



TSC-associated Neuropsychiatric Disorders (TAND) and the TANDem project

Tuesday 20 May, 17:00 – 18:30 (CET time)

Chair by Prof Anna Jansen



Project Manager Anne Hugon

2025

Welcome – Technical points

- We are please to be numerous > 65 registrations
- Webinar being recorded
- Thank you for
 - Turn off your microphone and disconnect your camera
 - Raise your hand at the time of the questions and discussions
 - We will answer the questions sent in the registration form
 - A satisfaction survey will be proposed on last slide QR code
- Webinars # will be available on ITHACA's Website <https://ern-ithaca.eu/webinars/>
- Anne Hugon Project Manager ERN ITHACA - anne.hugon@aphp.fr

Agenda

Our expert speakers will provide insights on the following topics

- Welcome and Introduction
- TSC-Associated Neuropsychiatric Disorders and the TANDem project
 - Pr Anna Jansen - Antwerp University Hospital, Antwerp, Belgium
- The journey with TSC, a family perspective
 - Mary Vasseghi - ePAG - TSC Ireland and Trinity College Dublin
- Focus on caregiver wellbeing
 - Liezl Schlebusch - University of Cape Town, South-Africa
- Discussion time & Conclusion

Welcome and Introduction

Tuberous Sclerosis Complex (TSC) is a multi-system genetic disorder with various TSC-Associated Neuropsychiatric Disorders (TAND) that significantly impact the mental health and wellbeing of individuals with TSC and their caregivers.

TAND represents the number one concern to families worldwide, yet is highly under-identified and under-treated. In this webinar we will introduce the concept of TAND and propose strategies for management.

Guest speakers

- Anna Jansen, Antwerp University Hospital, Antwerp, Belgium
- Mary Vasseghi, ePAG - TSC Ireland and Trinity College Dublin
- Liezl Schlebusch, University of Cape Town, South-Africa

TSC-Associated Neuropsychiatric Disorders and the TANDem project

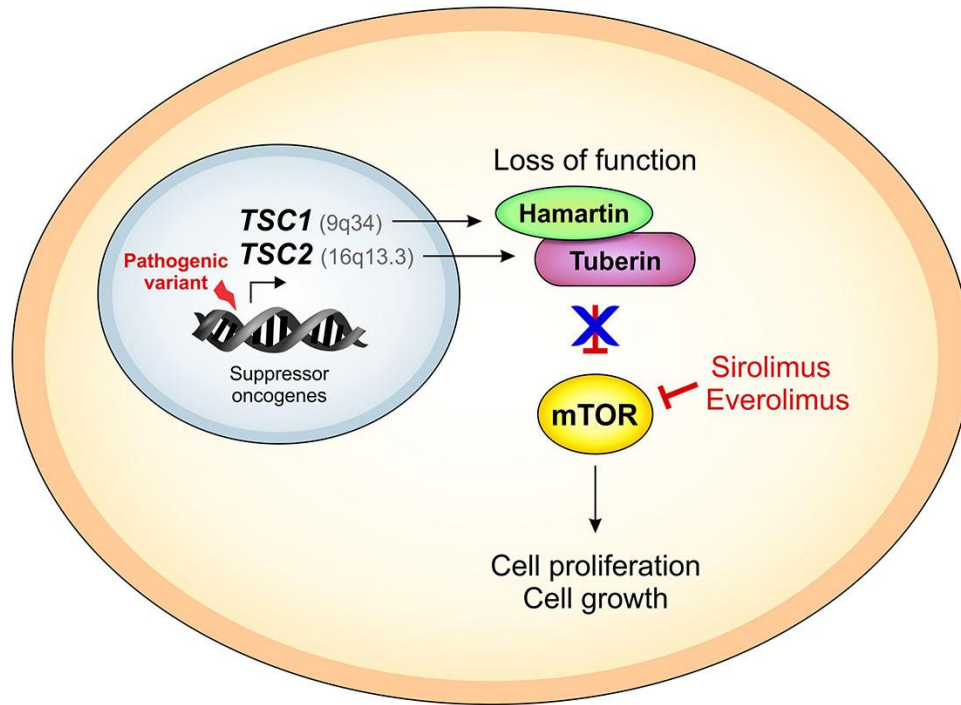
Pr Anna Jansen - Antwerp University Hospital, Antwerp, Belgium

TSC-Associated Neuropsychiatric Disorders and the TANDEM project

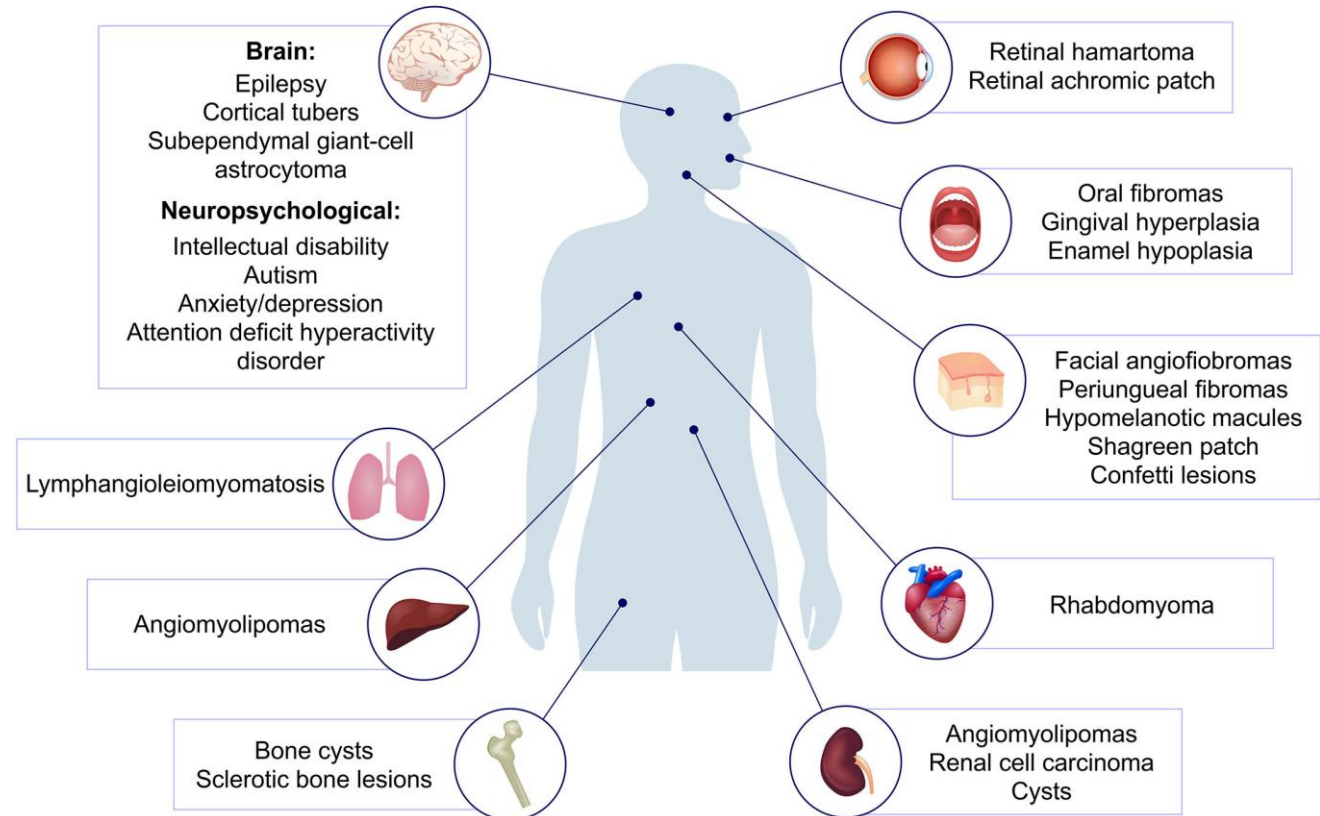
Prof. Anna Jansen

Mary Vasseghi, Liezl Schlebush, Nola Chambers, Tosca Heunis,
Liesbeth De Waele, Petrus de Vries and the TAND Consortium

Tuberous Sclerosis Complex



Tuberous sclerosis complex (TSC)



TAND

TSC-associated neuropsychiatric disorders

Survey TSA UK 2010

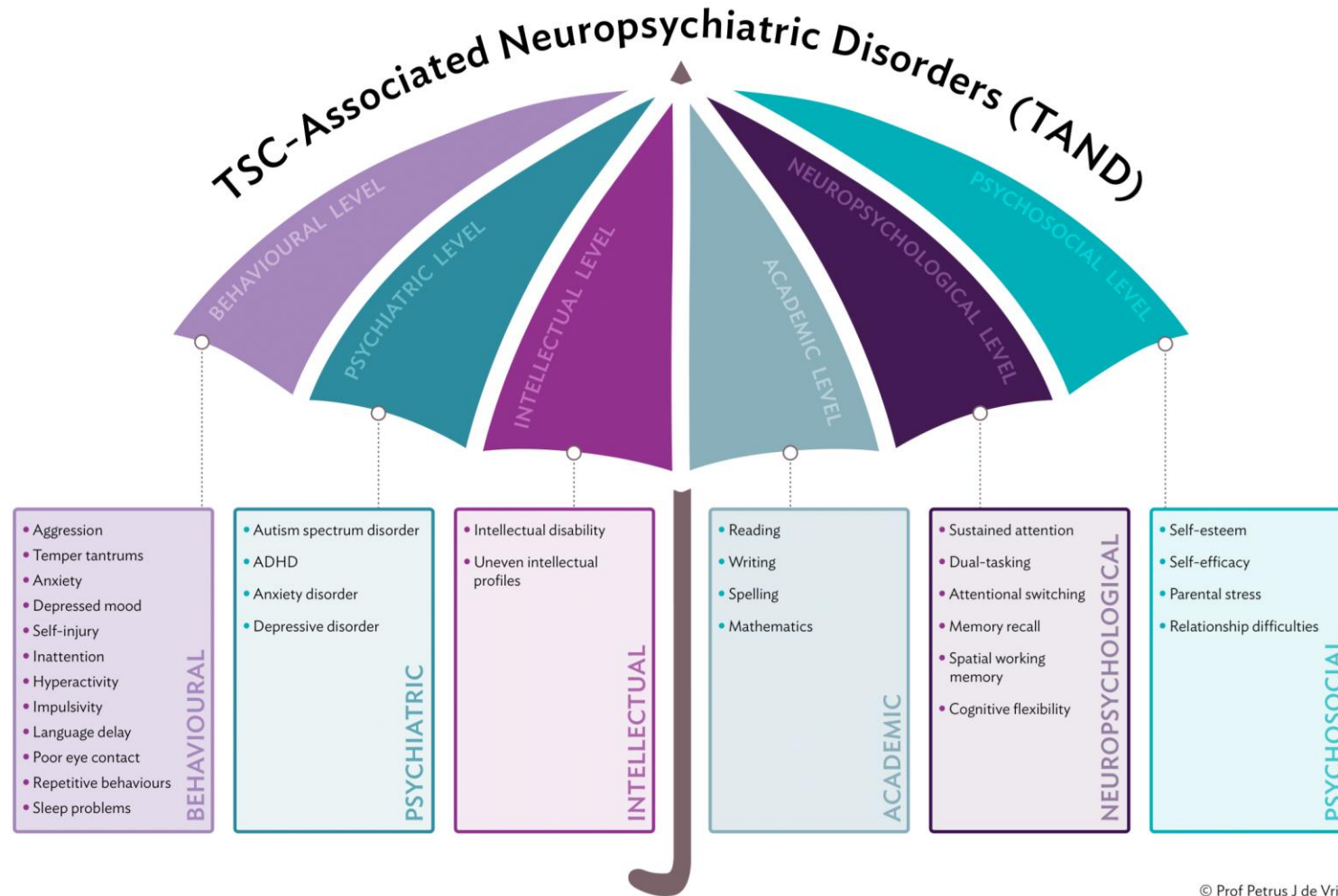
~**90%** of people with TSC will have some biopsychosocial difficulties in their lifetime

<**20%** receives appropriate evaluation and/or guidance

‘ASSESSMENT & TREATMENT GAP’

de Vries PJ et al. *Pediatr Neurol*. 2015;52:25-35.

The six levels of TAND



© Prof Petrus J de Vries

TAND Checklist

- Focusing on key aspects across 10 sections
- It comprises simple “yes” and “no” questions
- Administered by an appropriate clinician with the parent or person with TSC
- 10 – 15 minutes to administer

de Vries et al., *Pediatric Neurology*, 2015
www.tandconsortium.org

THE TAND CHECKLIST

Lifetime version (TAND-L)

Tuberous Sclerosis Complex (TSC) is associated with a range of neuropsychiatric disorders which we refer to as **TAND (TSC-Associated-Neuropsychiatric-Disorders)**. All people with TSC are at risk of having some of these difficulties. Some people with TSC have very few, while others will have many of them. Each person with TSC will therefore have their own TAND profile, and this profile may change over time. This checklist was developed to help clinical teams, individuals with TSC and their families

a) screen for TAND at every clinic visit and b) prioritize what to do next.

Instructions for use

The TAND Checklist was designed to be completed by a clinician with relevant knowledge and experience in TSC, in partnership with individuals with TSC or their parents/carers.

The Checklist should take about 10 minutes to complete.

Where individuals answer YES to an item, the clinician should explore the difficulty in sufficient detail to help guide decisions about further evaluation or treatment. All items should be completed.

About the interview

Name of TSC Subject: DOB: / / Age:

Name of Interviewer: Date of interview: / /

Name of interviewee: Self / Parent / Carer / Other (circle)

Let's begin

As you will know, the majority of people with TSC have some difficulty in learning, behaviour, mental health, specific aspects of their development and so on. We are going to use this checklist to help us check for these kinds of difficulties. I am going to ask you a number of questions.

