

Invitation Letter for recruitment via email

Dear A-T Society Member,

We would like to invite you to participate in our survey that aims to explore physiotherapy approaches for children with A-T as it is appraised by their parents or guardians but also by older children with A-T themselves.

Before you participate, please read the following information to find out more about the survey.

Treatment approaches for Ataxia-Telangiectasia's currently remain symptomatic, with no treatments known to slow or stop the neurodegeneration. Commonly children with A-T are referred to physiotherapy to target gait ataxia along with other movement related changes. However, there is little evidence guiding physiotherapy approaches with respect to this. This survey aims to collect service user perspectives and experiences regarding physiotherapy to better understand what physiotherapy could offer children with AT in the future.

You are eligible to participate in this survey if you are:

- A parent or guardian of child/children with A-T who is at the time of survey completion under 18 years of age.
- A young person with A-T above the age of 13 but under the age of 18 years and only if your parent/ guardian gives consent to do so by forwarding this link to the survey on to you.

Unfortunately, you are not eligible to participate in this survey if the individual concerned who has AT is 18 years of age or older. This is to ensure that this survey remains focused to our understanding of paediatric physiotherapy services on this occasion. We also request you/your child to not participate should you have accessed physiotherapy services more than **one year** ago as this could introduce some recall error to the results of the survey.

You do not have to take part but if you do decide to participate, we anticipate it will take about 10-15 minutes to complete the survey. During the survey you would have the right to withdraw your participation at any time by not responding to questions. If you change your mind after consenting and want all of your responses to be deleted, please use the tickbox on every page of the survey to make this clear to the researcher, who will then securely delete all of your responses. Once all survey questions are submitted there will be no method to withdraw responses owing to the anonymous participation method.

A summary of the results will be submitted in the web page of A-T Society UK to provide you with relevant information. Additionally, if you request it, a copy of the results could be sent to you via email address. Please remember that this may act to identify you to the researcher as a possible respondent, but the research team will not know which response is yours. All email correspondence with the researchers will be securely destroyed after summary reports are sent out.

After the end of the survey, your responses would be exported to an Excel document and held by the University of Plymouth's data protection officer in a secure, encrypted and password protected electronic file until being securely destroyed after 10 years in line with GDPR (2018) and the University's data management policies.

<You can access the online survey using the link below>

<https://plymouth.onlinesurveys.ac.uk/a-tphysio>

If you have any further questions, please do not hesitate to contact me via email, Myrto Karagianni-Xanthaki
email: myrto.karagiannixanthaki@postgrad.plymouth.ac.uk. If you have queries, concerns or would like to complain about the study at any point, please contact Dr Tracey Parkin via email tracey.parkin@plymouth.ac.uk or telephone 01752588827 or, if you would prefer to contact an impartial representative of the University of Plymouth, please contact the ethics committee lead for the School of Health Professions: phill.buckhurst@plymouth.ac.uk or the Data Protection Officer via email: dpo@plymouth.ac.uk.

Kind Regards,

The research team