

Designing 'My A-Team Pack' for children and young people with Ataxia Telangiectasia



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COSTS: £89,862.48 over 36 months by Action for A-T

This study aims to undertake coproduction of an AT specific patient-held record we are initially calling 'My A-Team Pack' for children and young people with AT. By co-production we mean that all participants will work together to produce the design of the pack. This study is part of a wider project which ultimately aims to improve the care and management of children and young people with AT using the best available evidence.

This project has been funded by the charity 'Action for A-T' and is supported by 'The AT Society'. At the start of this project, parents with children with AT told us that healthcare professionals and school teachers are often uncertain about what AT is and how it affects the life of the child and the wider family. Parents also told us that it was difficult to keep track of information and often found themselves repeating information about AT to several different professional groups.

For more information about this study please contact munira.khan@plymouth.ac.uk

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[Information sheet for children aged 11-16yrs](#)

PROJECT: Exploring effectiveness, feasibility, and acceptability of a novel home-based complex intervention for children with ataxia telangiectasia: a pilot randomised controlled trial

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