Some may be directly relevant; some might not be relevant at all. Just answer as best as you can. At the end I will check to see if there are any additional difficulties we didn't talk about.

For parents/carers of individuals with TSC, please start with question 1.

For individuals with TSC who complete this about themselves, please start with question 3.

01

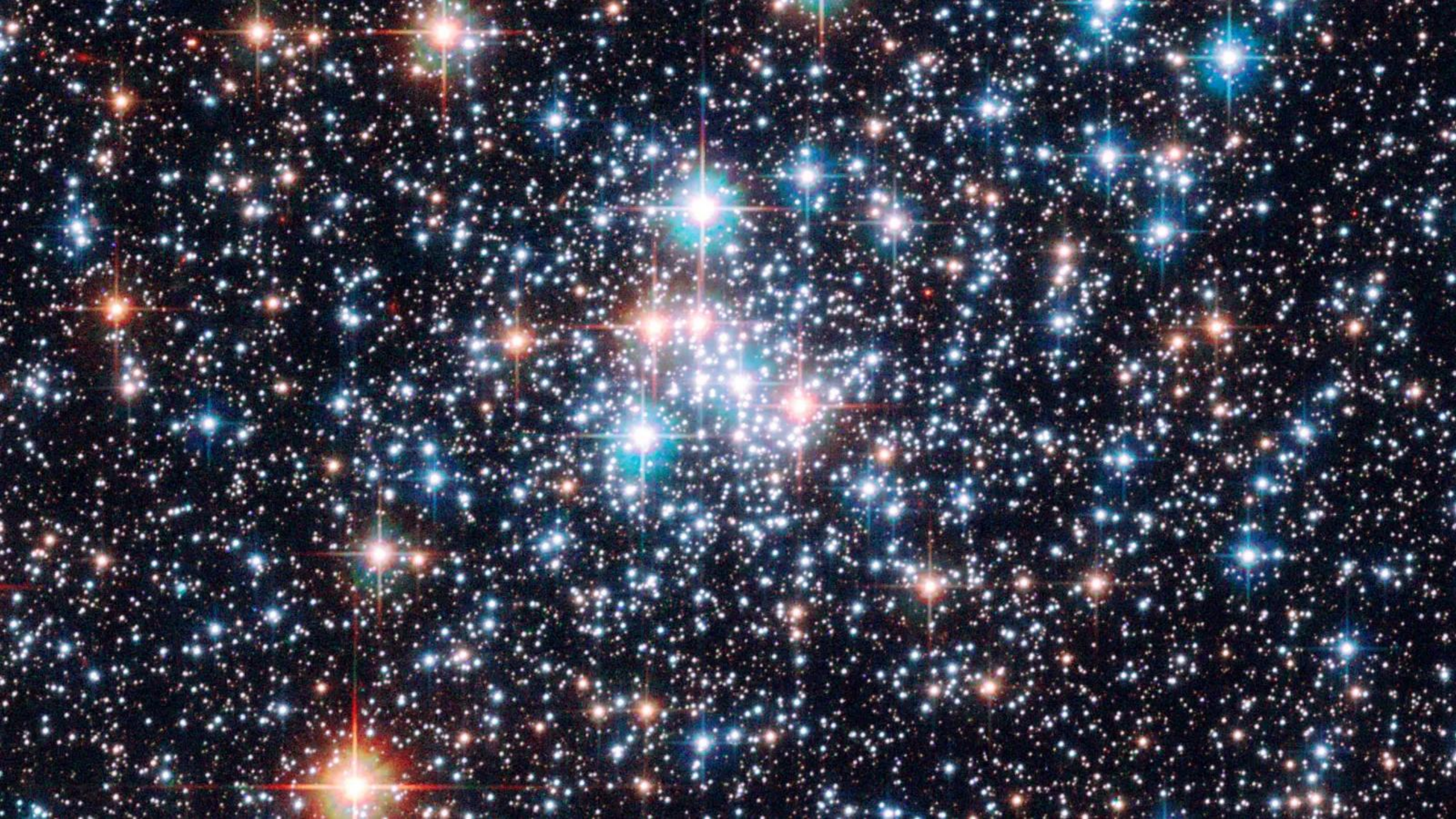
Let's begin by talking about [subject]'s development to get a sense of where they are at. How old was [subject] when he/she:

- | | | |
|---|---------------------------|-----------------------------------|
| a. First smiled? | Age: <input type="text"/> | Not yet: <input type="checkbox"/> |
| b. Sat without support? | Age: <input type="text"/> | Not yet: <input type="checkbox"/> |
| c. Walked without holding on? | Age: <input type="text"/> | Not yet: <input type="checkbox"/> |
| d. Used single words other than "mama" or "dada"? | Age: <input type="text"/> | Not yet: <input type="checkbox"/> |
| e. Used two words/short phrases? | Age: <input type="text"/> | Not yet: <input type="checkbox"/> |
| f. Was toilet trained during the day? | Age: <input type="text"/> | Not yet: <input type="checkbox"/> |
| g. Was toilet trained at night? | Age: <input type="text"/> | Not yet: <input type="checkbox"/> |

Uniqueness of TAND profiles

Panel A

		TP001	TP002	TP003	TP004	TP005	TP006	TP007	TP008	TP009	TP010	TP011	TP012	TP013	TP014	TP015	TP016	TP017	TP018	TP019	TP020
Sleep	Sleep																				
Food	Eating																				
Mood	Anxiety																				
	Depression																				
	Shyness																				
	Mood																				
Aggression	Aggression																				
	Temper																				
	Self-injury																				
ASD	Delayed Lang																				
	Repeat words																				
	Eye contact																				
	Peer Relations																				
	Repeat Bhv																				
ADHD	Rigid																				
	Hyper																				
	Attention																				
	Restless																				
	Impulsive																				





Overwhelming uniqueness

Treatment paralysis

TAND clusters



Leclezio 2017
Leclezio et al Ped Neurol 2018

Uniqueness of TAND profiles

Panel A

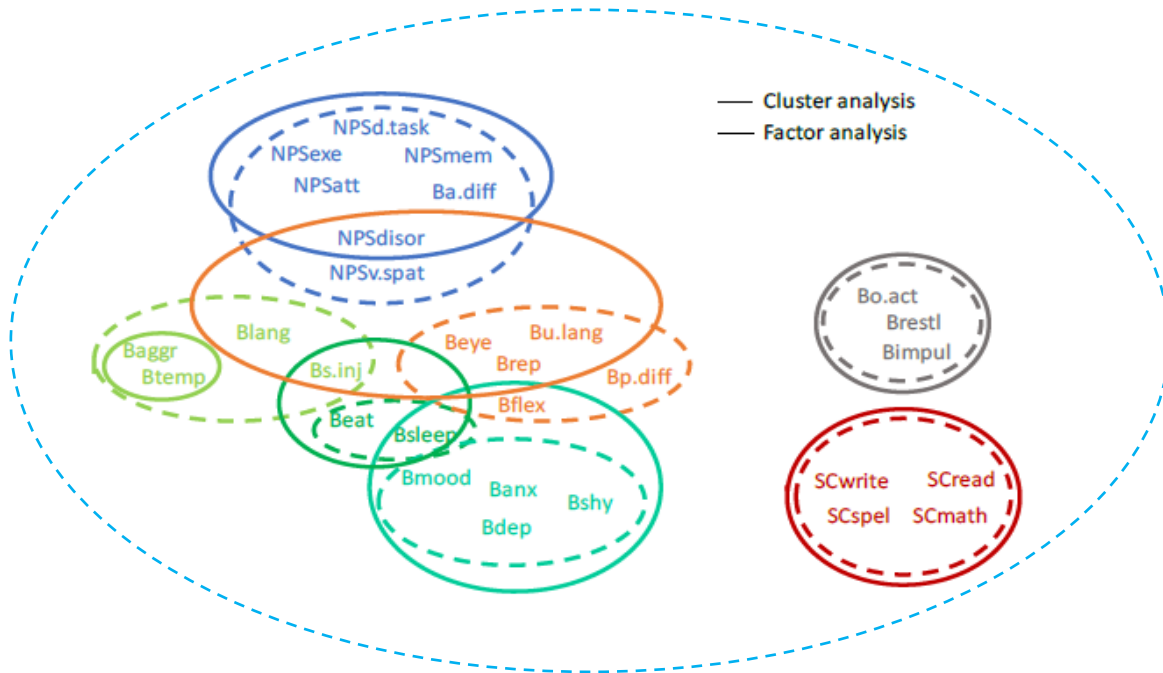
		TP001	TP002	TP003	TP004	TP005	TP006	TP007	TP008	TP009	TP010	TP011	TP012	TP013	TP014	TP015	TP016	TP017	TP018	TP019	TP020
Sleep	Sleep																				
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	Impulsive																				

Panel B

		TP009	TP002	TP014	TP011	TP012	TP007	TP008	TP016	TP003	TP010	TP006	TP015	TP018	TP013	TP004	TP019	TP005	TP001	TP017	TP020
Sleep	Sleep																				
Food	Eating																				
Mood	Anxiety																				
	Depression																				
	Shyness																				
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	Attention																				
	Restless																				
	Impulsive																				

Seven natural TAND clusters

+ a wrap-around psychosocial cluster



Cluster	#	TAND-L Checklist Items
Autism-like	6	Delayed language, Unusual language, Poor eye contact, Repetitive behaviour, Inflexibility, Peer difficulties
Mood/Anxiety	4	Mood swings, Depressed mood, Anxiety, Extreme shyness
Dysregulated Behaviour	3	Aggressive outbursts, Temper tantrums, Self-injury
Overactive/Impulsive	3	Overactive, Impulsivity, Restlessness
Scholastic	4	Reading, Writing, Spelling, Mathematics
Neuropsychological	7	Memory, Orientation, Attention, Visuo-spatial, Dual-tasking, Executive skills
Eat / Sleep	2	Eating / sleeping difficulties



Contents lists available at ScienceDirect

Pediatric Neurology

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



Original Article

Is It Feasible to Identify Natural Clusters of TSC-Associated Neuropsychiatric Disorders (TAND)?



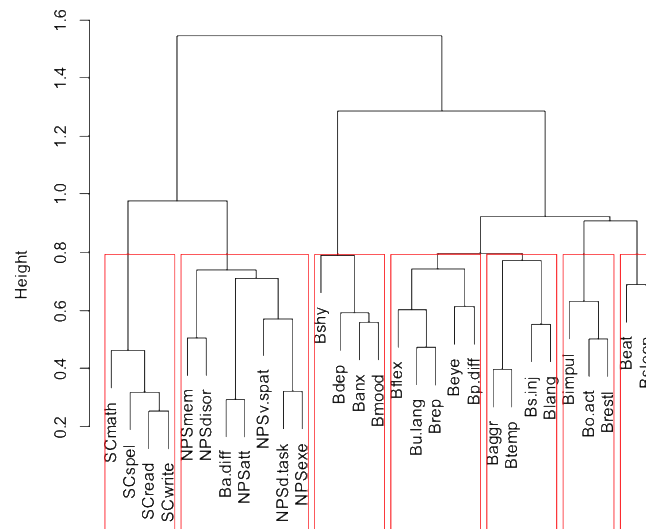
Loren Leclezio ^a, Sugnet Gardner-Lubbe ^b, Petrus J. de Vries ^{a,*}

^a Division of Child and Adolescent Psychiatry, University of Cape Town, South Africa

^b Department of Statistics and Actuarial Science, Stellenbosch

de Vries et al. *Journal of Neurodevelopmental Disorders* (2020) 12:24
<https://doi.org/10.1186/s11689-020-09327-0>

Journal of
Neurodevelopmental Disorders



RESEARCH

Open Access

Natural clusters of tuberous sclerosis complex (TSC)-associated neuropsychiatric disorders (TAND): new findings from the TOSCA TAND research project



Petrus J. de Vries^{1*}, Elena Belousova², Mirjana P. Benedik³, Tom Carter⁴, Vincent Cottin⁵, Paolo Curatolo⁶, Lisa D'Amato⁷, Guillaume Beure d'Augères⁸, José C. Ferreira⁹, Martha Feucht¹⁰, Carla Fladrowski^{11,12}, Christoph Hertzberg¹³, Sergiusz Jozwiak^{14,15}, John A. Lawson¹⁶, Alfons Macaya¹⁷, Ruben Marques^{7,18}, Rima Nababout¹⁹, Finbar O'Callaghan²⁰, Jiong Qin²¹, Valentin Sander²², Matthias Sauter²³, Seema Shah²⁴, Yukitoshi Takahashi²⁵, Renaud Touraine²⁶, Sotiris Youroukos²⁷, Bernard Zonnenberg²⁸, J. Chris Kingswood²⁹, Anna C. Jansen³⁰ and on behalf of TOSCA Consortium and TOSCA Investigators

RESEARCH

Open Access

Multivariate data analysis identifies natural clusters of Tuberous Sclerosis Complex Associated Neuropsychiatric Disorders (TAND)




Petrus J. de Vries^{1*} , Loren Leclezio^{1^}, Sugnet Gardner-Lubbe², Darcy Krueger³, Mustafa Sahin⁴, Steven Sparagana⁵, Liesbeth De Waele⁶ and Anna Jansen⁷

RESEARCH

Open Access

Symptom rates and profile clustering in tuberous sclerosis complex-associated neuropsychiatric disorders (TAND)



Samuel Alperin^{1,2*} , Darcy A. Krueger^{1,2}, David N. Franz^{1,2}, Karen D. Agricola^{1,2}, Gabrielle Stires^{1,2}, Paul S. Horn^{1,2} and Jamie K. Capal³

Mind the gap!

