

## Understanding treatment decision-making processes in families where a child or young person has relapsed or refractory rhabdomyosarcoma



**Project title:** Understanding treatment decision-making processes in families where a child or young person has relapsed/refractory rhabdomyosarcoma

**Lead researcher:** Professor Bob Phillips, University of York

**Project Stage:** Ongoing (started April 2021, planned end February 2025)

**Funded by:** CCLG and Angus' Door, Jacob's Join, Pass the Smile for Ben, Ollie's Star, Be More Ruby and Team Jake

### ABOUT THE PROJECT

In children whose rhabdomyosarcoma has not responded to treatment (refractory), or has come back after treatment (relapsed), there are difficult decisions to be made about what treatment to give. Only around one in five children with relapsed or refractory rhabdomyosarcoma can be cured, and so there are choices to be made about how to proceed. The options might include:

- Aggressive treatment aiming to cure
- Treatment to reduce the amount of disease, and therefore help symptoms
- Experimental trials of new treatments (also called early phase studies)
- Symptom control

Families may never know what the best option would have been and can spend years wondering what might have happened if they had chosen differently. In this project, Prof Bob Phillips' team will conduct two linked studies to help understand how decisions are made about treatments:

1. A "systematic review", where the researchers will look for all previous early phase studies in relapsed or refractory rhabdomyosarcoma and see how effective the different new treatments are for different children. This will help to give families and professionals more accurate information about what to expect from the options available.
2. An interview study, where the team will speak to patients and families about how they have made, or are making, decisions about treatment in relapsed or refractory rhabdomyosarcoma. This will help us understand the decision-making process and how best to support families making these choices.

The results of both of these studies will be combined in a best practice statement which will provide advice and support to clinicians and families about important things to consider when discussing treatment options. The project will include patients and parents in designing and performing the research to get the best results for families in the future.

## PROGRESS

The systematic review has now been completed. Overall, the team found 129 published studies, which included over 1,100 patients with relapsed and refractory rhabdomyosarcoma. The studies included multiple treatment types of treatment. The researchers also identified 99 relevant clinical trials. You can find out more about the review findings, and the follow on Living-REFoRMS project, here: [tinyurl.com/REFoRMS-projects](https://tinyurl.com/REFoRMS-projects)

For the qualitative research, Bob's team have now interviewed 7 mothers and 6 fathers about their experiences of making decisions for their child. The team are analysing over 17 hours of interviews and 8 completed Lifegrids (which are a timeline of a child's treatment, written by parents). This is taking longer than expected, so they have extended the project until February 2025. So far, they have identified four main themes from parents when making treatment decisions: Trust in provider; Feeling that you just have to do something; Family's social network for cancer; Distinction between living and being alive. In addition, there was a theme that was common for many parents: Doing their own research.

## WHAT'S NEXT?

The team held a meeting in November to finalise the results of the qualitative interview section of the project. They hope to submit their research to scientific journals shortly.

In the Living REFoRMS project, the team will regularly update an online resource with new studies to show up-to-date evidence on treatments for relapsed and refractory rhabdomyosarcoma. The results of these studies will be combined to provide advice and support for clinicians and families who are making difficult decisions about treatment options.



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