



**Sarcoma
Patients
EuroNet**

*Together We Can Make A Difference
For Those Affected By Sarcomas!*



**Sarcoma
Advocacy In Action
Award 2018**

Patient Perspectives of the Cancer Multi-Disciplinary Team

The objective was to find out

- What is a Cancer MDT?
- What differences do they make to patients, parents carers?
- How should patients be involved in them?
- How are MDT's viewed by patients and parents?

The target groups were child patients, parents and carers.

This project is currently completed; however the research was carried out using our group NEMDT and telephone interviews.

We established that MDT's are there to improve treatment as defined by NICE. Working in a team improves outcomes for patients, bringing together health professionals with a pool of knowledge and shared decision making should improve outcomes for patients. However, all the research so far really concentrates on Adults and there is very little focus on the merits for children.

Previous research noted that very little time was spent discussing patients and much of it wasn't patient focused and meeting attendance was not optimal. Most information was not specific to the patient or their QOL or preferences considered, very important for a child who then has to live with the consequences of that MDT decision. We conducted polls with Health professionals and parents and our research found that overwhelmingly patient views should be considered at MDT. However, when asked if patients/carers should attend MDT's the results were polar opposite with patients saying yes they should and health professionals disagreeing.

We ran two focus groups in our NEMDT Advisory Group where we concentrated on 3 main areas Understanding of the MDT, Making Choices and Communication.

We established that with reference to Understanding of the MDT many of our group felt there was an air of secrecy around MDTs, a conveyer belt approach, too much medical jargon and even a lack of expertise. Some felt the logistics of getting everyone together was difficult and treatment depended on them. Some parents assumed only their child was discussed when in reality it will be many.

Making choices was very varied with some feeling the decisions had already been made and they were just told what would happen. Some families felt they didn't have enough information to make informed choices and others wanted to know everything that had been discussed. Relationships become established and bad news needs to be delivered by people who know you and some doctors have a higher Emotional Intelligence than others.

So in conclusions we established that the MDT makes individual treatment plans. However, patients must be integral to that process therefore a shared more collaborative approach is required.

Additional value of your project for the sarcoma population

The Sarcoma population is as individual as every person, there is no journey the same or a person who has the same perspective. Tailor made recommendations are key and the QOL and sacrifice by the patient must be paramount in the decision making around treatment.

Hence, next steps are to devise a decision making tool for clinicians, carers and patients. This will enable MDT's to take into consideration the patient's wishes and dreams for life and what sacrifice they can tolerate to achieve a life going forward, clearly balanced with a healthy outcome.

We are also about to have an article published in The European Journal of Cancer Care.



**The Bone Cancer Research Trust
The National Ewings Multi-Disciplinary
Team Advisory Group (NEMDT)**