Multi-stakeholder dialogue for
priority setting in health research

Pilot: Tuberous Sclerosis Complex

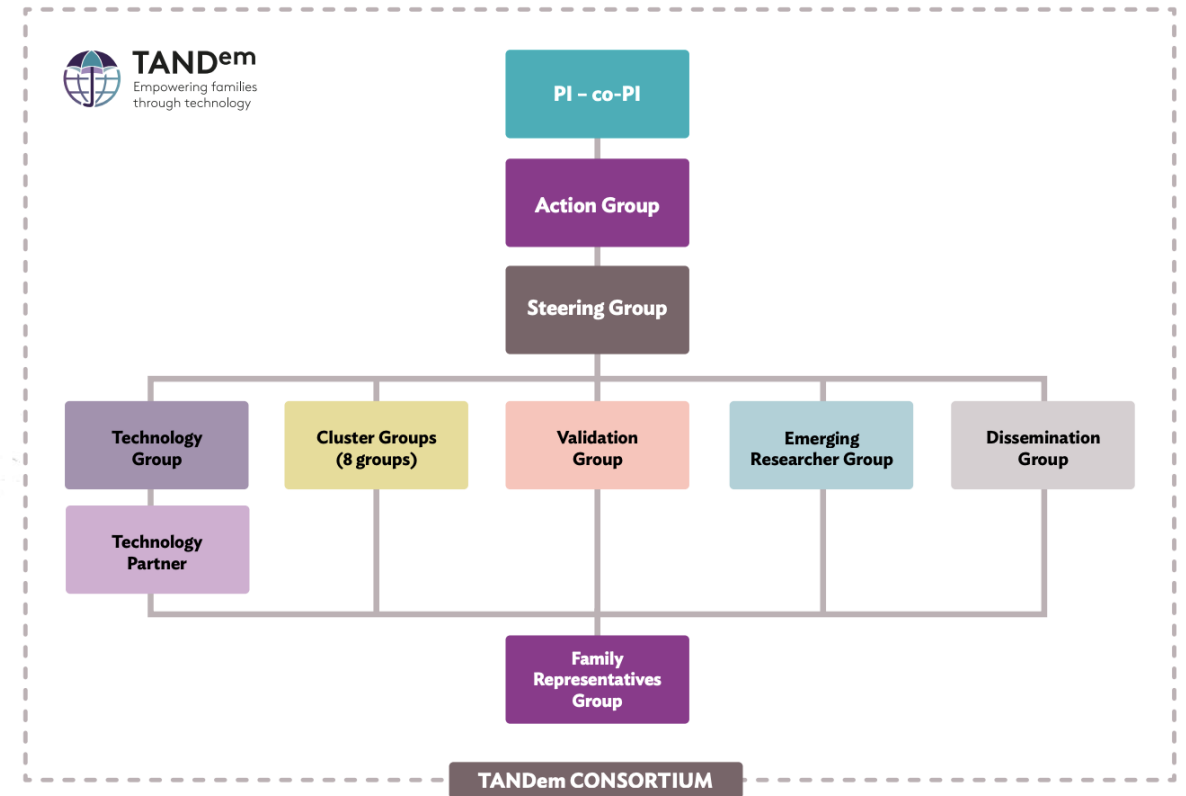
NEEDS FROM THE TSC COMMUNITY

1. Self-complete, quantified TAND Checklist
2. Smartphone app
3. TAND toolkit

TAND = Research Priority #1!

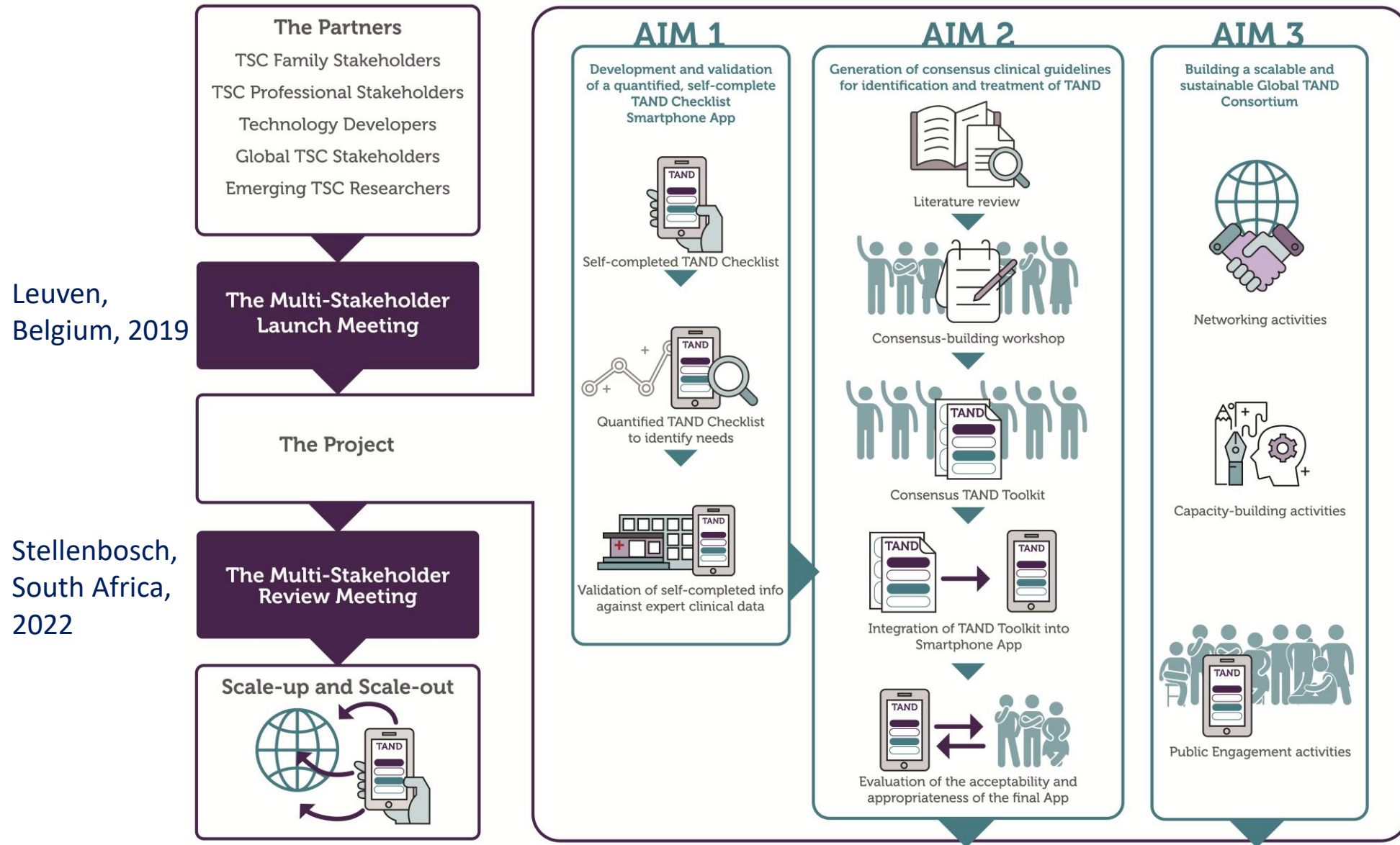
TANDem project

An international multistakeholder participatory research project



<https://tandconsortium.org/>

TANDem project plan



TANDem project protocol paper



Empowering Families Through Technology: A Mobile-Health Project to Reduce the TAND Identification and Treatment Gap (TANDem)

Tosca-Marie Heunis¹, Stacey Bissell², Anna W. Byars³, Jamie K. Capal⁴, Nola Chambers⁵, Sebastián Cukier⁶, Peter E. Davis⁷, Liesbeth De Waele^{8,9}, Jennifer Flinn¹⁰, Sugnet Gardner-Lubbe¹¹, Tanjala Gipson^{12,13}, J. Christopher Kingswood^{14,15}, Darcy A. Krueger^{16,17}, Aubrey J. Kumm⁵, Mustafa Sahin^{7,18}, Eva Schoeters^{19,20}, Catherine Smith²¹, Shoba Srivastava²², Megumi Takei²³, Stephanie Vanclooster¹, Agnies M. van Eeghen^{24,25}, Robert Waltereit²⁶, Anna C. Jansen^{1,27} and Petrus J. de Vries^{5}*

OPEN ACCESS



Development of the self-report quantified TAND Checklist (TAND-SQ)

AIM 1

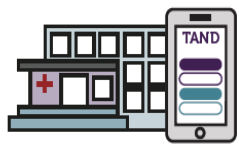
Development and validation of a quantified, self-complete TAND Checklist Smartphone App



Self-completed TAND Checklist



Quantified TAND Checklist to identify needs



Validation of self-completed info against expert clinical data

THE TAND CHECKLIST
Lifetime version (TAND-L)

Tuberous Sclerosis Complex (TSC) is associated with a range of neuropsychiatric disorders which we refer to as TAND (TSC-Associated Neuropsychiatric Disorders). All people with TSC are at risk of having some of these difficulties. Some people with TSC have very few, while others will have many of them. Each person with TSC will therefore have their own TAND profile, and this profile may change over time. This checklist was developed to help clinical teams, individuals with TSC and their families (a) screen for TAND at every clinic visit and (b) provide what is needed.

Instructions for use
The TAND Checklist was designed to be completed by a clinician with relevant knowledge and experience in TSC, in partnership with individuals with TSC or their parents/caregivers. The Checklist should take about 10 minutes to complete. Where individuals answer YES to any item, the clinician should explore the difficulty in sufficient detail to help guide decisions about further evaluation or treatment. All items should be completed.

About the interview
Name of TSC Subject: _____ DOB: []/[]/[] Age: []
Name of interviewer: _____ Date of interview: []/[]/[]
Name of interviewee: _____ Self / Parent / Caregiver / Other (indicate)

Let's begin
As you will know, the majority of people with TSC have some difficulty in learning, behaviour, mental health, specific aspects of their development and so on. We are going to use this checklist to help us check for these kinds of difficulties. I am going to ask you a number of questions. Some may be directly relevant to some people but not relevant to all. Just answer as best as you can. At the end I will check to see if there are any additional difficulties we didn't talk about. For parents/caregivers of individuals with TSC, please start with question 1. For individuals with TSC who complete this about themselves, please start with question 3.

01 Let's begin by talking about [subject's] development to get a sense of where they are at. How old was [subject] when he/she:

a. First walked?	Age:	Not yet
b. Sat without support?	Age:	Not yet
c. Walked without holding on?	Age:	Not yet
d. Used single words other than "mama" or "dada"?	Age:	Not yet
e. Used two words/short phrases?	Age:	Not yet
f. Was toilet trained during the day?	Age:	Not yet
g. Was toilet trained at night?	Age:	Not yet

TAND-SQ
Self-report, Quantified TAND Checklist (2023)

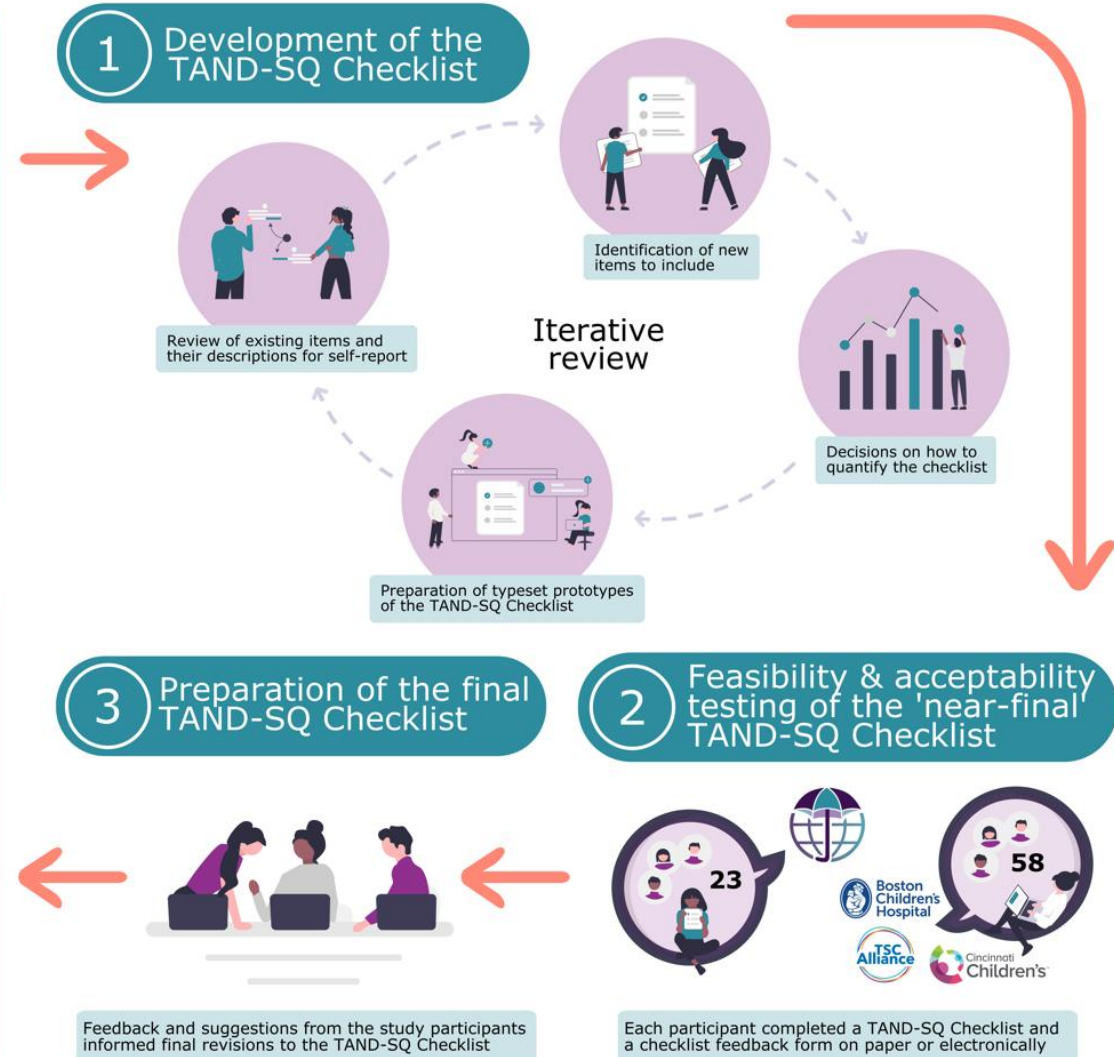
Tuberous Sclerosis Complex (TSC) is associated with a range of neuropsychiatric disorders that we refer to as TAND (TSC-Associated Neuropsychiatric Disorders). All people with TSC are at risk of having some of these difficulties. Some people with TSC have very few, while others will have many of these difficulties. Each person with TSC will therefore have their own TAND profile, and this profile may change over time. This checklist was developed for individuals and families who live with TSC to complete for themselves with the goal of (a) screening for TAND difficulties at home, (b) to quantify these difficulties, and (c) to help guide next steps for self-help and for further discussions with healthcare and other service providers.

