

# CCLG: The Children & Young People's Cancer Association research: A living review of new treatments for children and young people with relapsed and refractory rhabdomyosarcoma

**Project title:** Living-REFoRMS - A living systematic review of early phase studies for children and young people with relapse and refractory rhabdomyosarcoma

**Project stage:** Complete (ended August 2025)

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**Led by:** Dr Jess Morgan, University of York



## About the project

New treatments are continuously being developed for rhabdomyosarcoma that has not responded to initial therapy (refractory) or has come back after treatment (relapsed). Keeping track of new developments so that the most accurate information is used to make treatment choices is particularly difficult for families and clinicians.

A recent CCLG-funded study called REFoRMS included a systematic review of treatments for children and young people with relapsed and refractory rhabdomyosarcoma. Systematic reviews are a form of research where all previous studies in an area are found and assessed before the results are combined to summarise the best evidence available at that time.

Dr Jessica Morgan's research team at the University of York plan to develop a living systematic review of studies into new treatments for relapsed and refractory rhabdomyosarcoma, called Living-REFoRMS. Living systematic reviews are a new method where the evidence is regularly searched, assessed, and summarised so that the information is the most up-to-date that it can be. This living systematic review will look for completed research and currently open trials from all around the world. The researchers also want to develop a high-quality, regularly updated, online resource to share the findings from Living-REFoRMS that will be accessible to families and clinicians, and will help and support decision making in relapsed and refractory rhabdomyosarcoma. The online resource will be developed with and hosted by CCLG, so that families and clinicians only have to check one place instead of searching through many. The project will include a project steering group of families with experience of relapsed and refractory rhabdomyosarcoma, and professionals with expertise in this area, who meet regularly to advise the researchers on this project.

## Results

The CCLG-funded part of Living-REFoRMS is now finished. Across six updates, the team identified 179

early-phase studies looking at treatments for relapsed and refractory rhabdomyosarcoma. Altogether, these studies included information from more than 1,350 children and young people. All of the updates are available at [cclg.org.uk/our-research/our-research-projects/reforms-project](http://cclg.org.uk/our-research/our-research-projects/reforms-project). From this work, the team picked out 11 studies they think are worth looking at more closely, as each showed response rates of over 30%. They will also keep an eye on clinical trials that are currently open to rhabdomyosarcoma patients.

The data collected through Living-REFoRMS has also made it possible to explore further research questions, such as how response rates link to survival and how targeted treatments compare with non-targeted ones.

The new online resource, which will bring all of the findings about rhabdomyosarcoma treatments together in a clear and easy-to-use way for families and clinicians, is now planned for launch in early 2026.

### What's next?

Dr Jess Morgan is looking at ongoing funding to ensure the Living-REFoRMS project continues to provide up-to-date evidence for families and clinicians making decisions about treatment options for relapsed/refractory rhabdomyosarcoma.

She is also applying the 'living review' research method to other disease types, including neuroblastoma, and a type of sarcoma called desmoplastic small round cell tumour.



The Children & Young People's Cancer Association

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