

## **TS 2000 Study 2024 Summer Newsletter**

Hello everyone!

It's been a couple of months since we were last in touch, so we would like to update you on our progress on the TS 2000 study and associated projects. Thank you for your ongoing participation in the study!

### **Where are we now?**



Last year we began the fourth phase of the TS 2000 study. This phase aims to understand the everyday experiences of individuals with TSC as they move into adulthood.

We started phase 4 with an information gathering stage. We invited young adults with TSC and their Key Support Persons to focus groups and interviews to discuss the potential use of a smartphone app to track the daily lives of young adults with TSC. Please see the next page for the results of this study.



We are also running an advisory group who have been helping us organise phase 4! Please see below for more information.



We have now started the next study of phase 4 which is the testing study. We are inviting young adults with TSC to test out the smartphone app for two weeks. If you are interested in taking part, please see below for more information.



We are also organising a more general follow up study for all previous TS 2000 participants. More information about this will follow soon!

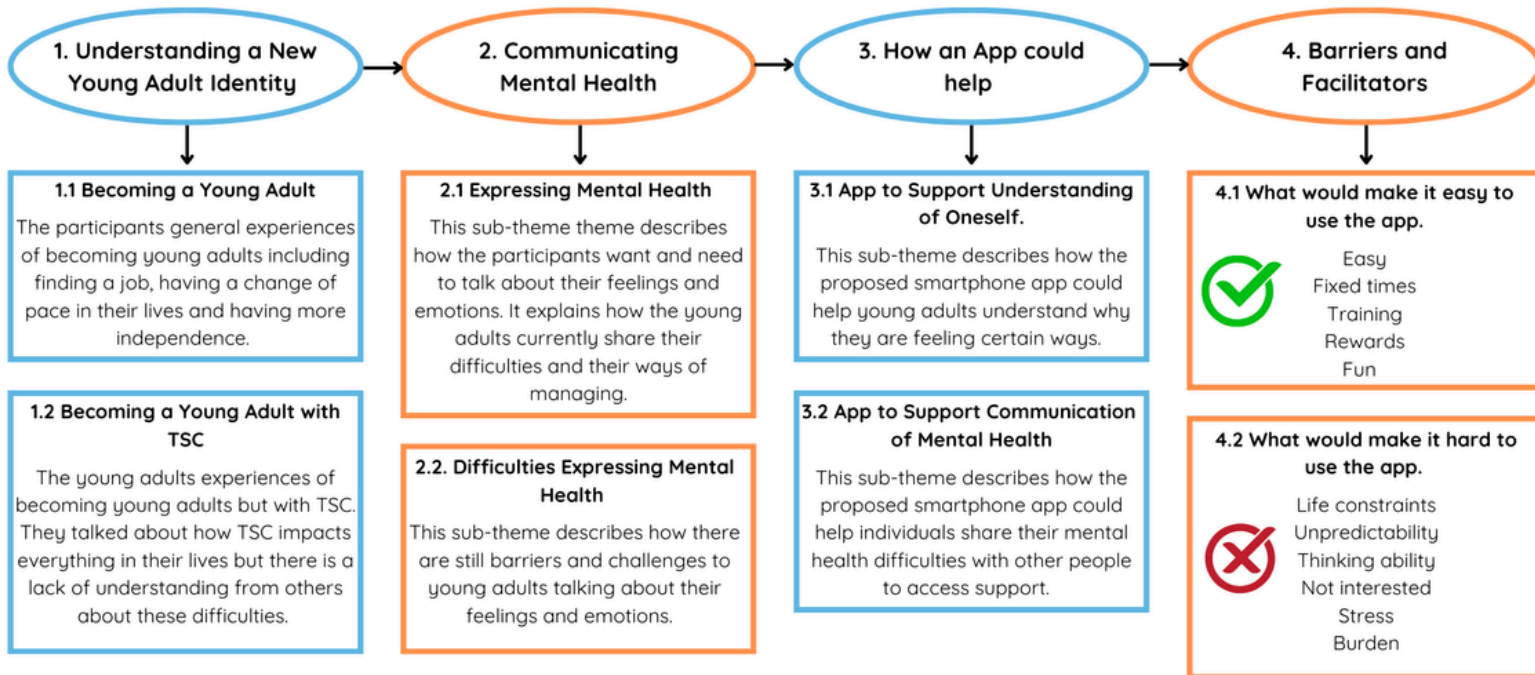


# Results of Information Gathering Study

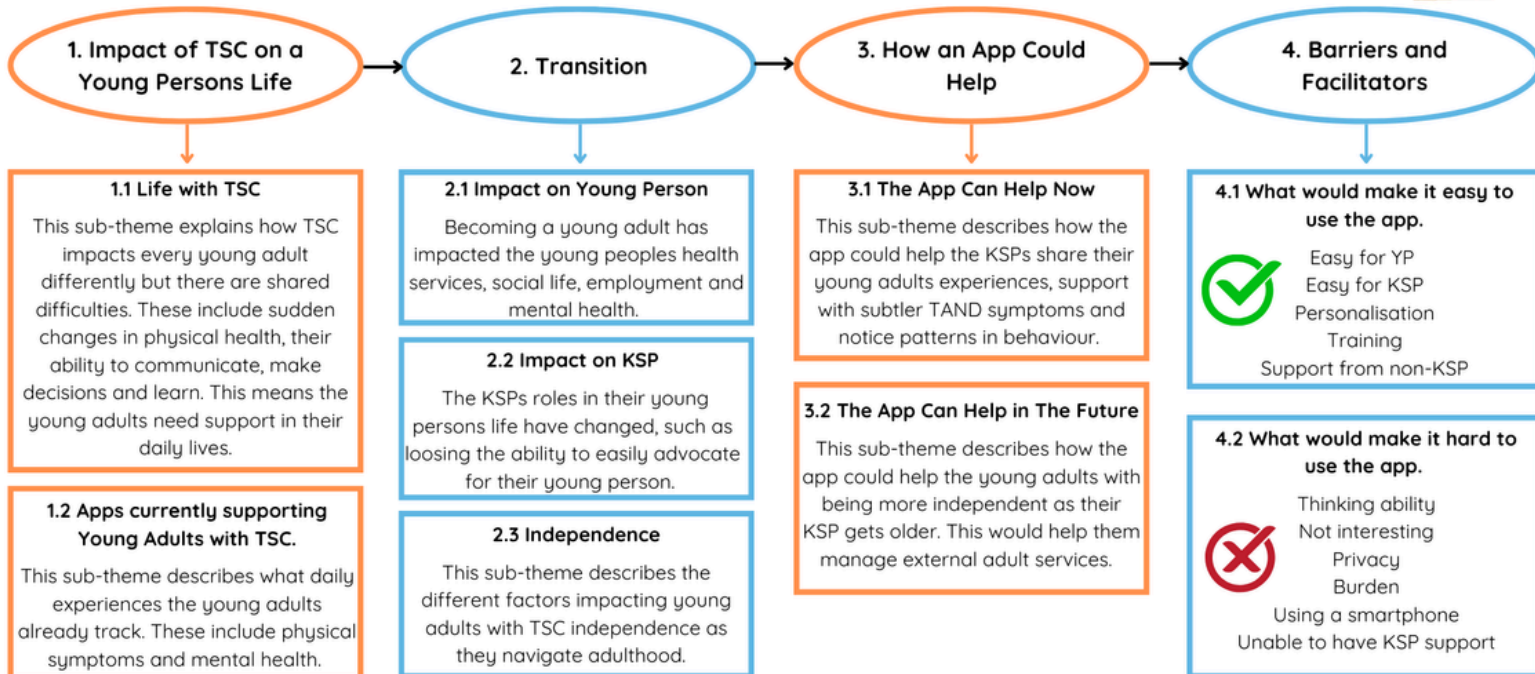
We invited 14 young adults with TSC and 7 Key Support Persons to focus groups and interviews. We asked them lots of questions about how their lives had changed since becoming a young adult. We then showed them an example of a smartphone app used to track daily experiences. The participants then discussed how they would use this app in their daily lives. We then analysed their answers and grouped them into 'Themes' and Sub-themes', see below for the results.



## WHAT DO YOUNG ADULTS WITH TSC THINK ABOUT USING SMARTPHONES TO TRACK THEIR EVERYDAY LIFE?



## WHAT DO KEY SUPPORT PERSONS THINK ABOUT YOUNG ADULTS WITH TSC USING SMARTPHONES TO TRACK EVERYDAY LIFE?



# We Are Now Recruiting!

Our next study: "Assessing Young Adults with TSC using Smartphones: A Feasibility Study" is now open for recruitment!

## Assessing Young Adults with Tuberous Sclerosis Complex Using Smartphones:



### A FEASIBILITY STUDY



Are you aged between 16 and 35 and have a diagnosis of Tuberous Sclerosis Complex?



Do you own and use a smartphone (a phone that can download apps)?

You are invited to our research study. You will be testing out a new smartphone app that can help track the day-to-day feelings or symptoms of young adults with TSC may face.

### Taking part involves...



Completing some online questions and assessments



You will test the app out for 14 days.



The app will ask you to complete 4 questionnaires a day about your emotions & feelings



You will be asked questions about what you liked/disliked about the app.

For more information visit our website:

[www.ts2000study.co.uk](http://www.ts2000study.co.uk)



You will be compensated with a shopping voucher.

If you would like to take part...

Please contact us using the email below and a member of the team will be in touch.

Contact us:

[ts2000@kcl.ac.uk](mailto:ts2000@kcl.ac.uk)

## Advisory Group

To help us design the smartphone testing study in phase 4, we have invited two young adults with TSC to be part of an ‘Advisory Group’.

An advisory group is a small group of individuals who are similar to the intended participants for a research study (young adults with TSC). They provide guidance on how to run the study in line with what is best for the participants.

The group has met 6 times this year via video call and they have helped with the following:

- Designing the advert and flowchart to recruit participants.
- Designing the training and smartphone app questions.
- Tested the smartphone app for two days.
- Designed how the results will be shared with the participants and the wider TSC community.

Finally, the group will be meeting face-to-face in London to design guidelines for how to include young adults with rare genetic conditions in smartphone studies and advisory groups.

“You’re never alone in life; you’ll always find connections with others who share your feelings with you”

*Navida (age 22)*



## CHARITY EVENTS



Kate, the PhD student on the study, attended Big Day 2024 run by the Tuberosus Sclerosis Association Charity. She presented the findings of the information gathering stage from the young people with TSC.



## UPDATES FROM THE TEAM



Katie is the current placement student on the TS 2000 Study who will be leaving us in the next couple of weeks to commence her final year of study.

We would like to say a massive thank you to Katie for all her hard work this past year and wish her good luck in her final year at University!

**THANK YOU!**

We will be welcoming Tamia in late August who will be taking on Katie's role in supporting the day-to-day running of the TS 2000 Study.

“It has been an absolute pleasure working as part of the TS 2000 Team for the last year. Being involved in the information gathering stage of the TS 2000 study gave me an incredible insight into the importance of our work, especially in capturing the variety of difficulties that young adults with TSC face.

Throughout my placement year I have also been heavily involved in the EDiTS Study run by Dr Charlotte Tye, which is looking at the Early Development of children with TSC. Being able to work so closely on both these studies has encouraged me to conduct my dissertation project with the TS 2000 Team next year. I hope to expand my knowledge of the relationship between specific communication abilities and behaviour within individuals with TSC.”

**- Katie**

## Contact details

If any of your contact details have changes, we would appreciate if you could drop us an email on [ts2000@kcl.ac.uk](mailto:ts2000@kcl.ac.uk) to let us know so that we can update our records.

# THANK YOU!

Once again, we would like to thank you for all of your participation taking part in the TS 2000 study.

With best wishes,

**Dr Charlotte Tye & the TS 2000 Study Team**

