



TANDEM

Empowering families
through technology

Annual Report 2023 (YEAR 4)



VRIJE
UNIVERSITEIT
BRUSSEL



PROJECT TITLE:

Empowering families through technology: a mobile-health project to reduce the TAND identification and treatment gap (TANDe^m)

FUNDER:

Fund Dr & Mrs Charles Tournay-Dubuisson, managed by the King Baudouin Foundation

AGREEMENT NUMBER:

2019-J1120010-213544

PRINCIPAL INVESTIGATOR:

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GRANT PERIOD:

4 years

STARTING DATE OF THE PROJECT:

1 November 2019

Contents

| | |
|---|----|
| Welcome from the TANDem PI and co-PI | 4 |
| The TANDem project in a nutshell..... | 6 |
| 1 Year 4 – the end of an incredible journey..... | 7 |
| 2 A powerful TAND Consortium review meeting in Stellenbosch, South Africa..... | 8 |
| 3 The 2023 TAND mini-symposium | 12 |
| 4 Keynote at the International TSC Research Conference, Washington DC, USA..... | 13 |
| 5 Many more impact and dissemination activities..... | 14 |
| 6 Manuel R Gomez Award to Anna Jansen | 16 |
| 7 Inaugural James C Harris Scholarship to Nola Chambers..... | 17 |
| 8 Publication of the TAND-SQ..... | 18 |
| 9 International consensus recommendations published | 19 |
| 10 Creative design of a web-based toolkit for the TAND Toolkit app | 20 |
| 11 Embedding the TAND Toolkit into the app | 21 |
| 12 Validation and feasibility evaluation underway..... | 22 |
| 13 Seeds from seed funding germinating..... | 23 |
| 14 Future steps for the TAND Consortium – towards TANDem 2..... | 24 |
| 15 Our final TAND Consortium meeting..... | 25 |



Welcome from the TANDem PI and co-PI

Welcome to the final report on the TANDem project, generously supported over the last 4 years by the King Baudouin Foundation Fund Dr & Mrs Charles Tournay-Dubuisson in Belgium, with supplemental funding from the Tuberous Sclerosis Association in the UK. In this report we will summarise key activities, achievements and celebrations from year 4 of the project and present some overall reflections on our journey with the TANDem project.

After a wonderful in-person launch event for the TANDem project in Leuven, Belgium (November 2019), the first two years of the project (2020 and 2021) took place almost 100% online as a result of the COVID-19 pandemic and international travel restrictions. Year 3 (2022) was a transitional year from the virtual world of research and collaboration back to in-person activities and events. Not long after a stimulating TSC World Conference (Dallas, USA) in September 2022, the TANDem team had the great pleasure of meeting up again (for the first time since 2019) as a full consortium in Stellenbosch, South Africa for our review and planning meeting. We deliberately linked the ‘multi-stakeholder review meeting’ (as it was described in the study protocol) with an impact event with individuals with TSC, families, and a range of professionals from health, educational and social services in South Africa. We even live-streamed the event! It was incredibly powerful and inspiring to be back with the consortium in person after all the work that happened remotely on the project.



Prof. Petrus J de Vries and
Prof. Anna Jansen



We hope that you will enjoy reading about everything that happened during year 4 of the TANDem project. In spite of the very ambitious aims of the project, the remarkable TAND Consortium achieved all the key aims of the project, and as we write this final report, we have published 4 peer-reviewed papers (a scoping review, the study protocol, the TAND-SQ, and international recommendations for TAND), have a new TAND Checklist (TAND-SQ) embedded in a TAND Toolkit app with a range of evidence-informed information and resources ready to launch, and participated in more than 50 impact events (including talks, workshops, national and international conferences, and our own TAND mini-symposia). We also have a beautiful website where all our project updates, publications, news, TAND Checklists and other relevant resources are available to the TSC community.



We hope that, in the coming years, we will be able to continue our incredible journey with TAND, the TAND Consortium and the TSC Community!

A handwritten signature in black ink, appearing to read 'P. de Vries', written in a cursive style.

Prof. Petrus J de Vries
MBChB, FRCPsych, PhD
PI (University of Cape Town)

A handwritten signature in black ink, appearing to read 'A. Jansen', written in a simple, straight-lined style.

Prof. Anna Jansen
MD, PhD
co-PI (Vrije Universiteit Brussel)





The TANDem project in a nutshell

Tuberous Sclerosis Complex (TSC) is a rare genetic disorder that affects about 1–2 million people around the globe. People with TSC have a wide range of physical manifestations including growths in many organs of the body, including the brain. **TSC-Associated Neuropsychiatric Disorders (TAND)** represent the number one concern to families around the globe, yet they are highly under-identified and under-treated – we refer to these as an ‘identification gap’ and a ‘treatment gap’^[1, 2].

Project background

In 2012 we introduced the term ‘TAND’ and in 2015 created the **TAND Checklist** to reduce the ‘identification gap’^[3]. Research using the TAND Checklist showed that we could identify seven natural TAND Clusters that may be useful to reduce both the identification and treatment gaps for TAND further^[4, 5]. Following our earlier work, community-based participatory research with families and a range of TSC stakeholders identified three next steps for action:

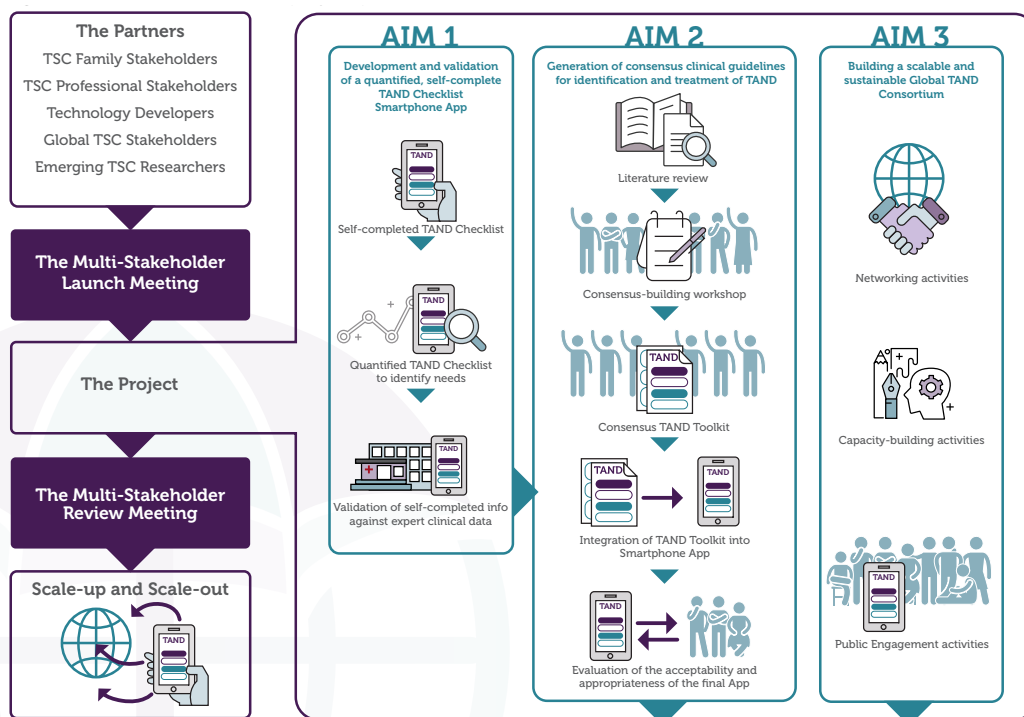
- 1 Creation of a self-report and quantified version of the TAND Checklist
- 2 Creation of a digital tool such as an app for the TAND Checklist
- 3 Generation of evidence-based guidelines and a toolkit for next-step management of TAND Clusters

TANDem project aims

The TANDem project was a direct result of the feedback from our TSC stakeholders, and has three aims:

- **AIM 1:** Development and validation of a quantified, self-report TAND Checklist (*TAND-SQ*), built as a mobile app
- **AIM 2:** Generation of consensus clinical guidelines for identification and treatment of TAND Clusters, to be incorporated as a toolkit into the app
- **AIM 3:** Establishment of a global TAND consortium through a range of networking, capacity-building and public engagement activities

More details on the project can be found in our published protocol paper^[1].



References:

- [1] Heunis et al., (2022) *Frontiers in Psychiatry*, 13: 834628
[2] King Baudouin Foundation (2018) *Mind the Gap! Working together to set research priorities for Tuberous Sclerosis Complex*. Pub No 3555
[3] de Vries et al., (2015) *Pediatric Neurology*, 52: 25–35
[4] Leclezio et al., (2018) *Pediatric Neurology*, 81: 38–44
[5] de Vries et al., (2020) *Journal of Neurodevelopmental Disorders*, 12: 24

1 Year 4 – the end of an incredible journey

At the end of year 3 we agreed on 8 next steps to conclude the TANDem project. The goals were:

- a Publication of the TAND-SQ Checklist
- b Publication of consensus recommendations for the identification and treatment of TAND
- c Data collection and validation of the TAND-SQ Checklist against expert and real-world clinical data
- d Embedding the TAND toolkit into the app and feasibility evaluation of the overall TAND Toolkit app
- e Preparation of publications related to the TAND-SQ Checklist validation and app feasibility
- f Further networking and impact activities, including support to the ‘seed funding’ grants
- g Reviewing the TANDem project and planning of next steps for scale-up and scale-out of the TAND Toolkit app
- h Writing a final report to the King Baudouin Foundation

This report outlines achievements in relation to these goals in year 4, and represents the final report on the TANDem project.



2 A powerful TAND Consortium review meeting in Stellenbosch, South Africa

The TANDem project was set up to start with a multistakeholder launch meeting and end with a multistakeholder review meeting to underline the participatory and co-creation philosophy of the project.

Many TAND Consortium members will recall their slight discomfort when the launch meeting in Leuven, Belgium (November 2019) had a very limited agenda – and quickly realised that even agenda-setting was a participatory activity! After three full years of collaboration, we were therefore fortunate to be able to come together – for the first time since the launch of the project – to review our work, to discuss actions to be completed, and to think of future steps for the consortium.

From 4–8 November 2022 almost all consortium members were able to come to South Africa for the event. We were also delighted to have been joined by Annemie T'Seyen from the King Baudouin Foundation, who has supported the TANDem project over the last four years.



Everyone arrived after international flights on Friday, 4th November 2022 and were very excited to see one another at Banksia Boutique Hotel in Rosebank, Cape Town. From there the group transferred to Mont Fleur Retreat Centre in the Stellenbosch Mountains for welcome, orientation and dinner.

On Saturday, 5th November 2022, the consortium travelled to the Stellenbosch Institute for Advanced Studies (STIAS) for a very stimulating impact event where a group





of about 50 consortium members, families and professionals participated in discussions about TSC, international recommendations, and about the TANDem project. In addition, we held round table discussions around topics selected by participants. These included a) setting up a local TSC organisation, b) educational challenges in TSC, and c) use of medications in TSC. After a walking tour of Stellenbosch, the consortium returned to Mont Fleur for ‘sundowners’ (drinks while watching the sunset – a local tradition!) and a traditional South African Braai (barbeque) while listening to a local marimba band.

The next two-and-a-half days focussed on reviewing aims 1, 2 and 3 of the project, discussions



about seed funding projects and ideas for ‘TANDem 2’. We also used the opportunity to record short introductory movies for the TAND Toolkit and made a movie about the TANDem project which was launched on 15 May 2023 for World TSC Day. Social activities included a beautiful mountain walk, a picnic, wine tasting (congratulations to Sugnet on winning!), and a celebration dinner.

On Tuesday, 8th November 2022, we finalised next steps for 2023 and beyond, and wrapped up the meeting before saying our goodbyes to our amazing hosts at Mont Fleur and to one another.







3 The 2023 TAND mini-symposium

After a very successful TAND mini-symposium in 2022 we scheduled a second mini-symposium on 29 June 2023. Anna Jansen welcomed attendees and Nola Chambers presented a brief summary of the TANDem project to date.

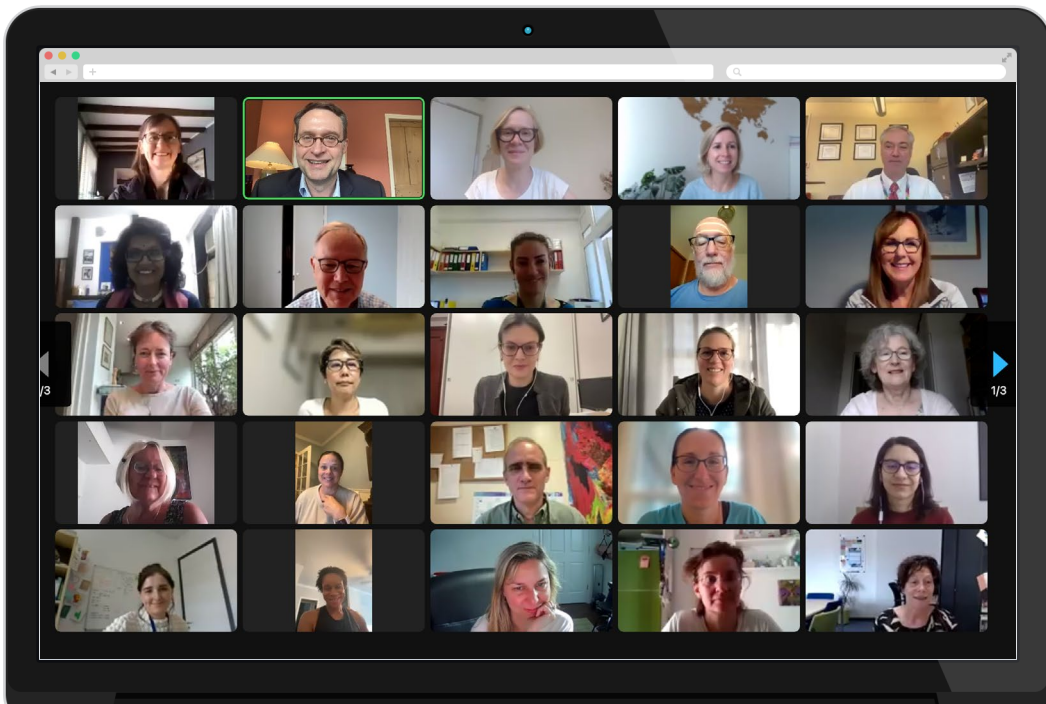
Eleven abstracts were accepted from seven countries (Poland, USA, Brazil, the Netherlands, India, UK and South Africa) and grouped into four very interesting rapid fire sessions – pre-clinical TAND research, TAND across the lifespan, understanding TAND, and TAND interventions and services research. We were joined online by 75 participants from all over the world!



The recording of the mini-symposium was posted on the TAND Consortium website, and the day received excellent feedback from participants.

“Excellent meeting!”

“Thank you for the wonderful opportunity,”



4 Keynote at the International TSC Research Conference, Washington DC, USA

For the first time since 2019, the international TSC research community was able to have an in-person research conference again.

The TSC Alliance hosted the event in Washington DC from 7–9 September 2023 with the theme ‘Fuelling the Future’. We were delighted that Dr Nola Chambers was invited to represent the TAND Consortium as keynote speaker during the event. Nola presented an excellent summary of the overall project and of our achievements to date.

We were also able to use the TSC Research Conference as an opportunity for focus group discussions with the TSCi community about the content and presentation of the TAND Toolkit.

Many thanks to the Kari Rosbeck, Steve Roberds and the TSC Alliance team for hosting the



conference. Great appreciation also to Katie Smith and our friends in TSCi for their invaluable comments, contributions and suggestions for the TAND Toolkit and the TANDem project as a whole.



5 Many more impact and dissemination activities

As part of aim 3 of the TANDem project, we have very deliberately and strategically participated in global impact activities across the four years of the study. Year 4 was no exception and included:

- ★ Oct 2022 Autism Europe, Krakow (Poland)
- ★ Nov 2022 TANDem Impact Event, Stellenbosch (South Africa)
- ★ Dec 2022 Japanese Society for TSC, Tokyo (Japan)
- 📺 Jan 2023 Seminar with Pretola, Online
- ★ Apr 2023 ESSENCE Conference, Cape Town (South Africa)
- ★ May 2023 Brazil TSC Association (ABET), Curitiba (Brazil)
- 📺 May 2023 Mexican TSC Association, Online
- 📺 May 2023 TSC New Zealand, Online
- 📺 June 2023 TANDem mini-symposium, Online
- ★ Sept 2023 International TSC Conference, Washington DC (USA)
- 📺 Sept 2023 SSBP (Society for the Study of Behavioural Phenotypes), Online
- ★ Oct 2023 Department of Psychiatry & Mental Health, University of Cape Town, Cape Town (South Africa)
- ★ Nov 2023 be-TSC, Mechelen (Belgium)
- ★ Nov 2023 Bloorview Research Institute, Toronto (Canada)
- ★ May 2024 International Child Neurology Congress, Cape Town (South Africa)
- 📺 Social Media dissemination including the TAND Consortium website, Instagram and Twitter/X



KEY

- ★ In-person event
- 📺 Virtual event



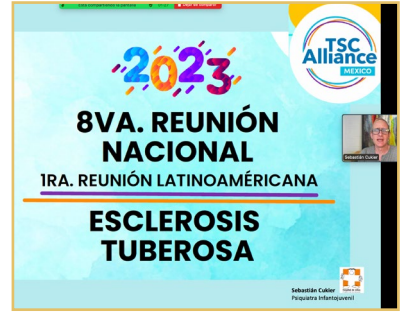
★ Autism Europe, October 2022, Krakow (Poland)



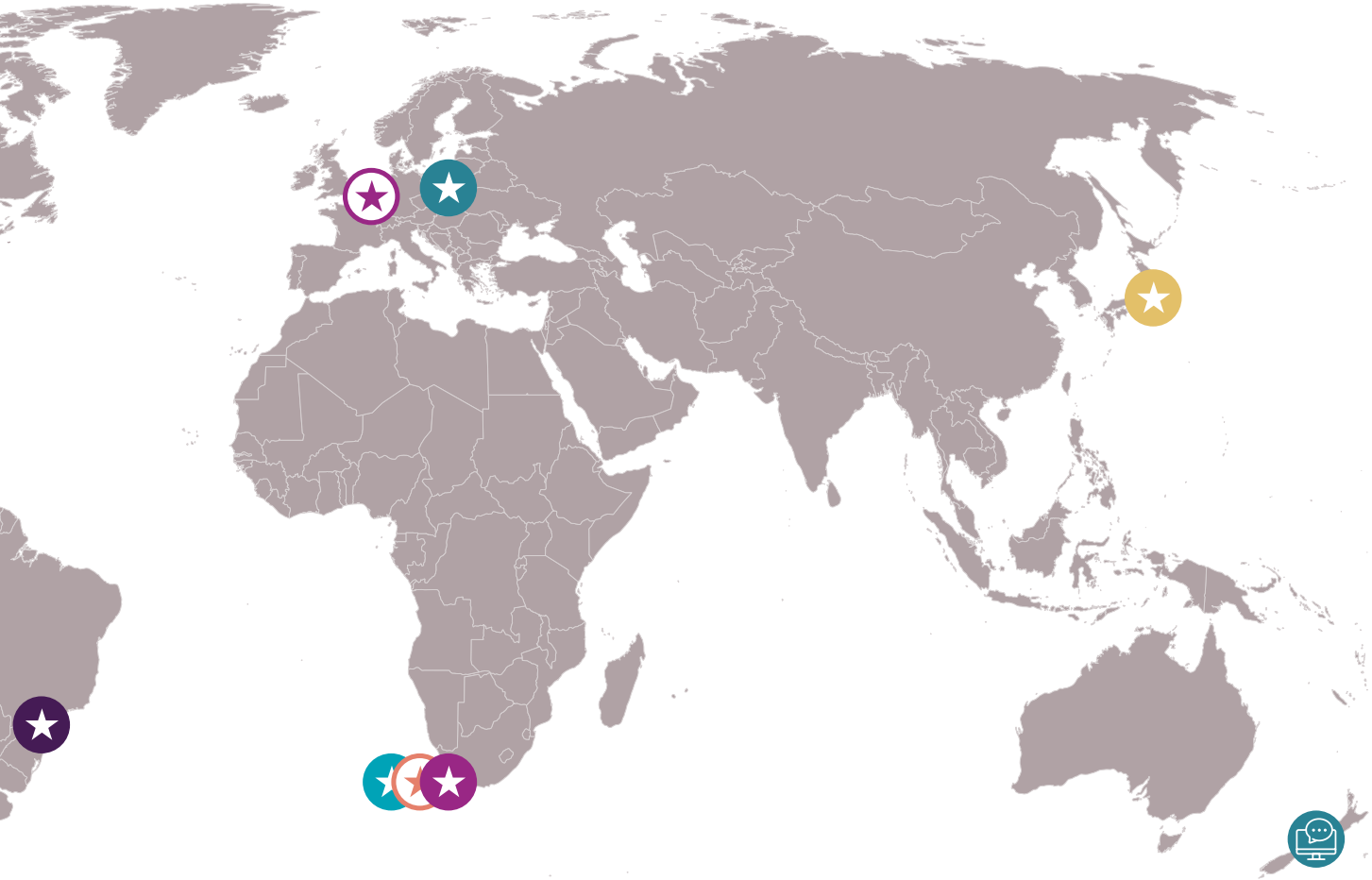
★ Bloorview Research Institute, November 2023, Toronto (Canada)



★ Belgian TSC Association (be-TSC), November 2023, Mechelen (Belgium)



★ Mexican TSC Association, May 2023, Online



★ Brazil TSC Association (ABET), May 2023, Curitiba (Brazil)



★ Brazil TSC Association (ABET), May 2023, Curitiba (Brazil)



★ SSBP (Society for the Study of Behavioural Phenotypes), September 2023, Online

6

Manuel R Gomez Award to Anna Jansen

Dr Manuel R Gomez (1928–2006) was a Spanish-American paediatric neurologist widely recognised as the ‘founding father’ of TSC research. In recognition for his compassionate care for people with TSC while doing pioneering research in TSC, the TSC Alliance created the Manuel R Gomez award in 1995 as a recognition to one individual per year who has made a significant impact on our understanding of TSC through research while contributing to clinical care and service delivery of those living with the condition.

We were delighted that our own Prof. Anna Jansen was announced as the 2023 winner of this highly prestigious award for her contributions to TSC and TSC research. Anna has a soft-spoken manner and does not seek the ‘limelight’, but her quiet yet thoughtful and principled approach to TSC and TSC research has been very inspirational to many researchers and families in the TSC community. In her unique and passionate way, she has made powerful and transformative contributions towards an understanding of TSC and improvements in the lives of those who live with it.

“Anna is a tremendous resource to the international TSC community. Working with her over the past 12 years, I have seen first-hand her incredible dedication and contributions to the TSC field. Her energetic approach to research and compassionate care for all members of the TSC community, local and global, has been critical in moving forward important projects in TSC and TAND. As a collaborator on many international activities, including TSC International (TSCi), she is incredibly thoughtful and driven. To Anna, each individual is equally important, and she goes out of her way to make every person feel heard and empowered. She has truly made a difference in the lives of so many TSC families and individuals around the world.”



After receiving the award, Anna said: *“It has been a privilege and honour to work with the TSC community over the years. The synergies between families, patient advocacy groups, clinicians, researchers, pharmaceutical companies and regulators is quite unique in the field of rare diseases and creates tremendous power to move the field forward. The participatory nature of the TANDem project, where the TSC community serves as a compass pointing the way forward has strongly influenced my view on research.”*



7 Inaugural James C Harris Scholarship to Nola Chambers

Prof. James C Harris (1940–2021) was the Professor of Developmental Neuropsychiatry at Johns Hopkins University in Baltimore, USA. He was a pioneering clinician and researcher in the behavioural phenotypes of children with rare genetic disorders. He had a particular interest and expertise in Lesch-Nyhan Syndrome. Jim (as he was known) was also a founding member of the SSBP (Society for the Study of Behavioural Phenotypes) in 1987 and has been a delightful and characterful presence at almost all SSBP conferences over the years. After he passed away in 2021 the SSBP in partnership with his wife, Dr Catherine D DeAngelis, decided to create a scholarship in his memory.

The James C Harris Scholarship is an annual award for a researcher from a low/middle-income country to attend the SSBP conference to present their work. We were delighted that Dr Nola Chambers, member of the TANDem action group, received the inaugural scholarship in September 2023, to present the TAND Consortium paper on the development of international consensus recommendations for the identification and treatment of TAND.

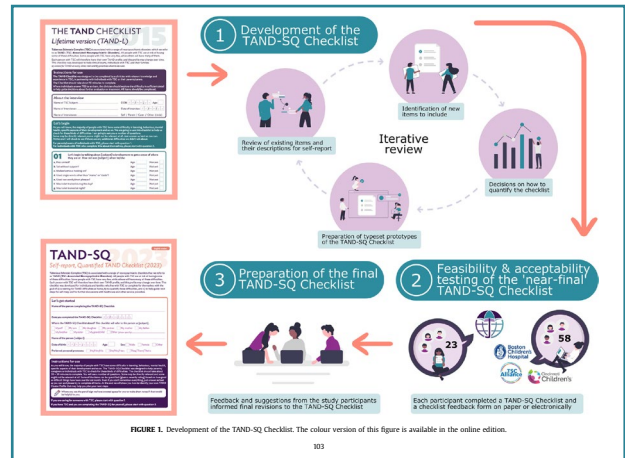
Nola said: *“It was a great honour to be selected for this inaugural scholarship. The scholarship makes it possible for researchers from low/middle-income countries to attend and present at SSBP and to learn from and make invaluable connections with other researchers. It was a pleasure to accept the award at the SSBP AGM and to meet and thank Dr DeAngelis personally for this award”.*



8 Publication of the TAND-SQ

One of the exciting milestones of the TANDem project was the creation and feasibility evaluation of the self-report and quantified TAND Checklist, the TAND-SQ. The aim was addressed in three phases: first, development of the draft TAND-SQ through a highly iterative process by the TAND Consortium; second, feasibility and acceptability testing of the 'near-final' version; and third, preparation and publication of the final TAND-SQ Checklist. Participants in the study included 23 consortium members and 58 lived experts.

Overall feedback about completeness, clarity, ease of use and likely future use was very positive. We were delighted to see that everyone who had previous experience with the original TAND-L Checklist (the Lifetime version) reported that the TAND-SQ was 'equally good', 'better' or 'much better' than the TAND-L. The TAND-SQ was



published in the journal *Pediatric Neurology* and is now available for free download. The TAND Consortium has already started the process of initiating authorised translations of the TAND-SQ.

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journal homepage: www.elsevier.com/locate/pnu

Research Paper

Development and Feasibility of the Self-Report Quantified Tuberosus Sclerosis Complex-Associated Neuropsychiatric Disorders Checklist (TAND-SQ)

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^s Rowland Stone Zander Translational Neuroscience Center, Boston Children's Hospital, Boston, Massachusetts
^t Belgian TSC Association (the TSC) Market, Belgium
^u Tuberosus Sclerosis International (TSCI), Montreal, Belgium
^v TSC Alliance, Silver Spring, Maryland
^w Society of Parents of Children with Autism Disorders (SOPAN), Maharashtra, India
^x Japanese Society of Tuberosus Sclerosis Complex, Family Network, Tokyo, Japan
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^{ae} Department of Translational Neuroscience, University of Antwerp, Antwerp, Belgium

Author contributions: P.J.d.V. and A.C.J. were co-PIs and conceptualized the TANDem project, secured funding, and recruited members of the TAND consortium. P.J.d.V., A.C.J., T.M.H., N.C.S.V., and L.D.W. were all members of the Action Group and managed the overall project. All consortium members contributed to the design, drafting, and revising of the TAND-SQ Checklist. T.H., N.C., and P.J.d.V. wrote the first draft of the manuscript. All consortium members reviewed and approved the final manuscript before submission.

Funding: This work was funded by the Dr. & Mrs. Charles Trouman-Duisson fund administered by the King Baudouin Foundation to P.J.d.V. and A.C.J. (2019-1120010-212544) and supplemental funding from the Tuberosus Sclerosis Association (UK) (TSCA) to P.J.d.V.

* Communications should be addressed to: Prof. de Vries, Division of Child and Adolescent Psychiatry, Centre for Autism Research in Africa (CARA), University of Cape Town, 46 Sawkins Road, Rondebosch, Cape Town, South Africa, 7700. E-mail address: petrus.de.vries@uct.ac.za (P.J. de Vries).

<https://doi.org/10.1016/j.pedneur.2023.07.001>
 0887-8994/2023 The Author(s). Published by Elsevier Inc. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

“Some of the new response options on sections are really nice! I love that career, processing speed and sensory sensitivities have been added”

9

International consensus recommendations published

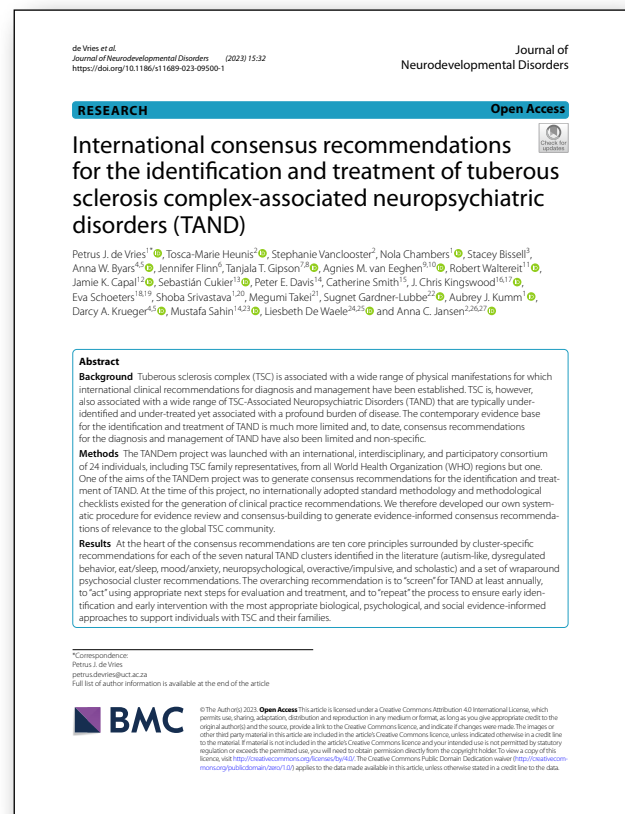
One of the key outputs of aim 2 of the TANDem project was publication of the international consensus recommendations for the identification and treatment of TAND.

After almost 3 years of work by the consortium, the recommendations were published in September 2023 in the *Journal of Neurodevelopmental Disorders*. The article is open-access and can therefore be downloaded (free of charge) by anyone. Prof. Petrus de Vries,

first author of the paper said: “It was a lot of hard work by all of us to get the paper in its published form. However, it was incredible to see the immediate positive feedback on social media both within the journal and outside. Within the first month, more than 1,500 people had read the article on the journal website alone. There was clearly a significant need for it in the TSC community and that really made it feel worth all the effort!”

“Immense gratitude for your wonderful work, as a parent struggling with TAND and feeling a strong connection to all navigating the TAND burden of disease worldwide”

“TANDem is the biggest advance in TAND in decades...Such a powerful tool for families to make progress”



10 Creative design of a web-based toolkit for the TAND Toolkit app

Over the last two years a lot of work was done by the Cluster leads and TAND Consortium to identify evidence-informed, accessible and acceptable content to include in the TAND Toolkit.

In 2022 we decided to use a web-based mechanism to develop and design the toolkit to ensure that it is easily adaptable in future. In partnership with Zanmari Norman, a South African graphic designer, a series of creative design activities took place to develop the toolkit.

The TAND cluster working groups developed the content and identified reputable external resources to be included in the cluster toolkit. Content included information about the cluster, what families can 'seek' from professionals to identify and treat each TAND cluster, and what families can 'do' themselves to address TAND at home. Cluster leads also created introductory videos for each cluster incorporated into the toolkit.

Tosca Heunis, the TANDem project coordinator (and our own tech expert!) built the components of the toolkit and incorporated the text, videos and resources into the toolkit framework. Zanmari provided invaluable help with selecting cluster-specific colours and icons to represent each cluster, as well as creating designs for other components such as navigation buttons and subtheme 'cards' within clusters.

Iterative reviews within the consortium led to a final draft version that was shared with families at the TSC Alliance and TSC International for their consideration and comments. Their qualitative and quantitative feedback was considered and their recommendations were implemented in the TAND Toolkit website.

We are extremely grateful to Zanmari Norman for her excellent contributions to this stage of the project.

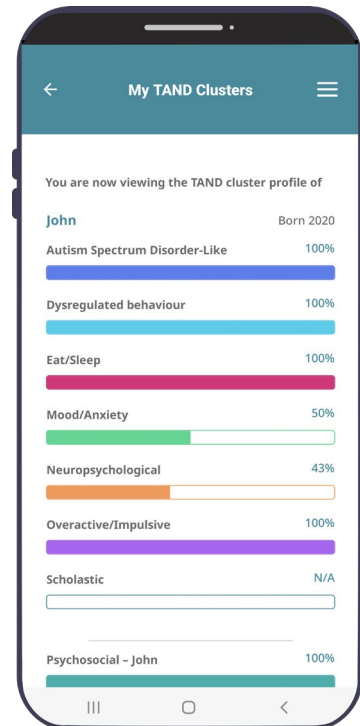
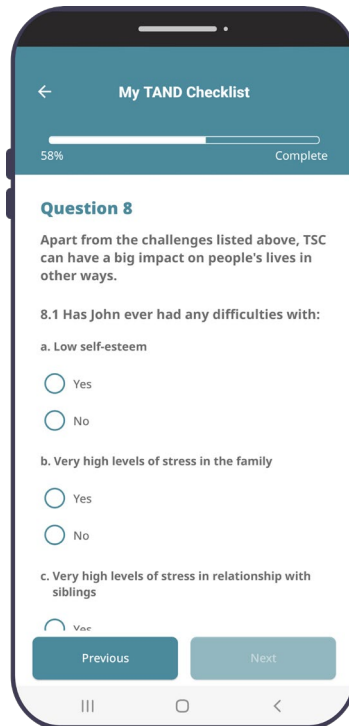
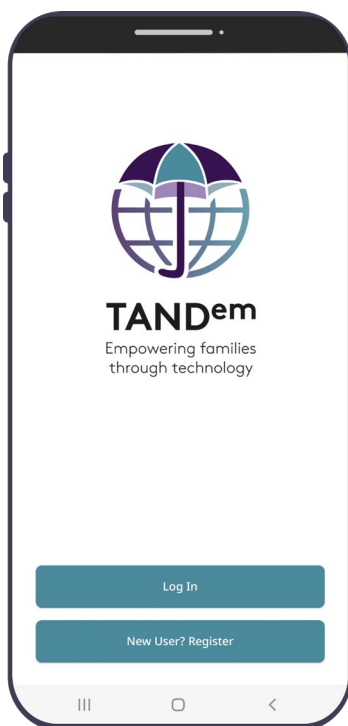


11 Embedding the TAND Toolkit into the app

As the TAND Toolkit website was finalised, Tosca Heunis adapted the toolkit to be compatible with viewing on a mobile device. Then, along with our IT partners at Rubico, Tosca led the process of linking the toolkit to the TAND app.

The end result is that once families have completed the TAND-SQ Checklist and have generated a TAND Cluster Profile in the TAND app, they are able to click on a TAND cluster in their profile and get taken directly to the relevant sections of the toolkit on their mobile device!

This creates a seamless link for families and individuals to a personalised toolkit of relevant, evidence-informed steps of 'what to seek' from others, and a collection of evidence-informed strategies of 'what to do' themselves.



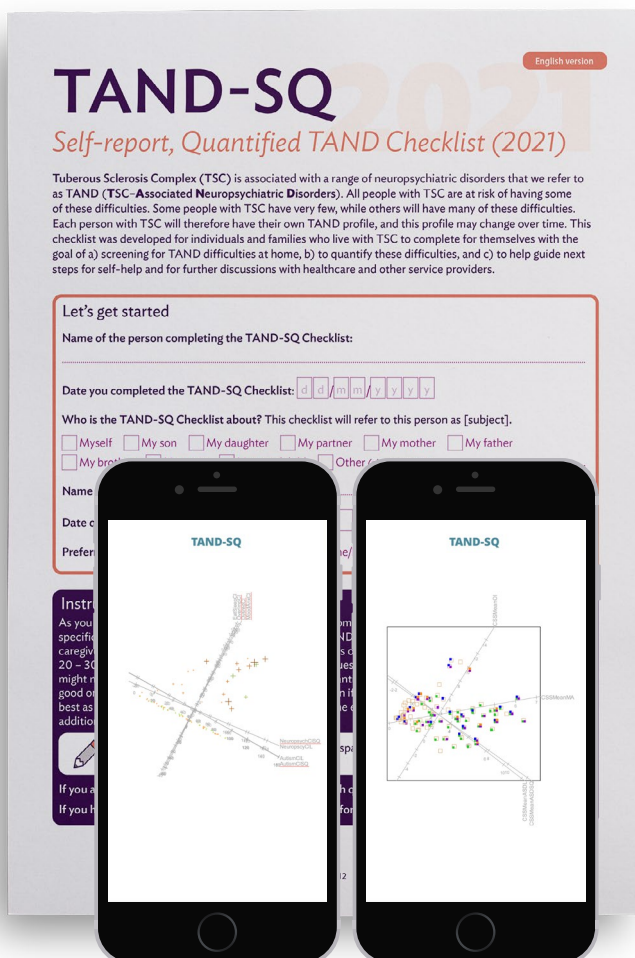
12 Validation and feasibility evaluation underway

The TAND-SQ was very well received in the TSC community, and we are now in the process of validating the TAND-SQ Checklist. We are using two different data sources to do this – firstly, ‘messy’ real-world data from the TSC Alliance Natural History Database (69 participants) and secondly, ‘clean’ gold-standard research data collected as part of the Rare Diseases Clinical Research Network study on TSC, based at Boston Children’s and Cincinnati Children’s Hospitals (23 participants). The validation phase has two purposes. The first is to examine and describe the ‘internal’ characteristics of the TAND-SQ – the

relationship between different items inside the checklist and the extent to which data from one part of the checklist relates to another part. The second is to examine and describe the ‘external’ characteristics of the checklist – how it relates to other standardised tools already used in the research and clinical community. We are aiming to have a manuscript on the validation of the TAND-SQ ready for submission by the end of 2023.

The final TAND Toolkit app which includes the TAND-SQ and is linked to the TAND Toolkit has one more step before going ‘live’ to anyone in the world to download and use. This step is called feasibility evaluation and will be done in Belgium and the Netherlands. A group of families and individuals with TSC will be invited to download the app onto their smartphones, to complete the app information, including a TAND-SQ, to look at their TAND cluster profiles which would then guide them to the TAND Toolkit. Once they have had a chance to use the app, they will be asked to fill in a feedback form about their app experience. In addition, they will then be invited to participate in focus groups to talk about what worked well and what should still be changed in the TAND Toolkit app. Feedback from families will then help us to finalise the app before going ‘live’.

We are very much aware that the TAND Toolkit app will be a first step in the journey, and that the app will require ongoing updates and improvements just like any other app. We are, however, very excited to make it available to the global community early in 2024!



13 Seeds from seed funding germinating

In 2022 three seed awards were made by the TAND Consortium in collaboration with the TSA UK. Stacey Bissell (Birmingham, UK) was funded to study sleep difficulties in TSC, a very important but highly under-researched area. Shoba Srivastava (Mumbai, India) was funded to explore TAND in India, a country with >1 billion people where very little is still known about TSC and TAND. Liezl Schlebusch (Cape Town, South

Africa) was funded to find out if a caregiver wellbeing programme for developmental disabilities could be used in TSC, given that almost no research to date has examined interventions to support caregivers.

We are very excited to see the developments of these three seed funded projects in the coming year.



Over the last year **Stacey** and her colleague Dr Georgie Agar (Aston University, UK) have engaged with the TSA UK volunteer network and increased the scope of the project to include family and paid caregivers, and to capture experiences of those caring for children, adolescents and adults with TSC. To date, they have received several responses from caregivers in the UK and USA, and interviews are scheduled until the project end date in December 2023.

Shoba Srivastava became a registered PhD student at the University of Cape Town and developed her study protocol. In September 2023 she presented her protocol to external and internal reviewers and it was accepted. This was a lovely milestone for Shoba's important work in India!



Liezl Schlebusch drafted her study protocol and has also engaged with the TSA UK volunteer network for feedback on her proposed project. She is planning to do data collection in the UK and South Africa early in 2024.

14 Future steps for the TAND Consortium – towards TANDem 2

At the multistakeholder review meeting at Mont Fleur in Stellenbosch, TAND Consortium members were divided into different 'teams' to outline and 'pitch' potential next step projects after completion of the TANDem project. Project ideas ranged from further work with already-collected information such as cluster chapters, to more technology development work, and new research questions to ask with the data that will be emerging from the 'live' TAND Toolkit app.

There was great enthusiasm to keep the TAND Consortium active and to use the TANDem project as a foundation for further creative and impactful research in the TSC community.

At the time of this report, the consortium had contributed to two grant submissions for potential next steps towards 'TANDem 2'.

As part of our next steps, the TAND Consortium will set up a mechanism so that consortium members and researchers external to the consortium can submit requests for access to data to be used in non-commercial research.

We were delighted to have received a 12-month no-cost extension on the TANDem project from the King Baudouin Foundation to keep our activities going during the transition to our next funded project.



15 Our final TAND Consortium meeting

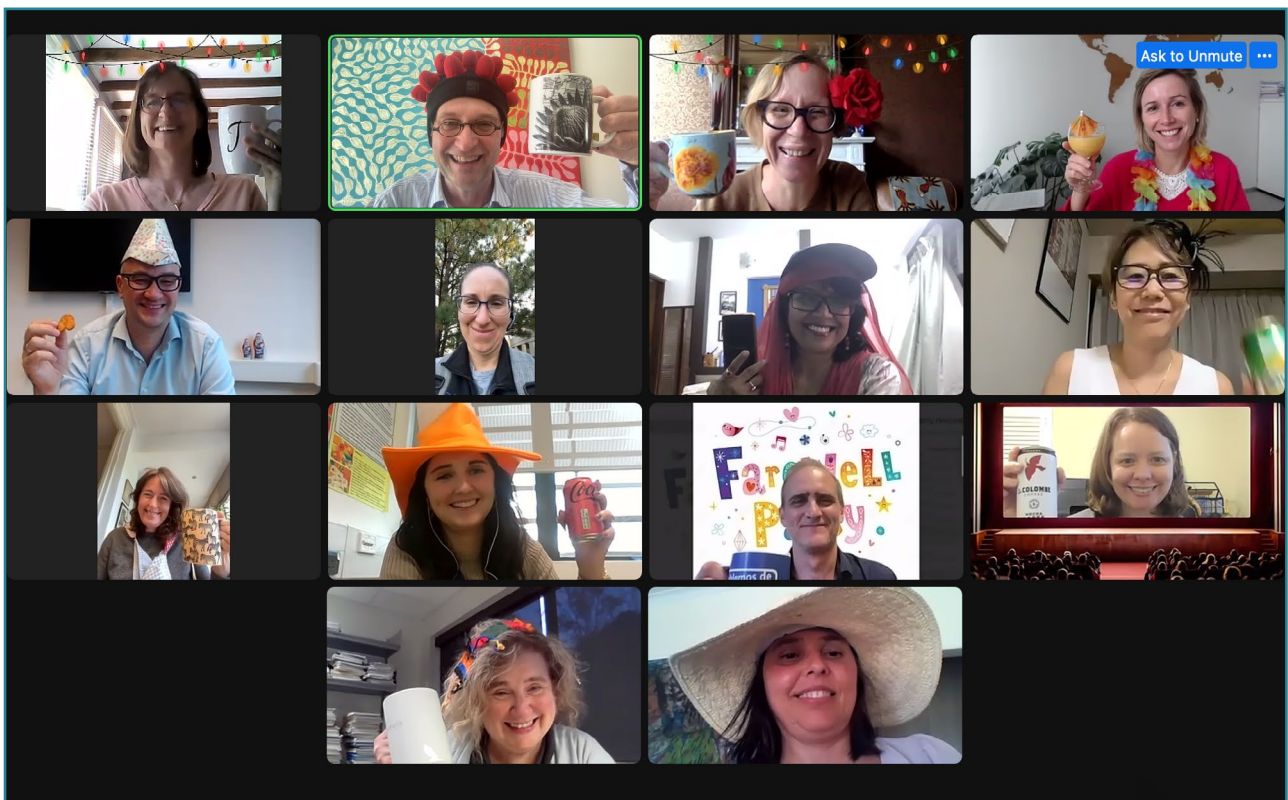
On Thursday, 26th October 2023 the TAND Consortium held its final meeting as part of the TANDem project. Anna Jansen and Petrus de Vries did a short presentation on 'TANDem over the years' to remind the consortium of our incredible journey over the last 4 years.

After final updates about outstanding actions (validation and feasibility publications, going live of the app), consortium members were asked for final reflections on their experience of the TANDem project and how it impacted them.

“[The TANDem project] completely changed the course and direction of my career. This has probably been the most important group I’ve ever been part of,”

“It’s been great to see how just an idea can turn into such a big, impactful movement in TSC,”

“I hope we can continue to be together. It’s a beacon of hope for families,”









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