Let's get started
Name of the person completing the TAND-SQ Checklist: _____
Date you completed the TAND-SQ Checklist: []/[]/[]
Who is the TAND-SQ Checklist about? This checklist will refer to this person as [subject].
Myself / My son / My daughter / My partner / My mother / My father / My brother / My sister / My grandchild / Other (please specify): _____
Name of the person [subject]: _____
Date of birth: []/[]/[] Age: [] Sex: [] Male [] Female []
Preferred personal pronouns: [] He/him/his [] She/her/hers [] They/their/theirs

Instructions for use
As you will know, the majority of people with TSC have some difficulty in learning, behaviour, mental health, specific aspects of their development and so on. The TAND-SQ Checklist was designed to help parents/caregivers or individuals with TSC to check for these kinds of difficulties. The checklist should take about 10-15 minutes to complete. You will see a number of questions. Some may be directly relevant to some people but not relevant to all. Some of the items can be quantified (given a severity rating) based on how good or difficult things have been over the last month. Some you can answer yes/no/never, just answer as best as you can and please try to complete all items. At the end we will show you how to identify your own TAND Check Profile and how to use your own next steps.

Where you see the pencil icon we have created space for you to make short notes if that would be helpful to you.

If you are caring for someone with TSC, please start with question 1.
If you have TSC and you are completing the TAND-SQ for yourself, please start with question 3.



Publication of the TAND-SQ Checklist

AIM 1

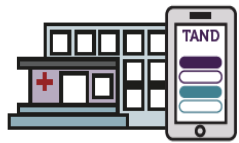
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Self-completed TAND Checklist



Quantified TAND Checklist
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Validation of self-completed info
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Pediatric Neurology 147 (2023) 101–123



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



Research Paper

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



Tosca-Marie Heunis, PhD ^a, Nola Chambers, PhD ^b, Stephanie Vanclooster, PhD ^a, Stacey Bissell, PhD ^c, Anna W. Byars, PhD ^d, Jamie K. Capal, MD ^e, Sebastián Cukier, MD ^{f,g}, Peter E. Davis, MD ^h, Magdalena C. de Vries, BMus ^b, Liesbeth De Waele, MD, PhD ^{i,j}, Jennifer Flinn, EdD ^k, Sugnet Gardner-Lubbe, PhD ^l, Tanjala Gipson, MD ^{m,n}, J. Christopher Kingswood, MBBS, MSc, FRCP ^{o,p}, Darcy A. Krueger, MD, PhD ^{q,r}, Aubrey J. Kumm, BVSc, MSc Med Neurosci ^b, Mustafa Sahin, MD, PhD ^{h,s}, Eva Schoeters, BA, MA ^{t,u}, Catherine Smith, BA ^v, Shoba Srivastava, BEd, MA ^{b,w}, Megumi Takei, BA ^x, Agnies M. van Eeghen, MD, PhD ^{y,z}, Robert Waltereit, MD ^{aa,ab}, Anna C. Jansen, MD, PhD ^{a,ac,ad}, Petrus J. de Vries, MBChB, FRCPsych, PhD ^{b,*}



Self-report quantified TAND Checklist (TAND-SQ)

AIM 1

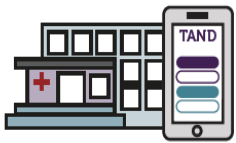
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Self-completed TAND Checklist



Quantified TAND Checklist
to identify needs



Validation of self-completed info
against expert clinical data

TAND-SQ

Self-report, Quantified TAND Checklist (2023)

English version

Tuberous Sclerosis Complex (TSC) is associated with a range of neuropsychiatric disorders that we refer to as TAND (TSC-Associated Neuropsychiatric Disorders). All people with TSC are at risk of having some of these difficulties. Some people with TSC have very few, while others will have many of these difficulties. Each person with TSC will therefore have their own TAND profile, and this profile may change over time. This checklist was developed for individuals and families who live with TSC to complete for themselves with the goal of a) screening for TAND difficulties at home, b) to quantify these difficulties, and c) to help guide next steps for self-help and for further discussions with healthcare and other service providers.

Let's get started

Name of the person completing the TAND-SQ Checklist:

Date you completed the TAND-SQ Checklist: / /

Who is the TAND-SQ Checklist about? This checklist will refer to this person as [subject].

☐ Myself ☐ My son ☐ My daughter ☐ My partner ☐ My mother ☐ My father
☐ My brother ☐ My sister ☐ My grandchild ☐ Other (please specify).....

Name of the person [subject]:

Date of birth: / / Age: Sex: ☐ Male ☐ Female ☐ Other

Preferred personal pronouns: ☐ He/Him/His ☐ She/Her/Hers ☐ They/Them/Theirs

Instructions for use

As you will know, the majority of people with TSC have some difficulty in learning, behaviour, mental health, specific aspects of their development and so on. The TAND-SQ Checklist was designed to help parents/caregivers or individuals with TSC to check for these kinds of difficulties. The checklist should take about 20 – 30 minutes to complete. You will see a number of questions. Some may be directly relevant and some might not be relevant at all. Some of the items can be quantified (given a severity rating) based on how good or difficult things have been over the last month. Even if you can't remember everything, just answer as best as you can and please try to complete all items. At the end we will show you how to identify your own TAND Cluster Profile that may help you plan your next steps.



Where you see the pencil sign we have created space for you to make short notes if that would be helpful to you.

If you are caring for someone with TSC, please start with question 1.

If you have TSC and you are completing the TAND-SQ for yourself, please start with question 3.

01

Let's begin by talking about [subject]'s development to get a sense of where they are at. How old was [subject] when they:

- a. First smiled? ☐ Not yet ☐ < 2 months ☐ 2 – 4 months ☐ 4 – 6 months ☐ > 6 months
☐ Not sure (within normal range) ☐ Not sure (delayed)
- b. Sat without support? ☐ Not yet ☐ < 6 months ☐ 6 – 8 months ☐ 8 – 10 months ☐ 10 – 12 months
☐ > 12 months ☐ Not sure (within normal range) ☐ Not sure (delayed)
- c. Walked without holding on? ☐ Not yet ☐ < 10 months ☐ 10 – 12 months ☐ 12 – 14 months ☐ 14 – 16 months
☐ 16 – 18 months ☐ > 18 months ☐ Not sure (within normal range) ☐ Not sure (delayed)
- d. Used single words other than 'mama' or 'dada'? ☐ Not yet ☐ < 12 months ☐ 12 – 14 months ☐ 14 – 16 months ☐ 16 – 18 months
☐ 18 – 20 months ☐ > 20 months ☐ Not sure (within normal range) ☐ Not sure (delayed)
- e. Used two word or simple phrases (e.g. play park, drink juice...)? ☐ Not yet ☐ < 18 months ☐ 18 – 22 months ☐ 22 – 26 months ☐ 26 – 30 months
☐ 30 – 36 months ☐ > 36 months ☐ Not sure (within normal range) ☐ Not sure (delayed)
- f. Was toilet trained during the day? ☐ Not yet ☐ < 24 months ☐ 24 – 30 months ☐ 30 – 36 months ☐ 36 – 48 months
☐ > 48 months ☐ Not sure (within normal range) ☐ Not sure (delayed)
- g. Was toilet trained at night? ☐ Not yet ☐ < 3 years ☐ 3 – 4 years ☐ 4 – 5 years ☐ 5 – 6 years
☐ 6 – 8 years ☐ > 8 years ☐ Not sure (within normal range) ☐ Not sure (delayed)



02

What is [subject]'s current level of:

- a. Language: ☐ non-verbal/minimally verbal ☐ simple language ☐ fluent
- b. Self-care: ☐ dependent on others ☐ some self-care skills ☐ independent
- c. Mobility: ☐ wheelchair ☐ needs significant support ☐ some difficulty
☐ completely mobile



Integration of the TAND-SQ in the app

AIM 1

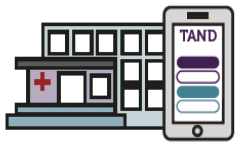
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☐ My brother ☐ My sister ☐ My grandchild ☐ Other (please specify):

Name of the person [subject]:

Date of birth: [01/01/2023] Age: [] Sex: ☐ Male ☐ Female ☐ Other

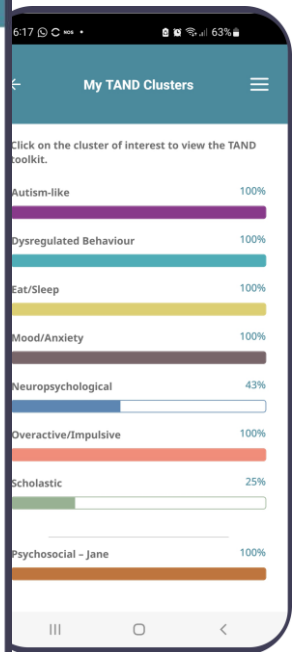
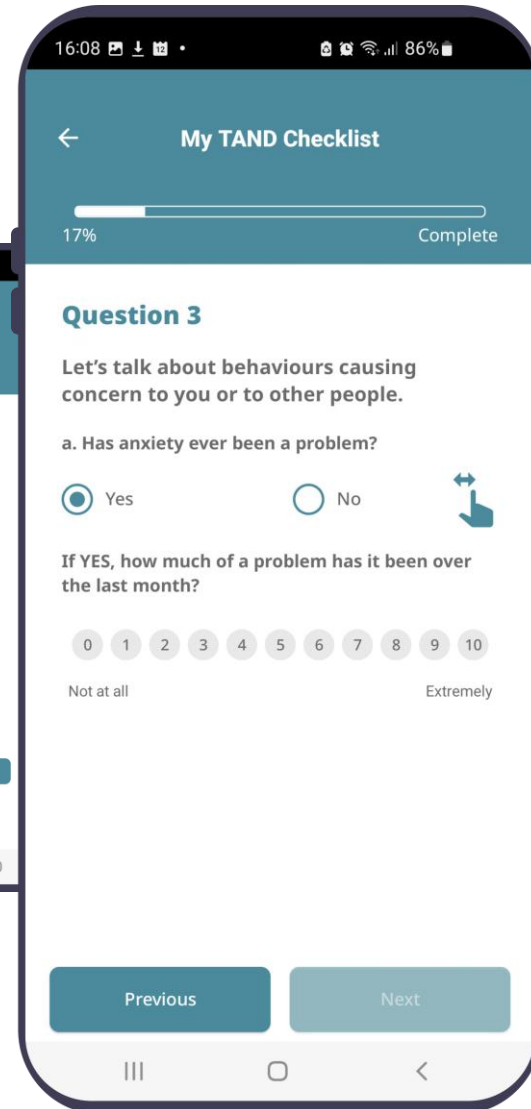
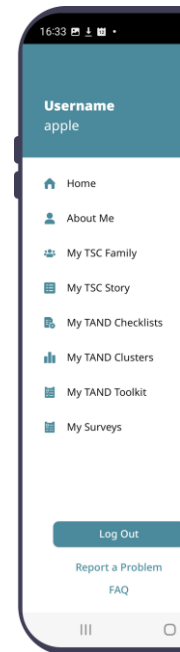
Preferred personal pronouns: ☐ He/him/his ☐ She/her/hers ☐ They/Them/Theirs

Instructions for use

As you will know, the majority of people with TSC have some difficulty in learning, behaviour, mental health, specific aspects of their development and so on. The TAND-SQ Checklist was designed to help parents/ carers or individuals with TSC to check for these kinds of difficulties. The checklist should take about 20 - 30 minutes to complete. You will see a number of questions. Some may be directly relevant and some might not be relevant at all. Some of the items can be quantified (given a severity rating) based on how good or difficult things have been over the last month. Even if you can't remember everything, just answer as best as you can and please try to complete all items. At the end we will show you how to identify your own TAND Cluster Profile that may help you plan your next steps.

Where you see the pencil sign we have created space for you to make short notes if that would be helpful to you.

If you are caring for someone with TSC, please start with question 1.
If you have TSC and you are completing the TAND-SQ for yourself, please start with question 3.



