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

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BACKGROUND

Tuberous Sclerosis Complex (TSC) is a multi-system genetic disorder with a **wide range of neuropsychiatric difficulties** across different levels. They are the number one concern to families, but are **highly under-identified and under-treated**.

To reduce this identification and treatment gap, we coined the **term 'TAND'** (TSC-associated neuropsychiatric disorders) and developed a **'TAND Checklist'** for clinicians[1-4].

We used TAND Checklist data in an international group of ~500 people with TSC and identified seven robust **natural TAND clusters**[5].

Community-based participatory research next identified three themes:

1. Families liked the TAND Checklist, but wanted a version that they could **complete for themselves**
2. Families were keen to have **quantification** of difficulties
3. Families wanted the TAND Checklist on a **digital platform** such as smartphone or iPad, and that the information entered should be **connected to advice on next-step interventions** for TAND.

AIMS

The TANDem project has **3 main aims: (Figure 1)**

1. Development and validation of a quantified, self-complete TAND Checklist (TAND-SQ), designed as a **Smartphone 'App'**.
2. Generation of **consensus clinical guidelines** for treatment of TAND clusters, to be incorporated into the TAND App.
3. Development of a **Global TAND Consortium** through a range of networking, capacity-building and public engagement activities.

STAKEHOLDERS

The TANDem project will bring together a wide group of stakeholders, including

- TSC family and professional stakeholders
- technology developers
- global TSC stakeholders
- emerging TAND researchers

RESEARCH APPROACH

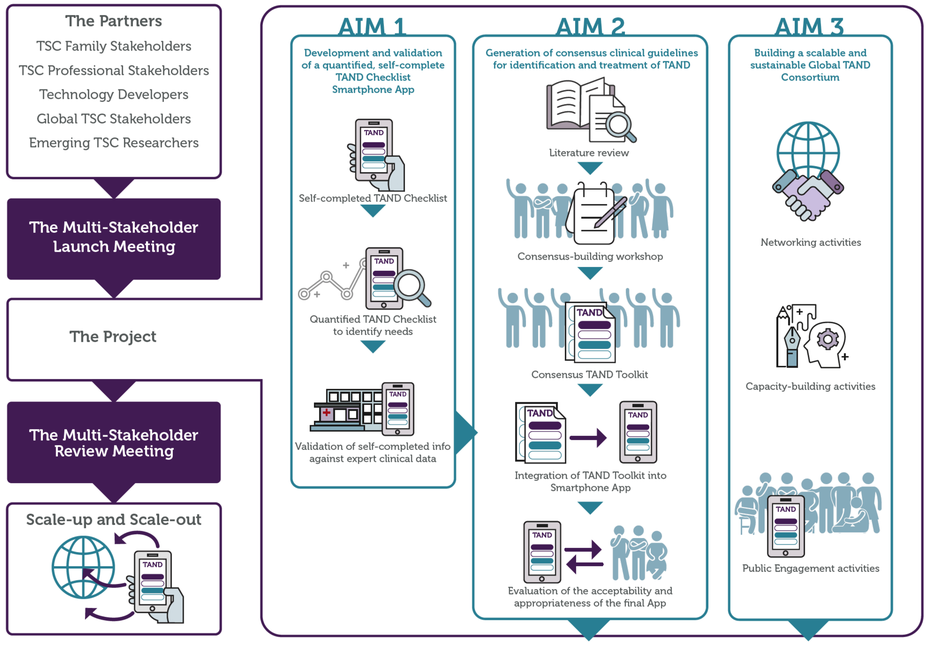

Figure 1: The TANDem project plan

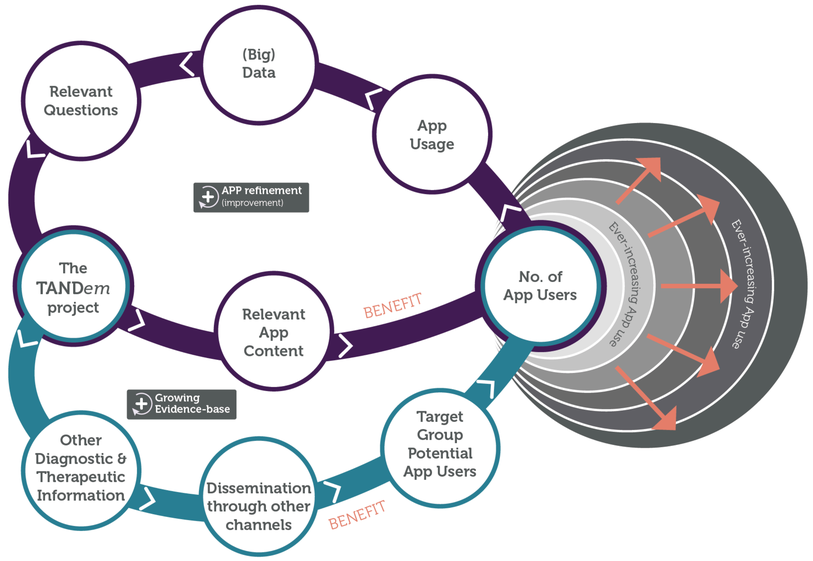

Figure 2: Impact loop of the TANDem project

CONCLUSIONS

A successful project will add to existing knowledge in multiple ways as based on the three aims.

Our overarching proposal is that a self-complete, quantified TAND Checklist (TAND-SQ) and **Smartphone App** will be a tool to empower families who live with TSC around the world by putting existing knowledge about identification and treatment of TAND in their hands.

We propose that the App, once developed and validated with a **TAND toolkit** embedded into it, will also become a mechanism for **global data collection** about TAND that can guide **future TAND research** and can continue to optimize the evidence-base for TAND treatment by the **global TAND Consortium** which we will establish and nurture. **(Figure 2)**

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