

Online Remote Behavioural Intervention for Tics (ORBIT): A Preliminary Update

NIHR Health Technology Assessment

Dr Beverley J Brown
aka Dr Rocket



WHAT ARE TICS AND TOURETTE SYNDROME?

Tics are abrupt, purposeless, automatic movements (motor tics) or sounds (vocal tics)

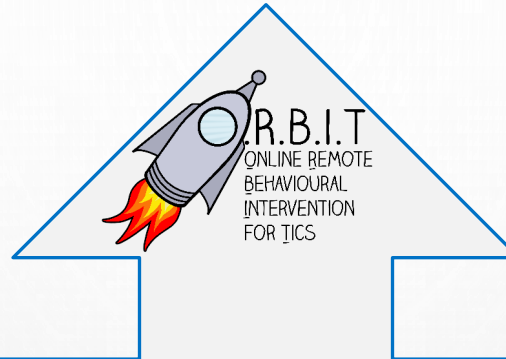
- 'Urge' may be felt prior to a tic – also known as a premonitory urge (PMU)

Tourette syndrome (TS) most well-known tic condition

- Motor & vocal tics for >1 year
- ~70,000 children & young people (CYP) in England have TS
- Mean age of onset - 7 years²



TREATMENT OF TICS?



Treatment for tics² – varies across UK:

- Medication
- Behavioural therapy (BT), e.g. Exposure & Response Prevention (ERP)
- Only 1 in 5 of those with TS/tics in the UK are able to access behavioural therapy
- Lack of trained therapists in Behavioural interventions
- Very few specialist clinics (London and Nottingham)
- Lack of trained therapists)
- Currently no NICE guidelines. HTA synthesis recommends BT should be offered as first line treatment in a stepped approach.

THE RESEARCH QUESTION

NIHR HTA 16/19



ORBIT: What is the clinical and cost-effectiveness of a therapist supported online-delivered behavioural intervention for tics in children and young people compared to therapist supported online-delivered education?

WHAT'S THE INTERVENTION?

Two online remote behavioural interventions – 10 chapters over 10 weeks

Exposure with Response Prevention (ERP)

- Breaking the urge-tic-relief cycle through training **to resist the urge to tic**
- Allow tic urge to become as strong as possible – and then withholding the tic for as long as they can
- **Gaining control over tics** through behavioural practice

Psychoeducation

- Increasing knowledge about tics
- Taking steps to inform others about tics
- Increase understanding and change beliefs
- **Becoming an expert in tics**



Child and their Supporter each have their own intervention accounts

THERAPIST AND SUPPORTER INVOLVEMENT



Therapist



Child



Supporter

Therapist checks in weekly with YP & supporter:

- Respond to messages
- Check their responses to questions presented in intervention
- Monitor ERP practice **OR** learning processes (psychoeducation)
- Encouragement & addressing barriers to progress

Supporter completes their own intervention:

- Compliments what YP is learning - can help them with their intervention
- Parenting and lifestyle factors affecting tics
- How to support YP in ERP practice **OR** support them in learning new knowledge & completing their 'missions'

SETTING & RECRUITMENT

2 sites:

Nottingham (Queen's Medical Centre) and
London (Great Ormond Street Hospital)

Nottinghamshire Healthcare
NHS Foundation Trust

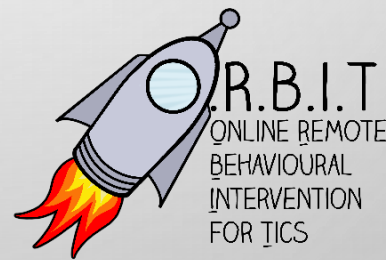


Great Ormond Street
Hospital for Children
NHS Foundation Trust



Referrals:

- Multiple NHS Trusts act as Patient Identification Centres (PIC)
- Participants also self-refer via Tourette's Action and the study website



TARGET POPULATION

220 participants aged 9-17 years with TS or chronic tic condition (CTC).