Data collection using the app

AIM 1

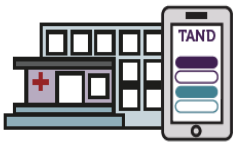
Development and validation of a quantified, self-complete TAND Checklist Smartphone App



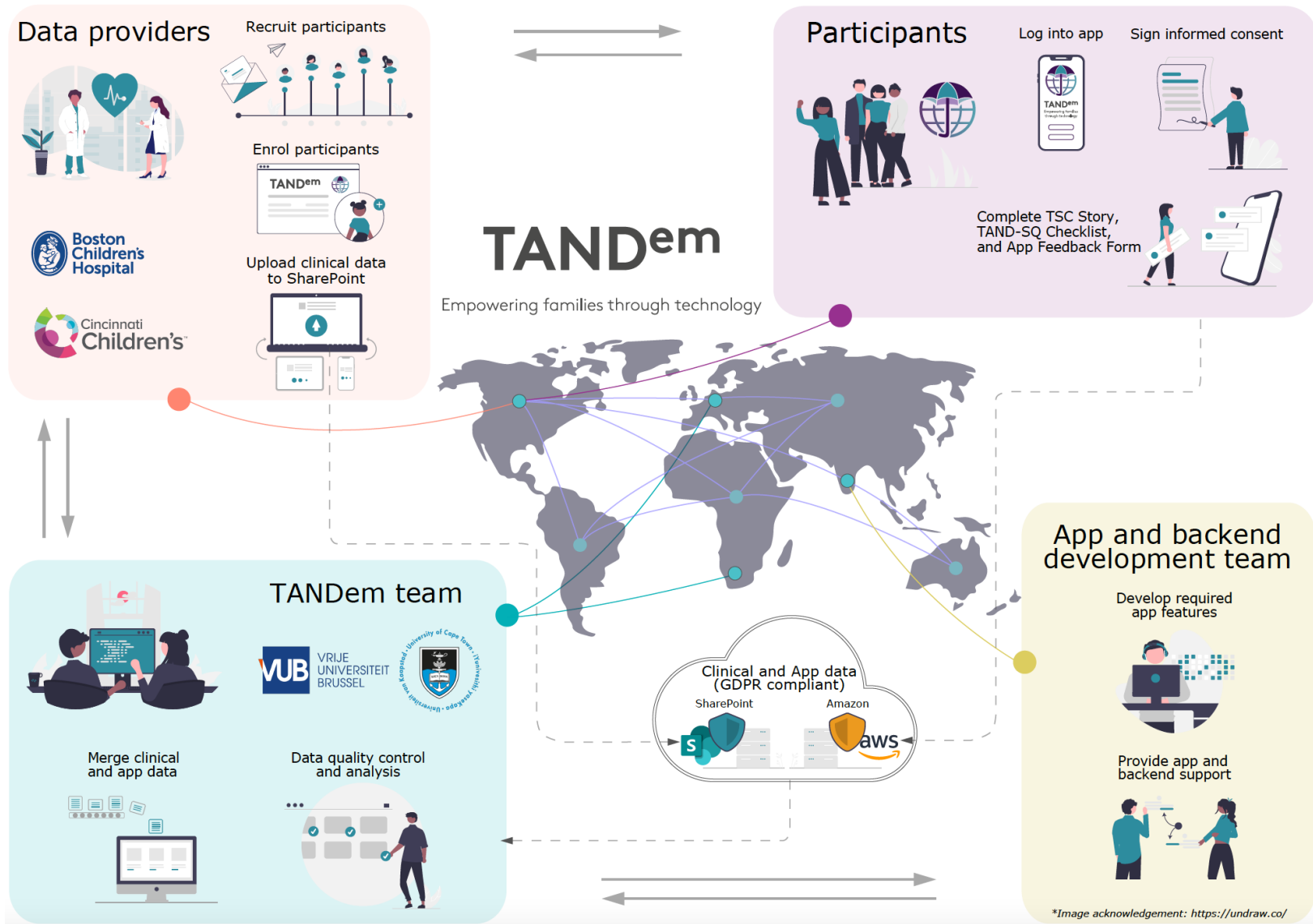
Self-completed TAND Checklist



Quantified TAND Checklist to identify needs



Validation of self-completed info against expert clinical data



AIM 1

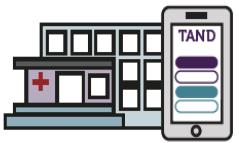
Development and validation
of a quantified, self-complete
TAND Checklist
Smartphone App



Self-completed TAND Checklist



Quantified TAND Checklist
to identify needs



Validation of self-completed info
against expert clinical data

Validation of the TAND-SQ

- Responses on the TAND-SQ can be quantified into Cluster Scores (CS), Cluster Severity Scores (CSS), and Total TAND Severity Scores (TTSS).
- Findings provide support for the **internal consistency** of the CS and CSS, and **convergent validity** of the CS, CSS and TTSS both within the TAND-SQ and with data independent of the TAND-SQ in two cohorts.
- **TAND clusters are valid constructs** and thus can **guide clinical decision-making** and care for individuals with TSC. However, the TAND Clusters are NOT a diagnostic tool.
- For patients with high symptom burden, CSS might **help families prioritise further evaluations**.
- For patients with low symptom burden, endorsing ANY item (e.g. sleep) should still prompt further referral/evaluation.

Development of international consensus clinical recommendations

AIM 2

Generation of consensus clinical guidelines for identification and treatment of TAND



Literature review



Consensus-building workshop



Consensus TAND Toolkit



Integration of TAND Toolkit into Smartphone App



Evaluation of the acceptability and appropriateness of the final App

Vanclooster *et al.*
Journal of Neurodevelopmental Disorders (2022) 14:13
<https://doi.org/10.1186/s11689-022-09423-3>

Journal of
Neurodevelopmental Disorders

REVIEW

Open Access

The research landscape of tuberous sclerosis complex–associated neuropsychiatric disorders (TAND)—a comprehensive scoping review



Stephanie Vanclooster^{1†}, Stacey Bissell^{2†}, Agnies M. van Eeghen^{3,4}, Nola Chambers⁵, Liesbeth De Waele^{6,7}, Anna W. Byars⁸, Jamie K. Capal⁹, Sebastián Cukier¹⁰, Peter Davis¹¹ , Jennifer Flinn¹², Sugnet Gardner-Lubbe¹³, Tanjala Gipson^{14,15}, Tosca-Marie Heunis¹, Dena Hook¹⁶, J. Christopher Kingswood^{17,18}, Darcy A. Krueger^{19,20}, Aubrey J. Kumm⁵, Mustafa Sahin²¹ , Eva Schoeters²², Catherine Smith¹⁶, Shoba Srivastava^{5,23}, Megumi Takei²⁴, Robert Waltereit²⁵, Anna C. Jansen^{1,26} and Petrus J. de Vries^{5*}



Development of international consensus clinical recommendations

AIM 2

Generation of consensus clinical guidelines for identification and treatment of TAND



Literature review



Consensus-building workshop



Consensus TAND Toolkit



Integration of TAND Toolkit into Smartphone App



Evaluation of the acceptability and appropriateness of the final App

1 Include all members of the TAND consortium in the consensus panel

2 Creation of cluster groups

3 Review of the literature

4 Generation of cluster chapters, summary statements and recommendations

5 Presentation and review of summary statements and recommendations per cluster

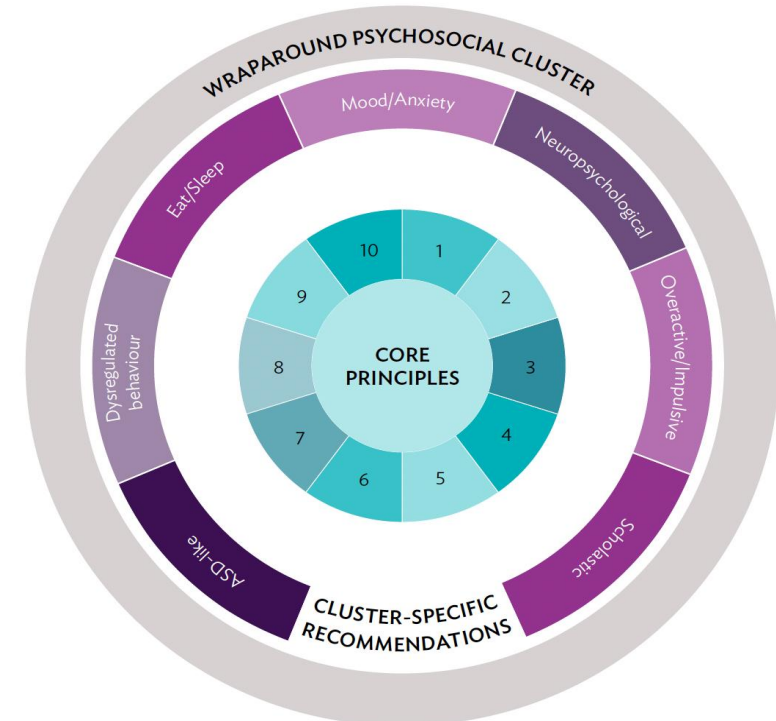
6 Electronic voting and prioritisation of summary statements and recommendations

7 Consensus conference

8 Identification of core principles

9 Electronic voting and prioritisation of core principles

10 Generation of the final set of evidence-informed consensus recommendations for identification and treatment of TAND



Publication of international consensus clinical recommendations

AIM 2

Generation of consensus clinical guidelines
for identification and treatment of TAND



Literature review



Consensus-building workshop



Consensus TAND Toolkit



Integration of TAND Toolkit into
Smartphone App



Evaluation of the acceptability and
appropriateness of the final App

de Vries et al.
Journal of Neurodevelopmental Disorders (2023) 15:32
<https://doi.org/10.1186/s11689-023-09500-1>

Journal of
Neurodevelopmental Disorders

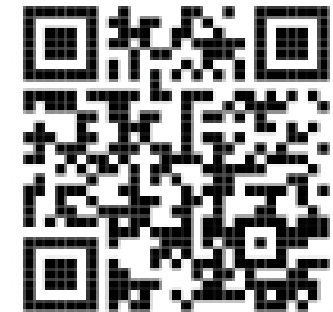
RESEARCH

Open Access



International consensus recommendations for the identification and treatment of tuberous sclerosis complex-associated neuropsychiatric disorders (TAND)

Petrus J. de Vries^{1*}, Tosca-Marie Heunis², Stephanie Vanclooster², Nola Chambers¹, Stacey Bissell³, Anna W. Byars^{4,5}, Jennifer Flinn⁶, Tanjala T. Gipson^{7,8}, Agnies M. van Eeghen^{9,10}, Robert Waltereit¹¹, Jamie K. Capal¹², Sebastián Cukier¹³, Peter E. Davis¹⁴, Catherine Smith¹⁵, J. Chris Kingswood^{16,17}, Eva Schoeters^{18,19}, Shoba Srivastava^{1,20}, Megumi Takei²¹, Sugnet Gardner-Lubbe²², Aubrey J. Kumm¹, Darcy A. Krueger^{4,5}, Mustafa Sahin^{14,23}, Liesbeth De Waele^{24,25} and Anna C. Jansen^{2,26,27}



Development of the TAND toolkit

AIM 2

Generation of consensus clinical guidelines for identification and treatment of TAND



Literature review



Consensus-building workshop



Consensus TAND Toolkit



Integration of TAND Toolkit into Smartphone App



Evaluation of the acceptability and appropriateness of the final App

1 Determine overarching toolkit structure across all clusters

2 Research TSC-specific and cluster-related practical evidence-informed resources for each cluster

3 Develop introductory video script and app screen wireframes per cluster

4 Present and review the introductory video script and app screen wireframes

5 Identify additional required content and visuals

6 Create new content, visuals, and introductory videos

7 Develop the toolkit website

8 Integrate the toolkit website into the app

9 Optimise the toolkit website for view on mobile devices

10 Incorporate feedback from user acceptance testing

Development of the TAND toolkit

AIM 2

Generation of consensus clinical guidelines for identification and treatment of TAND



Literature review



Consensus-building workshop



Consensus TAND Toolkit



Integration of TAND Toolkit into Smartphone App



Evaluation of the acceptability and appropriateness of the final App

TAND Toolkit



home

Welcome

Welcome to the TAND toolkit! TAND are Tuberous Sclerosis Complex (TSC) Associated Neuropsychiatric Disorders. TAND consist of a range of behavioural, psychiatric, scholastic, neuropsychological, and psychosocial difficulties commonly seen in people with TSC, in addition to the physical challenges, and often have the greatest impact on family stress and quality of life. You can find out more about TAND by clicking [here](#).

The TAND toolkit was developed by the TAND consortium, a team of lived and professional experts from across the globe, in response to requests from individuals with TSC and their caregivers. It is designed around the seven natural TAND clusters identified by researchers to help families prioritise their goals. The tips and strategies are based on detailed evidence reviews both within the field of TSC and fields outside TSC relevant to the TAND clusters, for example, the autism literature. The toolkit is designed to help you prioritise and plan your next steps for assessment, intervention and support. More information on what this toolkit contains can be found in the video below.



Resource panel

More about

- TAND
- Consensus recommendations

TAND Clusters

- Autism-like
- Dysregulated Behaviour
- Eat/Sleep
- Mood/Anxiety
- Neuropsychological
- Overactive/impulsive
- Scholastic
- Psychosocial

The TAND-SQ Checklist
[\[pedneur.com\]](#)



Find a TSC Organisation
[\[tscinternational.org\]](#)



TAND Clusters

home > tand clusters

About

Here you will find ideas for what we recommend you **SEEK** and ideas of things you can **DO** if you or someone in your care is presenting with symptoms in any of the TAND clusters. Click on the cluster relevant to you for more information.



