reference Networks (ERNs) are a feature of the EU Directive on Cross-Border Healthcare aiming to unite the best specialists from across Europe to tackle complex or rare medical conditions that require highly specialised healthcare and a concentration of knowledge and resources.

What is a tumor board?

A tumor board comprises a multidisciplinary team of experts including pediatric oncologists, radiologists, surgeons, radiotherapists, pathologists, etc, that discuss clinical cases where the diagnosis and treatment plan is complex. The clinical management of a patient following a discussion at a tumor board takes into account the opinion of several experts participating in the meeting.

Tumor boards are standard practice in specialist pediatric oncology centres and are part of the normal decision making process for treatment of children with cancer.

What is a virtual tumor board?

A virtual tumor board is a special type of multidisciplinary meeting based on IT videoconference systems that can involve experts from different specialist centres throughout Europe. The tumor board meetings are 'virtual' because they are held via videoconference systems, allowing regular meetings and discussions between experts in different countries without needing to travel for a face to face meeting. The virtual tumor board can therefore convene rapidly to discuss urgent cases as soon as possible.

Why am I being asked for my child's case to be discussed in a virtual tumor board?

The particular case of your child is considered "complex". This means that the clinical features of your child's tumor are not typical or the type of tumor does not have a standard way of treatment and there may be several options that can be considered. Your doctor feels that a discussion between multiple international experts would help to determine the optimum treatment for your child. It is possible that several types of treatment may be needed and they will involve different types of specialists. Discussion with experts in the diagnosis and treatment of your child's cancer may help your doctor to decide the best option available.

Will my child's personal data be protected?

Yes. Data will be shared across secure IT platforms and videoconference systems that comply with the EU data protection regulations. Personal and medical details need to be provided in order to arrive to a decision but only physicians and data managers involved in the tumor board will have access to these data. All the members of the virtual tumor board and physicians whom the information is being shared will remain under the obligation of medical confidentiality.

What other options do I have?

Participating in an ExPO-r-Net tumor board is not obligatory and is not necessarily the only option to get advice for the treatment of your child. ExPO-r-Net tumor board ensures that the opinions of international experts in each type of cancer are taken into account. If you do not wish that your data is shared and evaluated by the multidisciplinary international team, you can follow the decision of your physician at your institution. This would be the standard way to decide the best treatment in a normal situation.

Is the decision of the tumor board the the final one?

No. The decision will be communicated by the Virtual Tumor Board co-ordinator to your doctor by means of a standard form that will summarize all the discussion and the agreed recommendations. Your physician will discuss these recommendations with you. You must be aware that you and your treating physician do not have to accept the recommendations made by the virtual tumor board. The final decision on the best treatment for your child will always be taken by your physician and yourself. The recommendations of the Virtual Tumour Board are an optional advice that can be used to take this decision.

Whom should you contact in case of any question or problem?

For questions about this information or a research related problem contact

Dr.....

Telephone contact

who will reply to all the questions that you wish to ask. This can be either prior to your decision to consent for your child to be discussed in the tumor boards, or after your child has been discussed.

**Virtual Tumor Board ExPO-r-Net Parent Informed Consent Form
(patients under 16 years)**

I..... (name of parent/guardian), as parent/guardian of
(patient's name):

- I confirm that I have read and understood the information contained in the information sheet.
- I have had the opportunity to ask questions and had satisfactory answers to them.
- I have received enough information about the virtual tumor board.

I have talked to:

..... (Physician name).

I understand that my child's participation is voluntary and that she/he is free to withdraw at any time. I also understand that the decisions taken are only recommendations that are optional to follow.

In my presence,(patient's name) has received all the information according to his/her level of understanding and she/he agrees to participate.

I approve that personal and medical data of my son/daughter(patient's name) is shared within the IT videoconference system and the expertise members of the virtual tumor board.

I hereby approve the participation of (patient's name) in the ExPO-r-Net tumor board.

Part for the Parent/Guardian & Patient	Part for the Physician
Full Name of Parent/Guardian:	Full Name:
Signature of Parent/Guardian:	Signature :
Date:	Date:

