

Empowering families through technology: a mobile health project to reduce the TAND identification and treatment gap (TANDem)



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Background

VIRTUAL CONGRESS

Tuberous Sclerosis Complex (TSC) is a multi-system genetic disorder with a wide range of TSC-associated neuropsychiatric disorders (TAND). TAND is the number one concern to families, but is under-identified and under-treated. We developed a TAND Checklist for clinicians to complete with families. Community-based participatory research identified three priorities: 1) the need for a self-complete, quantified version of the TAND Checklist; 2) to have a checklist as a smartphone app; 3) to receive next-step advice or 'TAND Tips' for management of TAND following completion of the app.

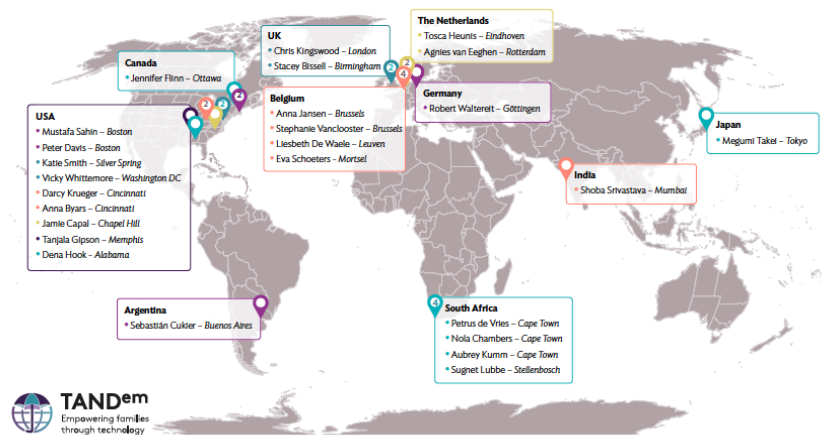
Methods

The TANDem project is an international, multi-stakeholder, community participatory project with three aims.

Aim 1: Development and validation of a quantified, self-complete TAND Checklist (TAND-SQ), designed as a smartphone app

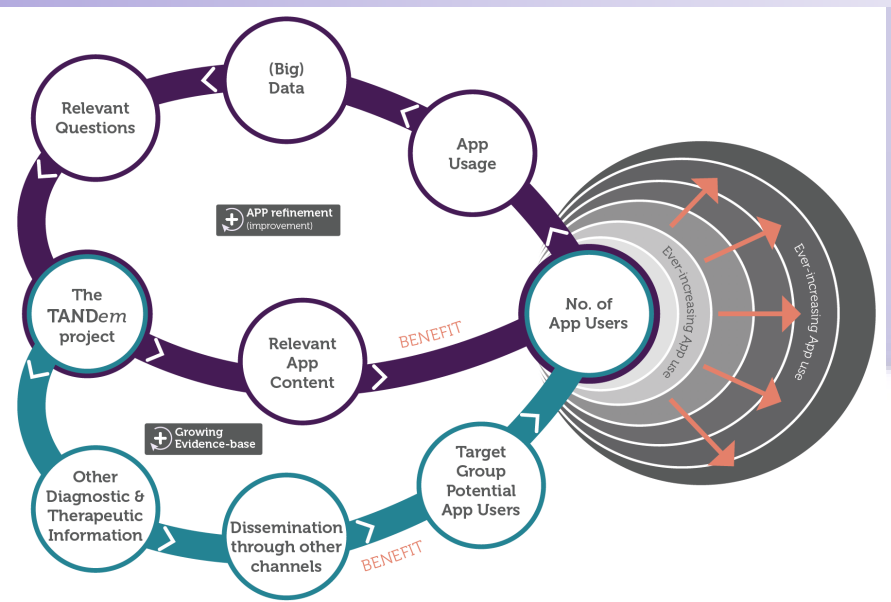
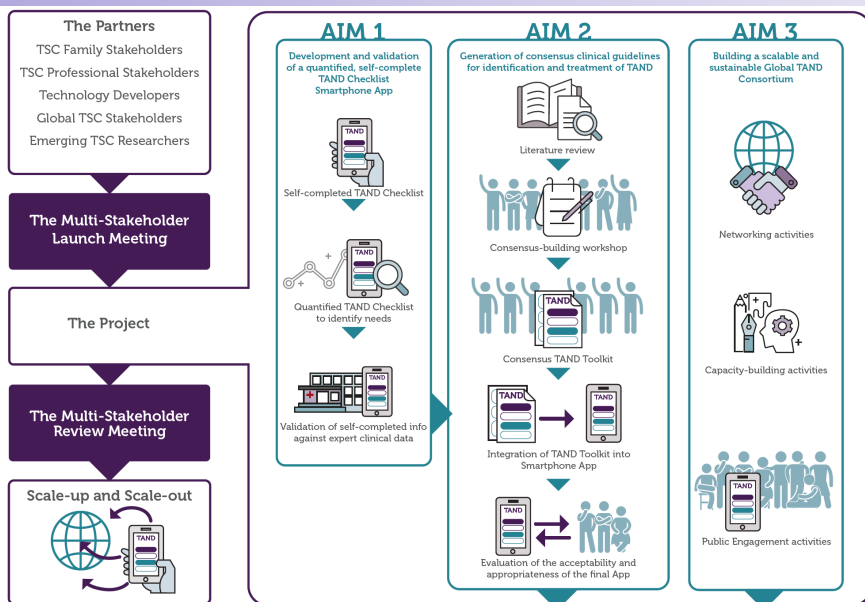
Aim 2: Generation of consensus clinical guidelines for management of TAND clusters, to be incorporated into this app

Aim 3: Development of a Global TAND Consortium through various networking, capacity-building and public engagement activities



The TANDem project plan

The TANDem impact loop



Conclusion

A successful project will transform the TAND landscape worldwide by empowering families through an easily accessible digital solution to identify their own TAND needs, and to provide them with consensus guidelines to prevent, treat and manage such needs. In addition, as shown in the TANDem impact loop, the TAND app will become a mechanism for global data collection to guide future TAND research that will optimize the evidence-base for TAND identification and treatment.