<https://tandtoolkit.org>

Evaluation of the TAND Toolkit App

AIM 2

Generation of consensus clinical guidelines for identification and treatment of TAND



Literature review



Consensus-building workshop



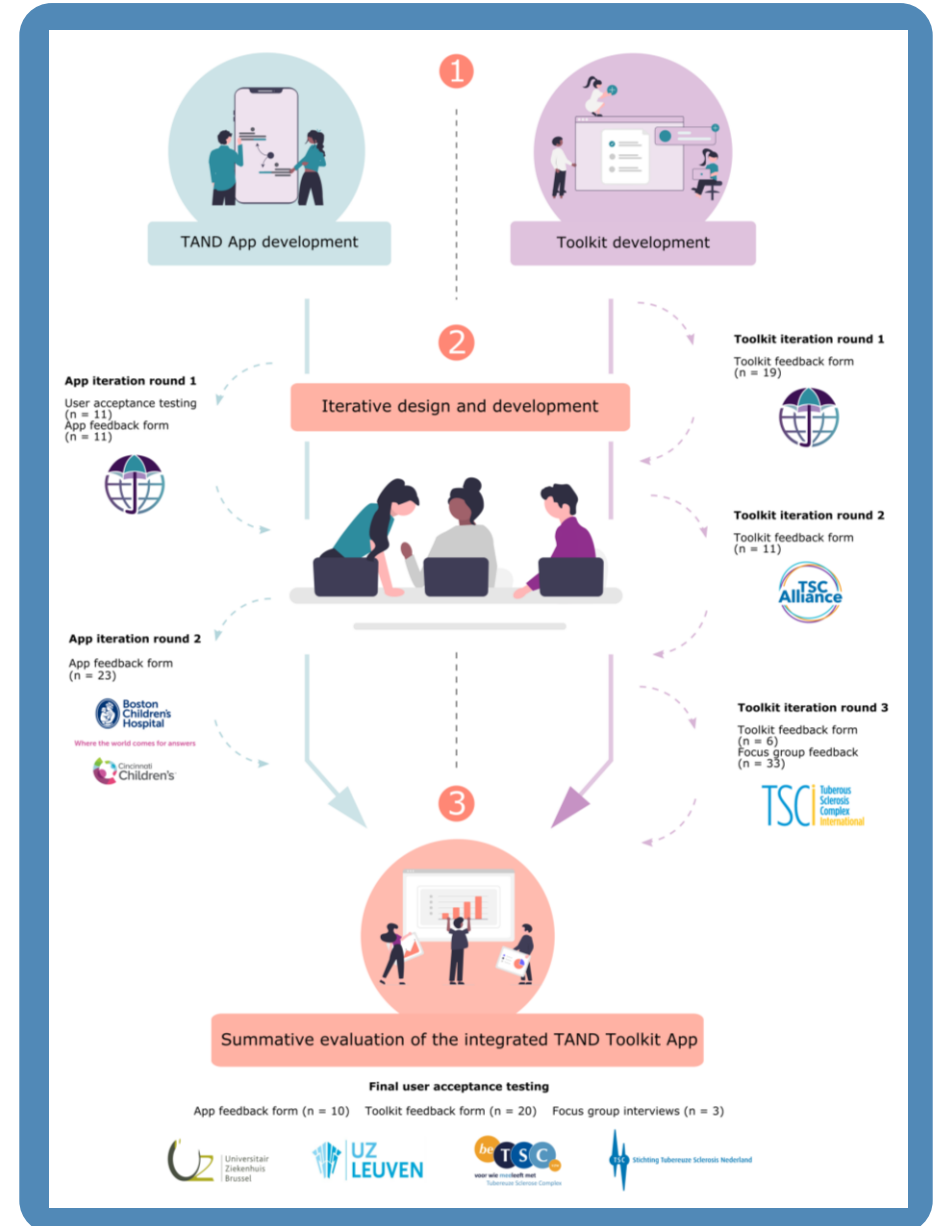
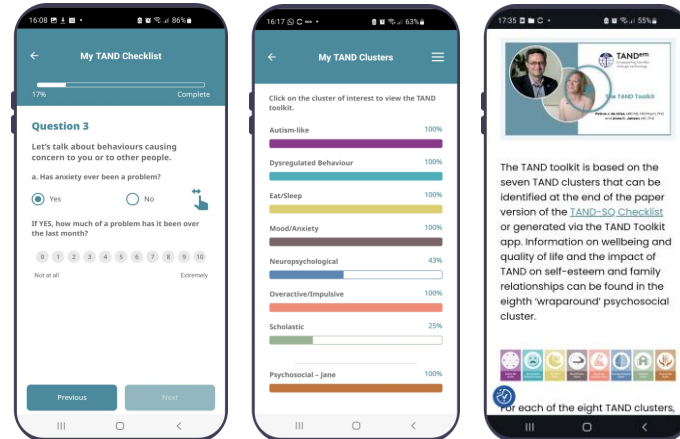
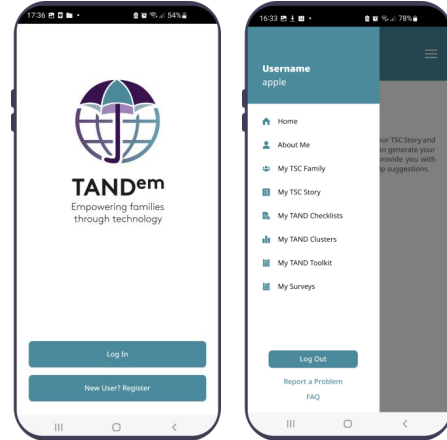
Consensus TAND Toolkit



Integration of TAND Toolkit into Smartphone App



Evaluation of the acceptability and appropriateness of the final App



Dissemination

AIM 3

Building a scalable and sustainable Global TAND Consortium



Networking activities



Capacity-building activities




Public Engagement activities

TAND

Mini-Symposium

2022




TSC-Associated Neuropsychiatric Disorders (TAND)


TAND

Mini-Symposium

2023




TSC-Associated Neuropsychiatric Disorders (TAND)



IACAPAP poster

The TANDem consortium presented an abstract at the 24th World Congress of the International Association of Child & Adolescent Psychiatrists and Allied Professions (IACAPAP) organized virtually in December 2020.


3 December 2020



DCAP presentation

An update on the TANDem project was presented at the annual DCAP (Division of Child and Adolescent Psychiatry) research mini-symposium virtually held on 27th November 2020.

27 November 2020



TSC Research Symposium 2020

At the International TSC Research Symposium organized virtually on 13th November 2020 an update was given on the first year of the TANDem project.

13 November 2020

Dissemination

AIM 3

Building a scalable and sustainable Global TAND Consortium



Networking activities



Capacity-building activities



Public Engagement activities

The TANDem project Annual Reports 2020–2023



VRIJE
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BRUSSEL



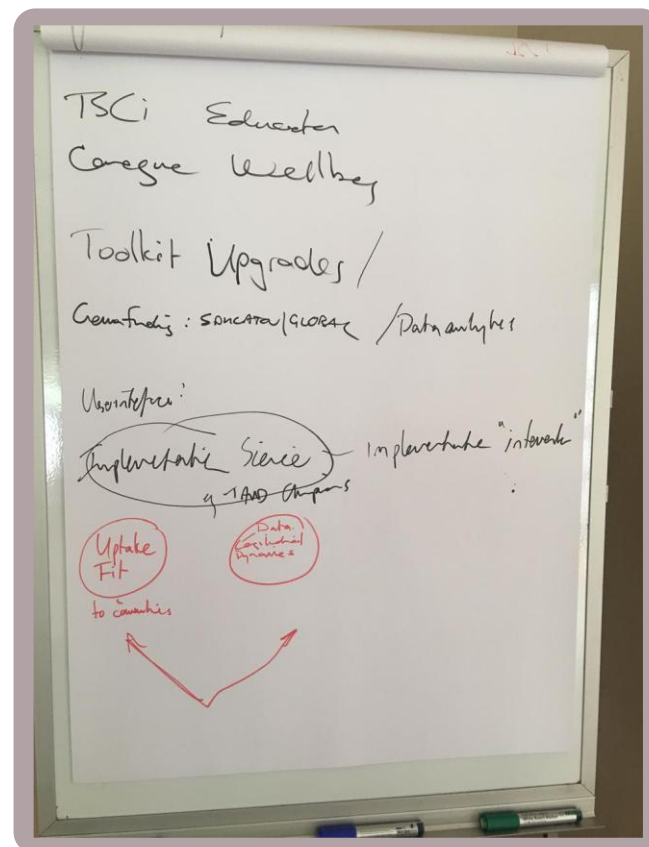
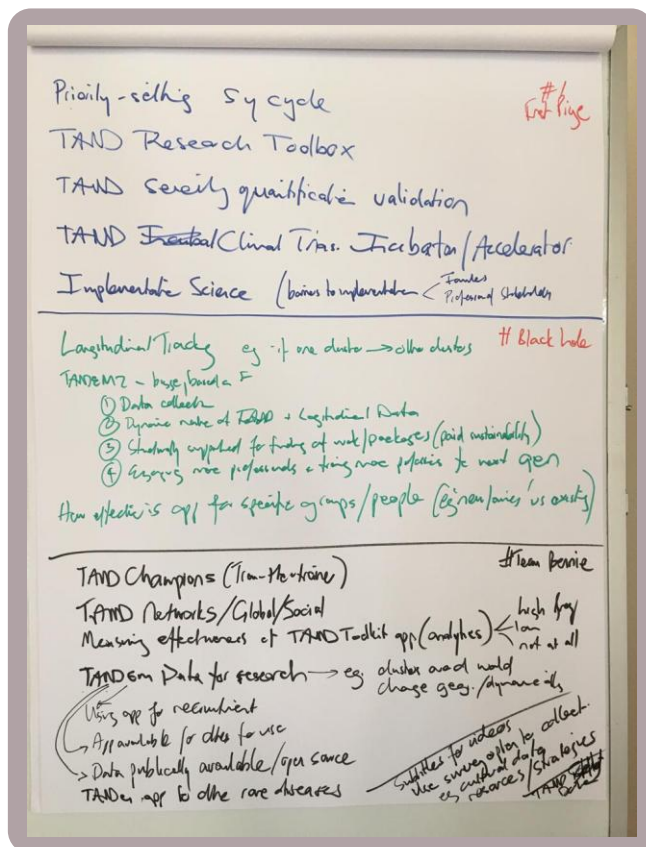
TANDem community outreach, Stellenbosch, South Africa, 2022



TANDem project consensus meeting, Stellenbosch, 2022



Participatory steps from TANDem to TANDem-2



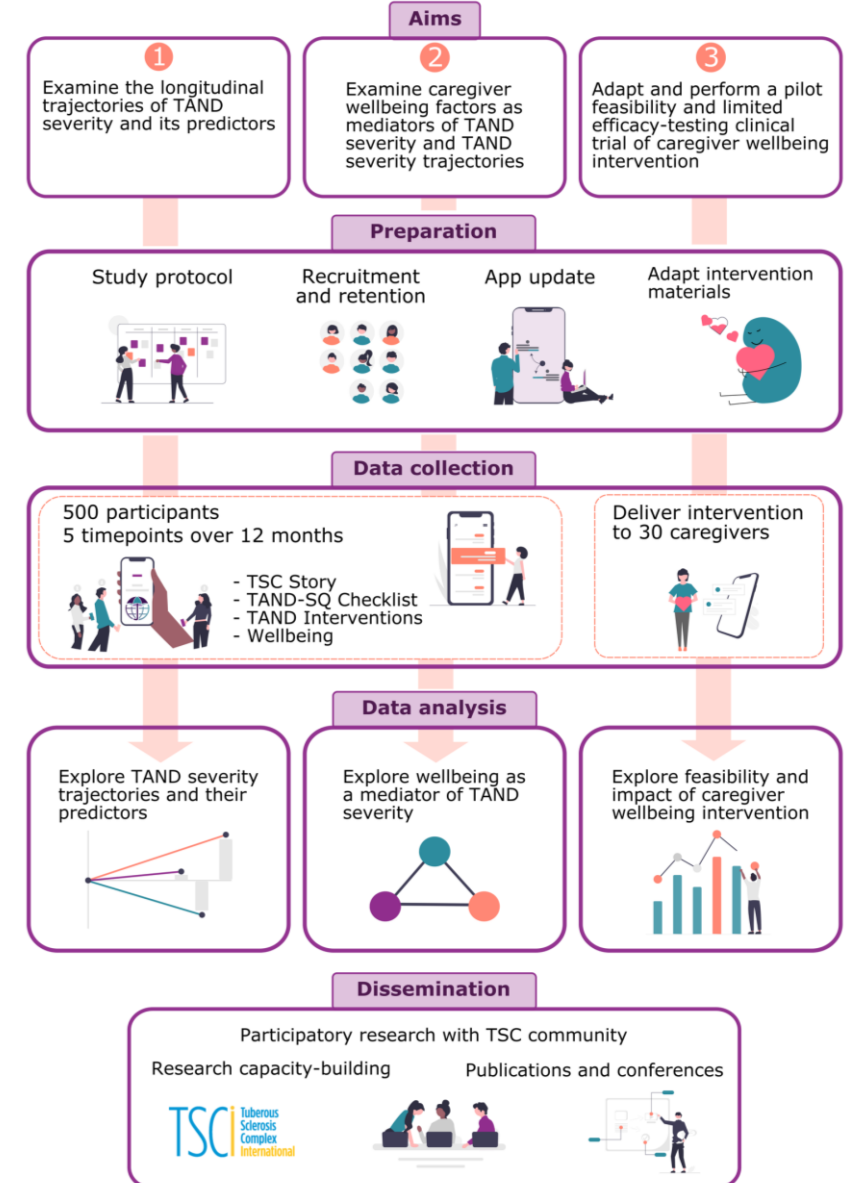
Understanding our journeys with TAND

- What do our journeys with TAND look like for families around the world?
- How can we understand family caregiver factors on this journey?
- Can we strengthen family caregiver wellbeing to support them on their journeys?

