

RESEARCH STRATEGY UPDATE 2025

STAGE ONE: EXPERT CONSULTATION



“
To provide
help for today
and a **cure** for
tomorrow
”

Shaping the future of TSC research

We are updating our research strategy in partnership with people affected by TSC and TSC research leaders.

The TSA is a catalyst for world-leading research and learning on TSC. Our research strategy will reflect the most important priorities of the TSC community and we are committed to driving progress to provide help for today and a cure for tomorrow.

Stage one involved consulting the TSC community to understand their research priorities.



What we did



Hearing from the TSC community

- We launched an **online ideas board** open to everyone affected by TSC



Expert conversations

- We held **13 interviews** with members of the TSC community

What we did: online ideas board

We opened our online ideas board in May 2025 for three weeks. We used the tool online, Padlet, during our consultation. Padlet was chosen as it offers an engaging, user-friendly and collaborative experience for people to share their ideas. Posting is anonymous.

We generated the following prompts to gain insights into priority areas:

- What is the hardest part of daily life with TSC?
- How does TSC affect your family, work or emotional well-being?
- What do you wish doctors or researchers better understood about your condition?
- If researchers could focus on one thing, what would you choose? Why?
- What are the most important unanswered questions in TSC?
- Are there any questions you've asked your doctor that didn't have a clear answer?

Optional demographic data was collected and there was an opportunity to leave additional comments.

Online ideas board: who we heard from



35 people engaged



88 comments shared

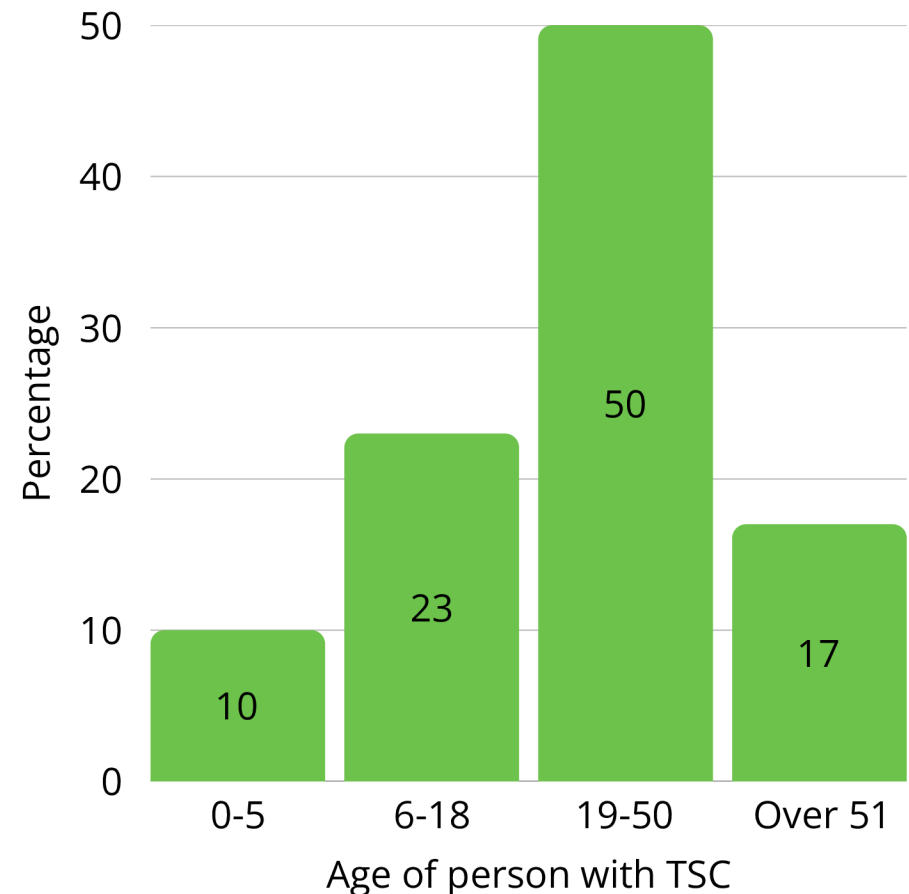


21 from England

2 from Scotland

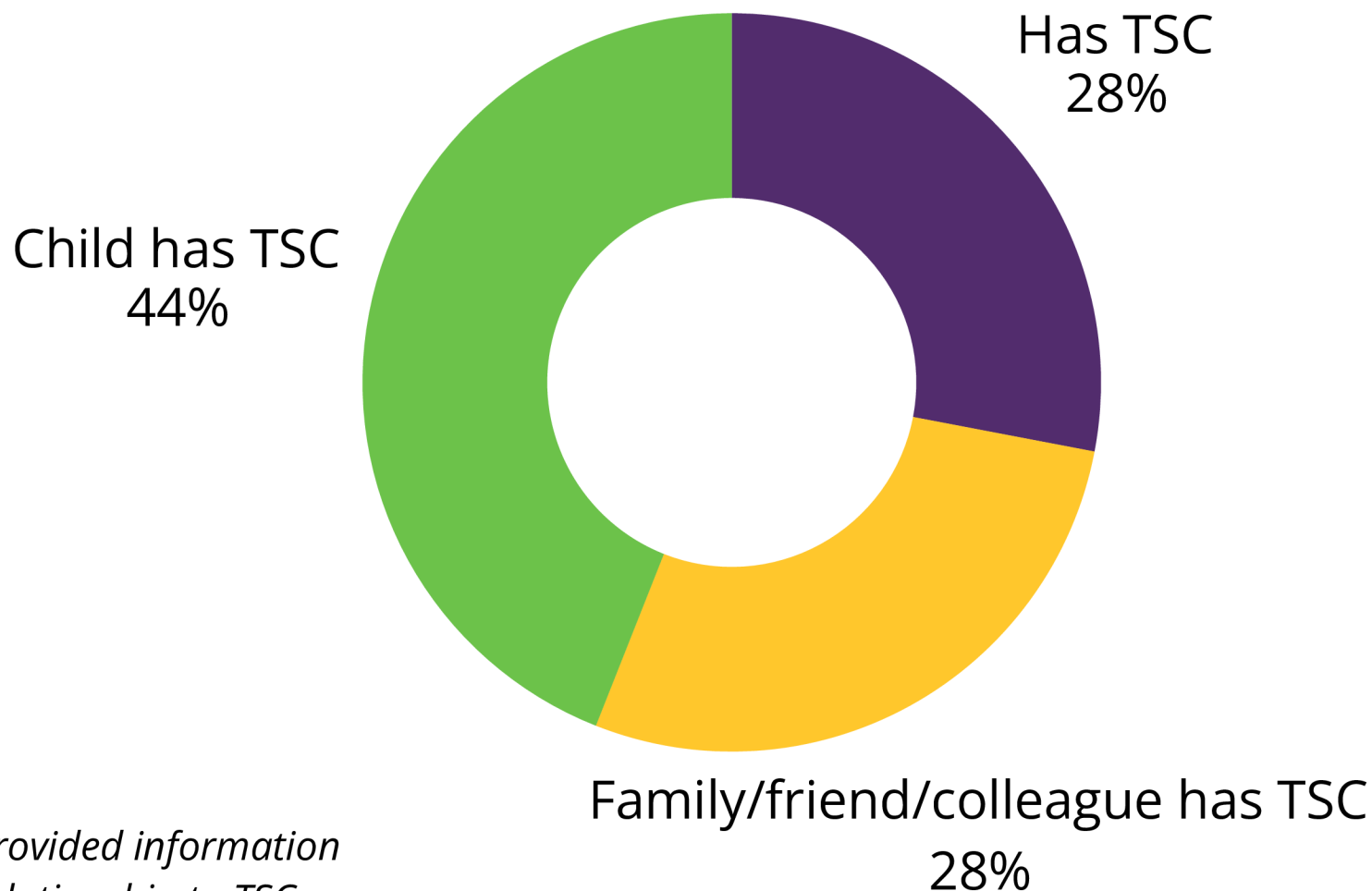
1 from Wales

3 from outside UK



*30 people provided information
on the age of the person with TSC*

Online ideas board: who we heard from



*32 people provided information
on their relationship to TSC*

What we did: expert conversations

To gain deeper insights into research priorities, we conducted semi-structured interviews with lived experience experts and technical experts.

Semi-structured interviews with lived experience experts centred around the padlet prompts, as previously detailed.

We generated the following prompts for researchers:

- What are the most important unanswered questions about TSC?
- Where are we not making enough progress in TSC research? Why?
- What are the areas of highest unmet need for people living with TSC?
- Are there specific emerging areas or technologies you believe hold promise for advancing TSC research?

For those with clinical experience we also asked:

- Where are patients or families asking questions we can't currently answer through evidence?
- What types of research would most improve outcomes or quality of life for your patients?

Expert conversations: who we heard from



5 lived experience experts



2 adults with TSC
3 parents



3 from England
1 from Scotland
1 from N.I



6 academic researchers
2 clinical researchers



15 years average in TSC research (from 3-25 years)