TANDem-2: Closing the gap to interventions for TAND

Project aims

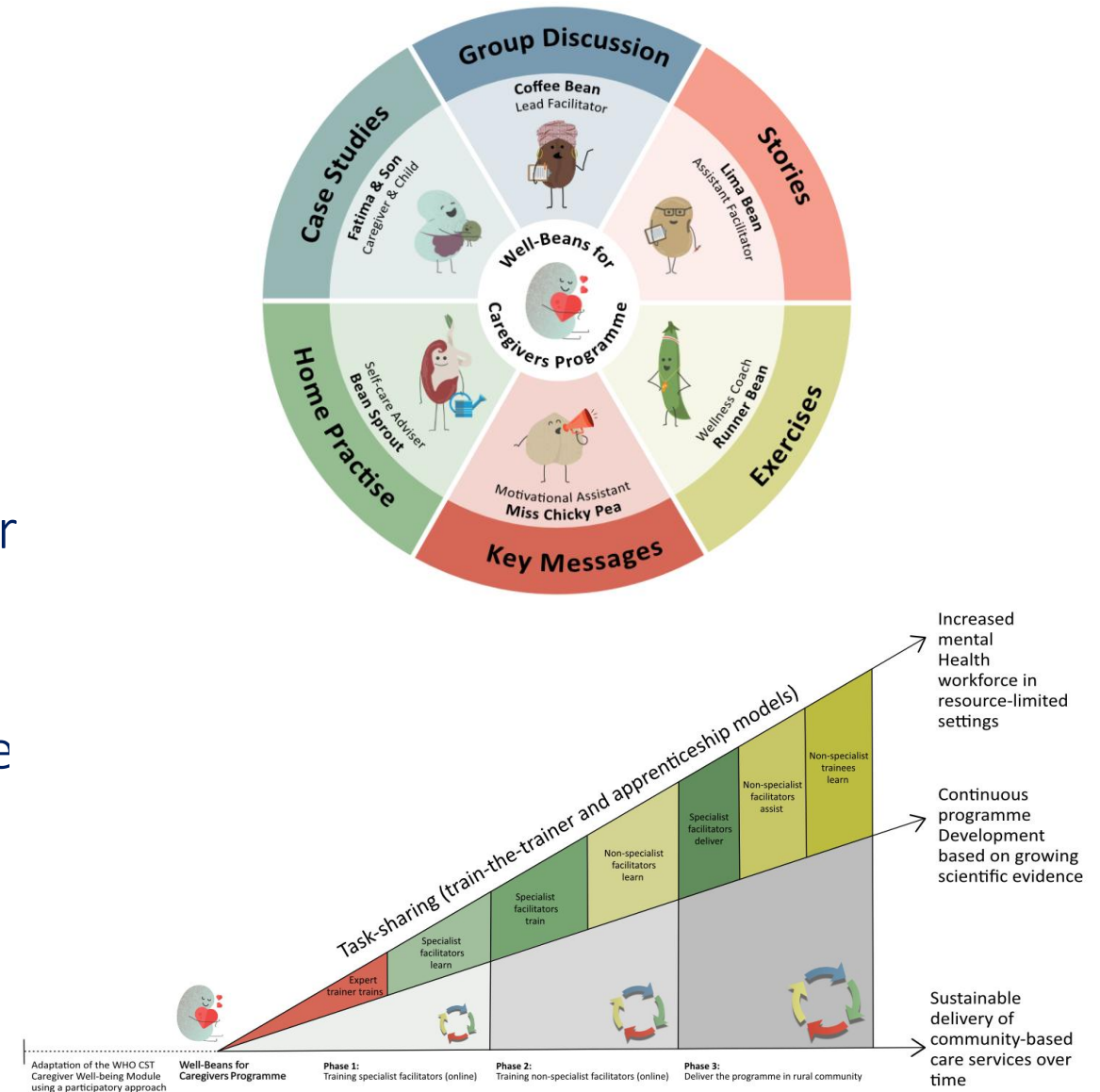
- 1) To describe the **longitudinal trajectories of TAND severity** and to examine potential **predictors** of differential trajectory membership.
- 2) To understand **caregiver wellbeing factors** and their contribution to TAND severity (both cross-sectionally and longitudinally).
- 3) To examine whether we can strengthen those caregiver wellbeing factors through an innovative ultra-brief **caregiver wellbeing intervention**.



Strengthening caregiver wellbeing

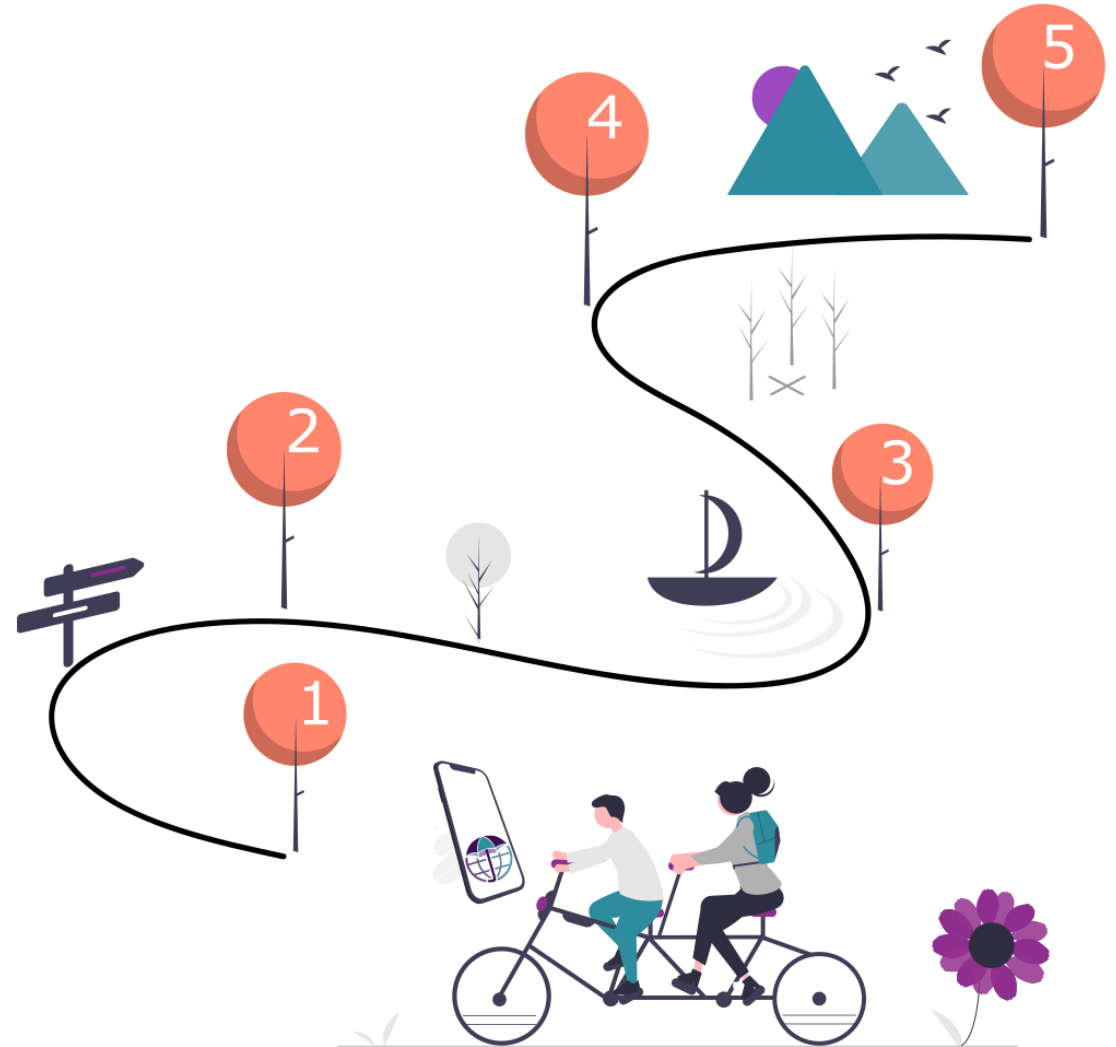
Well-Beans for Caregivers Programme

- Adapted from the World Health Organization Caregiver Skills Training (CST) Programme
- Global emphasis on caregiver skills training
- Little focus on caregiver capacity to care
- ACT (acceptance and commitment therapy) for autism, chronic illness, pain etc., i.e. a transdiagnostic intervention
- WHO CST ultra-brief caregiver wellbeing (three sessions)



'Umbrella goals' beyond the three aims of TANDem-2

- Training of providers
- Dissemination of existing information
- TAND toolkit
- Languages
- Research capacity-building
- Collaboration with others



TAND consortium



TANDconsortium



Thank you!

The journey with TSC, a family perspective

Mary Vasseghi - ePAG - TSC Ireland and Trinity College Dublin



Living, learning
&
striving together

2025

The “olog-ists”

Neurologist	Endocrinologist
Nephrologist	Gynaecologist
Radiologist	Gastroenterologist
Dermatologist	Neuropsychologist
Pneumologist	Physiotherapist
Ophthalmologist	Occupational Therapist
Cardiologist	Psychiatrist
Psychologist	Oncologist
Dentist	Geneticist
Dietician	Speech & language Therapist
General Practitioner	Nurses





*“Dominate the situation,
don’t let
the situation
dominate you”*







Focus on caregiver wellbeing

Liezl Schlebush - University of Cape Town, South-Africa



Focus on caregiver wellbeing

Liezl Schlebush - University of Cape Town, South-Africa

About the programme

- A three-session wellbeing programme for caregivers
- Successfully facilitated in South Africa
- Now we need to adapt it for TSC community & online delivery via Zoom

Special Issue: Autism Research in a Global Context

Supporting caregivers of children with developmental disabilities: Findings from a brief caregiver well-being programme in South Africa

Liezl Schlebusch¹ , Nola Chambers¹, David Rosenstein¹,
Petro Erasmus² , WHO CST Team^{3*} and Petrus J de Vries¹



Autism
1–16

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DOI: 10.1177/13623613221133182

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World Health Organization Caregiver Skills Training Programme (CST)



Main programme:

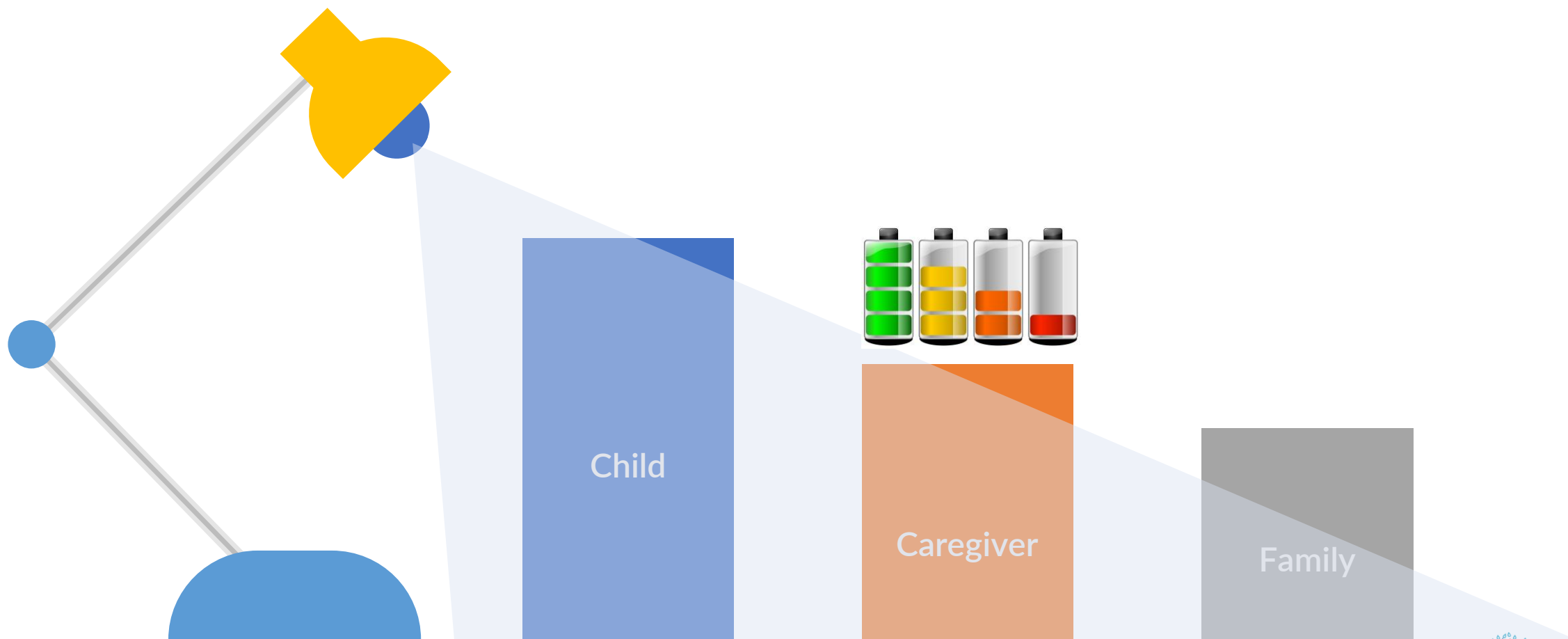
12-sessions focus on training caregiver skills to promote child development for children with developmental disabilities

- *free to families
- *free programme materials
- *group-based
- *global field-testing & feasibility in resource-limited settings

Optional

3-session caregiver well-being module

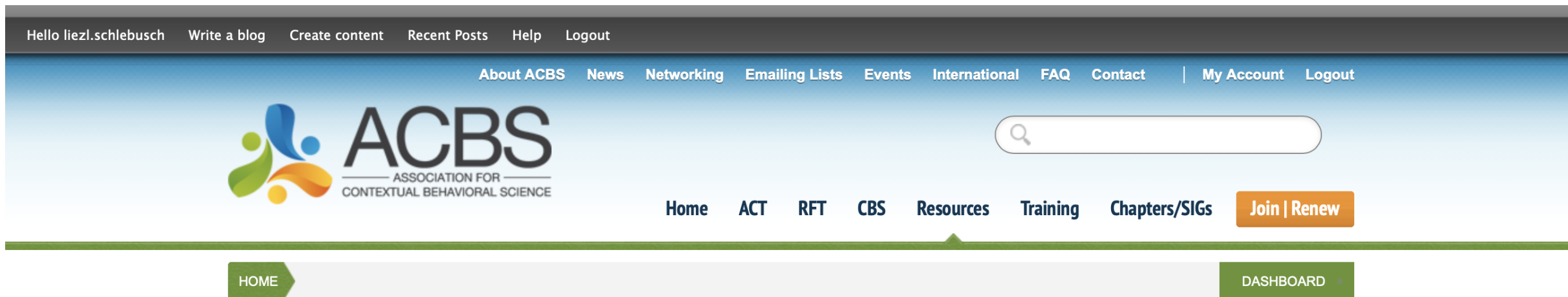
Why should we worry about caregiver well-being?



ACT

Acceptance & Commitment Therapy (ACT)

<https://contextualscience.org>



Acceptance & Commitment Therapy (ACT)



Psychology and Psychotherapy: Theory, Research and Practice (2020)
© 2020 The British Psychological Society
www.wileyonlinelibrary.com

A systematic review of the use of acceptance and commitment therapy in supporting parents

Gary Byrne^{1*} , Áine Ní Ghráda¹, Teresa O'Mahony¹ and Emma Brennan²

¹Health Service Executive, Dublin, Ireland

²School of Psychology, Trinity College, Dublin, Ireland

A Systematic Review: Acceptance and Commitment Therapy for the Parents of Children and Adolescents with Autism Spectrum Disorder

Julie Juvin¹ · Serine Sadeg¹ · Sabrina Julien-Sweerts² · Rafika Zebdi¹

Accepted: 10 February 2021

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Acceptance and commitment therapy for family caregivers: A systematic review and meta-analysis

Areum Han¹ , Hon K Yuen¹ and Jeremy Jenkins²

Mindfulness and Acceptance Interventions for Parents of Children and Adolescents Diagnosed with Chronic Medical Conditions: A Systematic Review

Danielle Ruskin, PhD, CPsych,^{1,2} Melissa Young, PsyD,¹ Carly Sugar, BHSc,^{1,3} and Jaclyn Nofech-Mozes, PhD, CPsych¹

Journal of Health Psychology
2021, Vol. 26(1) 82–102
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FACILITATOR Guide

1

Well-Beans for Caregivers Programme*



Session 1: What matters most to you?

* A three-session well-being programme for caregivers of children with developmental delays, disabilities and/or disorders. Adapted from the Caregiver Well-being Module of the World Health Organization Caregiver Skills Training Programme (CST)

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CAREGIVER Workbook

1

Well-Beans for Caregivers Programme*



Session 1: What matters most to you?

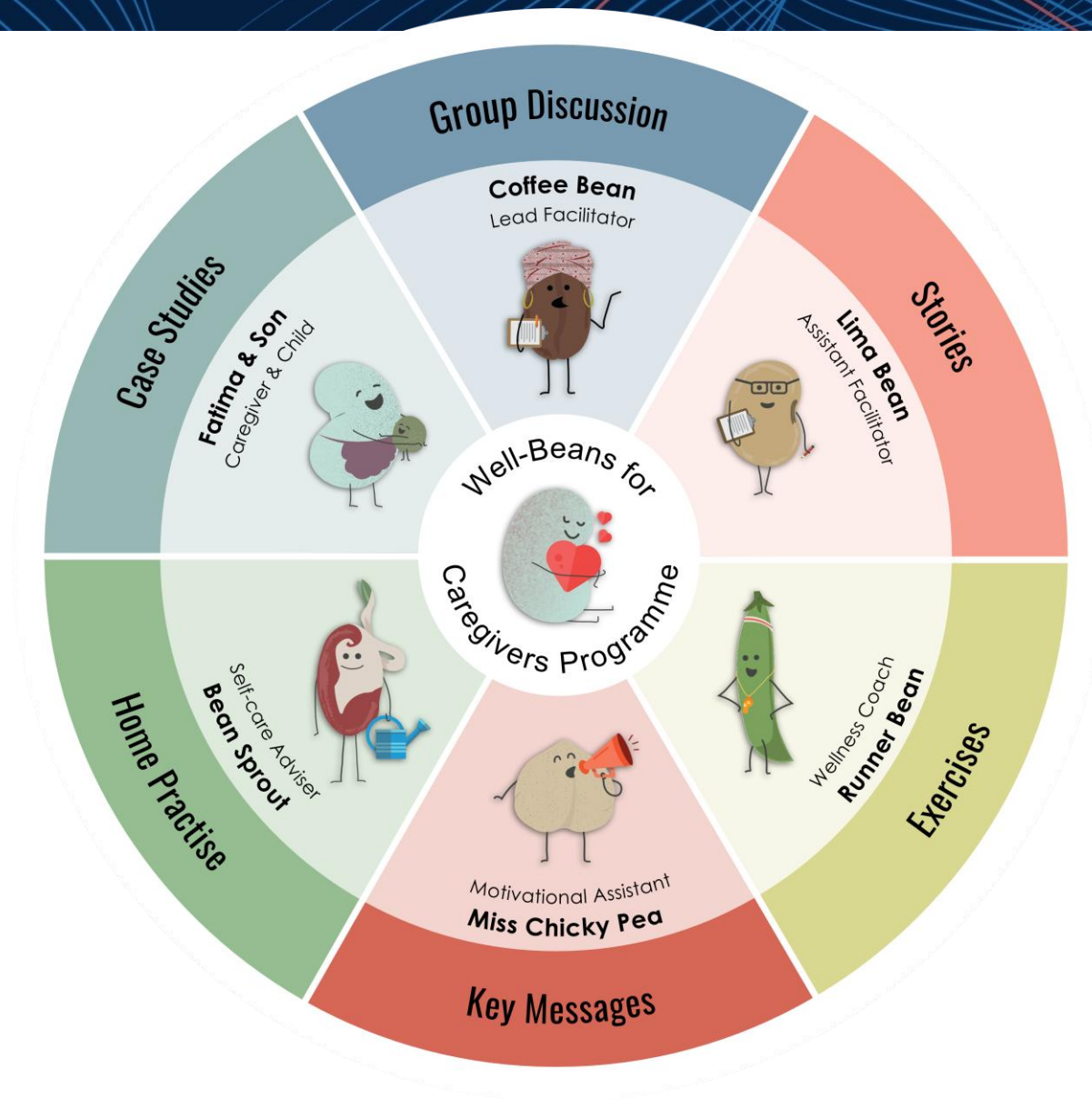
* A three-session well-being programme for caregivers of children with developmental delays, disabilities and/or disorders. Adapted from the Caregiver Well-being Module of the World Health Organization Caregiver Skills Training Programme (CST)

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European
Reference
Networks





EXERCISE 1 : GETTING PRESENT



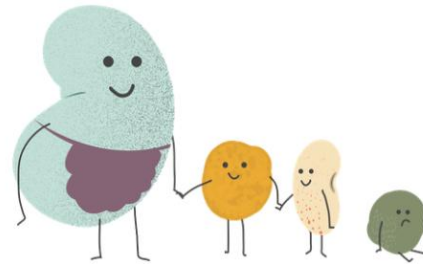
STORY 1: MEET FATIMA



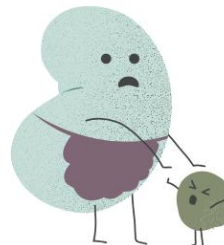
Fatima is a caregiver just like you. In every session we are going to hear about how she has experienced many of the things you may be experiencing right now. Before I introduce a new strategy, we are first going to hear how it applies to Fatima.

These stories will help you understand how each idea or strategy we talk about, can be used to cope with certain problems that might be similar to yours. This will teach you how to apply it to yourself and your family.

Let me tell you a little more about Fatima.



Fatima has three young children.



Her youngest son, Aziz, is 6 years old. He has a lot of difficulties and requires a lot of her time.

EXERCISE 2: IDENTIFYING JOYS AND CHALLENGES



Being a caregiver can bring many joys, as well as many challenges, especially if a child has developmental difficulties.

With these challenges, caregivers can forget to notice the joys.

I'd like you now to spend some moments reflecting on what you enjoy, and what you find difficult about being a caregiver.

This can be about your child with the developmental difficulties, as well as your other children. Think about joys and challenges, not just focusing on one or the other.



I will give you 5 minutes to think by yourself.

- **What do you enjoy about being a caregiver?**
- **What do find difficult about being a caregiver?**

When you are done, we will share as a group.



European
Reference
Networks



KEY MESSAGE 1



1 Being a caregiver *and* having a child with developmental difficulties can bring stress but also many joys

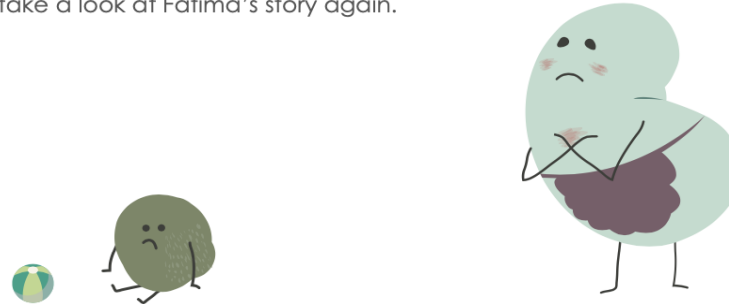
STORY 7: FATIMA'S ACCEPTANCE



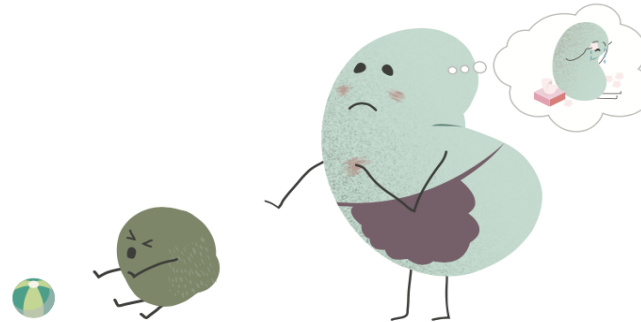
Now we are going to take a look at another strategy that can be helpful for dealing with difficult thoughts and feelings.

We call it acceptance.

Let's take a look at Fatima's story again.



Fatima spends a lot of her energy wishing that Aziz didn't have developmental difficulties. She realises that this isn't very helpful, it causes her a lot of pain, and the situation doesn't change. She heard a lot about this idea of 'acceptance' from other parents. She heard that 'accepting what cannot be changed is a helpful thing to do.'



She never really understood what it meant. Actually, she thought that it sounded kind of like giving up. But she has noticed that some of her thoughts and feelings that are difficult seem to be around things she can't change – like Aziz's challenges. It's natural for sad thoughts and feelings to come up for her about this, but when she focuses on this, it just makes her feel worse and worse, because she can't change the fact that he has these difficulties.

STORY 7: FATIMA'S ACCEPTANCE



She realises that it would be better for her to practise accepting that Aziz does have challenges and then use her energy to help him with learning, as this is one of her values for parenting.

She decides that this might be more helpful than using all of her energy wishing his challenges would go away. Accepting doesn't mean that she likes the situation; it just means that she stops fighting against it in her mind.

She remembers that her thoughts and feelings are similar to the weather – they come and go and change often – but she is not damaged by them. And, just like the weather, fighting against them is not likely to be helpful.

For Fatima, focusing on what she can do for Aziz, for her family, and even for herself, has been much more helpful. Practising acceptance of the difficult things she can't change has improved her well-being and improved her relationships with her family.

Sometimes when she is feeling very stressed, she repeats these three helpful reminders to herself:

1. I am going through a stressful time
2. All people go through stressful times in their lives
3. May I respond with kindness

GROUP DISCUSSION 11: WHAT ABOUT ACCEPTANCE?



The way we use the word **'acceptance'** here means something a little different than the definition that may come to mind.

- Acceptance is not about 'liking' the situation
- Acceptance is not about 'giving up' or 'giving in'
- Instead, it can be seen as a wise approach to a situation where we accept those things that *can't* be changed and rather use our energy on the things that *can* be changed
- It's a willingness to make space for something rather than struggling against it
- It is a process of 'dropping the fight' or 'letting go' of the struggle with your thoughts and feelings and making space for all emotions to come and go
- Not fighting with our experiences frees up energy and allows you to focus on the things you care about
- It is not something that is easy – it takes practise

What do you think about Fatima's experience with 'acceptance'?

Do you try to practise 'acceptance' yourself?

It can be helpful to share with others.

This brings us to Key Message 8.

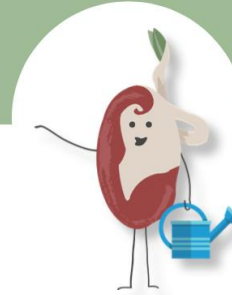


8 Acceptance can be seen as a wise approach to a situation where we cannot easily change the circumstances. We can accept the things we cannot change and rather use our energy on the things that matter to us

HOME PRACTISE: USE YOUR TOOLKIT OF STRATEGIES

I would like to encourage you to:

- Remember the 10 Key Messages
- Use your 'Toolkit of Strategies'
- Keep growing and practising your skills
- When feeling stressed, try to repeat these three helpful reminders to yourself...



1. I am going through a stressful time
2. All people go through stressful times in their lives
3. May I respond with kindness



‘Most useful’ for caregivers

“This was the first session and it was lovely meeting everyone. Most useful for me was hearing we are not alone in this as parents.”

“To use the exercises to help you get back to the present moment.”

“The closing of it - comparing our stresses and problems (thoughts and feelings) to the weather, it changes and shall pass as well.”

“No answer/comment from parents was wrong. Everybody listened, understood and had sympathy. Advice and encouragement were given. It was a positive session (all three were).”

Feedback from facilitators

“Very quick and easy to facilitate and prepare for.”

“There were several exercises and group discussions and along with these, the reflections from the parents made the content lengthy.”

“Very engaged and willing to share their own experiences.”

“They were very willing to share and take part in the conversations.”

Technology lessons learned

Positives

- Reach!
- Optimistic findings of feasibility, acceptability, and potential positive change

Challenges

- Electricity and connectivity
- Scheduling (parents and practitioners)
- Practical considerations (data, sharing a device, when to share materials, video on/off, bandwidth)
- Online group facilitation skills of practitioners

Discussion & Conclusion

- Time for questions



- Satisfaction Survey :
<https://forms.office.com/e/LtrdW8VXaA>
- Website :
 - <https://ern-ithaca.eu>
 - <https://ern-ithaca.eu/webinars/>

*Thank you for your
participation*

ERN ITHACA Satisfaction Survey
Webinar TSC TAND TANDem
Project