5 from England
3 from Wales

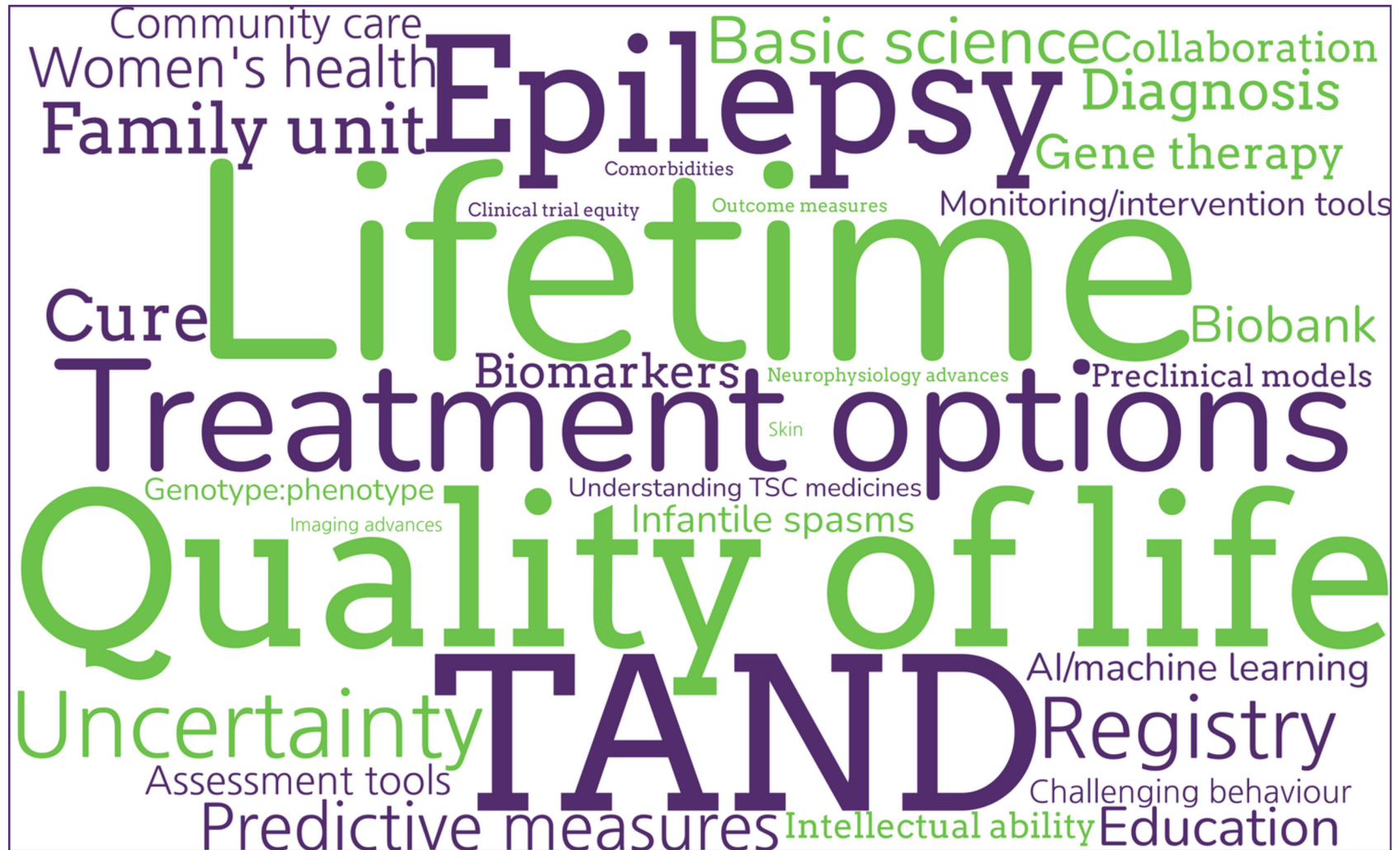
What we heard

We conducted a **thematic analysis**. A **thematic analysis** is a way of finding and organising common ideas or patterns in people's stories or experiences to better understand what matters most to them.

Common themes included the uncertainty of how TSC changes over time, TAND and the need for more treatment options.



What we heard



Picture showing the key themes arising during our expert consultation. The larger the word, the more often it was mentioned

What we heard



“The thing that I find really hard as a parent is the uncertainty... it would be really lovely as a parent to have some type of levels of risk in terms of us understanding and accepting things.”

Kate Garrard

Expert by lived experience
Mum to a teenager with TSC

What we heard

“Epilepsy hasn’t really progressed... of course we've got new drugs, new treatment, but it hasn't really been that effective for epilepsy. So that's something that really needs addressing.”

Dr Sam Amin

Consultant Paediatric Neurologist



What we heard



“I think having your access to those [psychological] services would have been good. I never really wanted to take antidepressants, and I was encouraged not to, because, I think again, because of the epilepsy more than anything else.”

Expert by lived experience
Adult with TSC

What we heard

“I think understanding development over time is one of the big unanswered questions. I think we know very little about how different things unfold in development. We know that there's age-related expression of different features in TAND for example, but we know very little about how they all interact.”

Dr Charlotte Tye

Senior Lecturer in Psychology



Next steps



Setting research priorities together

- We will group similar ideas into broader themes to help build a clearer picture of the TSC priorities
- These themes will help shape the next step: a community survey to decide which research areas should come first

Thank you to everyone who has contributed towards this first stage of updating the TSA Research Strategy, including everyone who shared comments on our online ideas boards, the lived experience experts and technical experts who participated in interviews and the TSA Research Committee.

If you have any questions about this report or research at the TSA please get in touch:
research@tuberous-sclerosis.org.

Acknowledgements

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Lived experience experts: Jacqueline Campbell, Nicola Daykin, Kate Garrard, Sarah Goy, R.G. (anonymous adult)

Technical experts: Dr Amanda Almacellas Barbanoj, Dr Sam Amin, Dr Stacey Bissell, Dr Jesse Champion, Dr Elaine Dunlop, Dr Thiloka Ratnaike, Professor Andrew Tee, Dr Charlotte Tye

TSA Research Committee: Professor Joseph Bateman, Professor Petrus de Vries, Professor Daniel Gale, Laura Hughes, Professor Anna Jansen, Professor Simon Johnson, Dr Emma McManus, Corrine Swainger