Main inclusion criteria:

- Presence of Tics
- Assessed using a standardised measure
Yale global Tic Severity Scale (YGTSS)

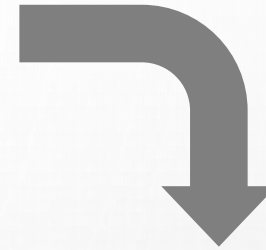
Exclusion criteria:

- Behavioural intervention for tics within last 12 months
- Change of medication for tics within previous 2 months
- Diagnosis of alcohol/ substance dependence, psychosis, suicidality
- Moderate/severe intellectual disability
- Parent/ child unable to read/ speak English



Study design

**Recruitment –
across the 2 Sites
(referred by PICS or
TA)**



**Consent to contact
received & initial
telephone Screening
carried out**



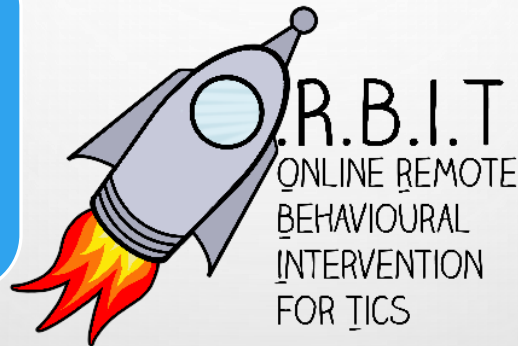
**Further Screening
(DAWBA) &
baseline
appointment
booked**



**Attend face to face
appointment –
consent & Baseline
Measures collected**



**If pass full baseline
assessment
randomised into
trial – allocated
intervention**



Study design...

**Follow up 1 – mid-treatment measures
@ 3 & 5 weeks –
online only**



**Follow up 2 –
Primary endpoint
(3 months) primary
& secondary
outcome measures**



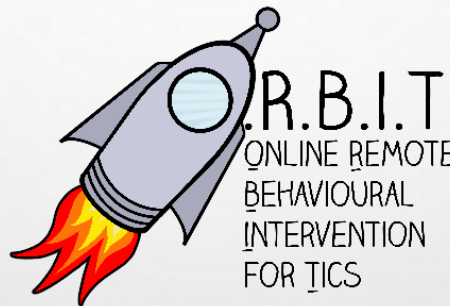
**Follow up 3 – (6
months) primary &
secondary outcome
measures**



**Follow up 4 – (12
months) primary &
secondary outcome
measures**



**Follow up 5 – (18
months) primary &
secondary outcome
measures**



OUTCOME MEASURES



Primary outcome measure:

- Yale Global Tic Severity Scale (YGTSS) Total Tic Severity Score (0-50) questionnaire

This questionnaire is administered by a blinded assessor, it is a semi-structured interview focussing on motor and vocal tic frequency and severity over the previous 7 days.

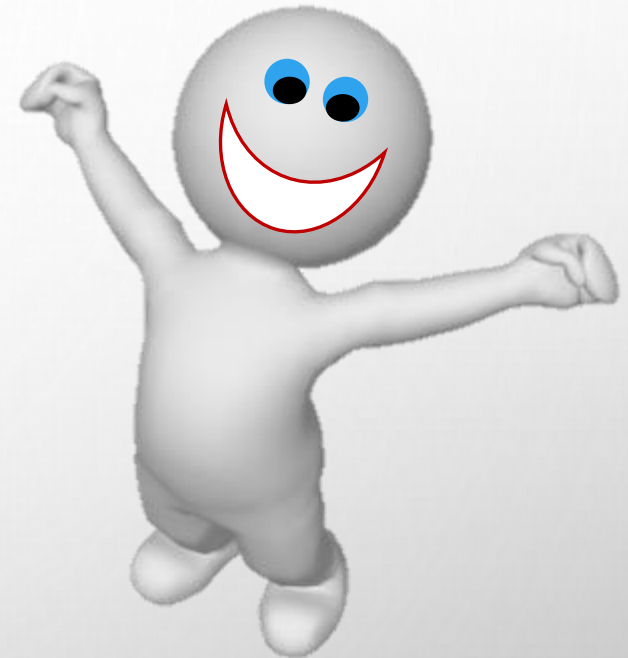
- Also contains a measure of impairment (0-50)
- We also collect a range of secondary measures

Internal Pilot and Key Dates

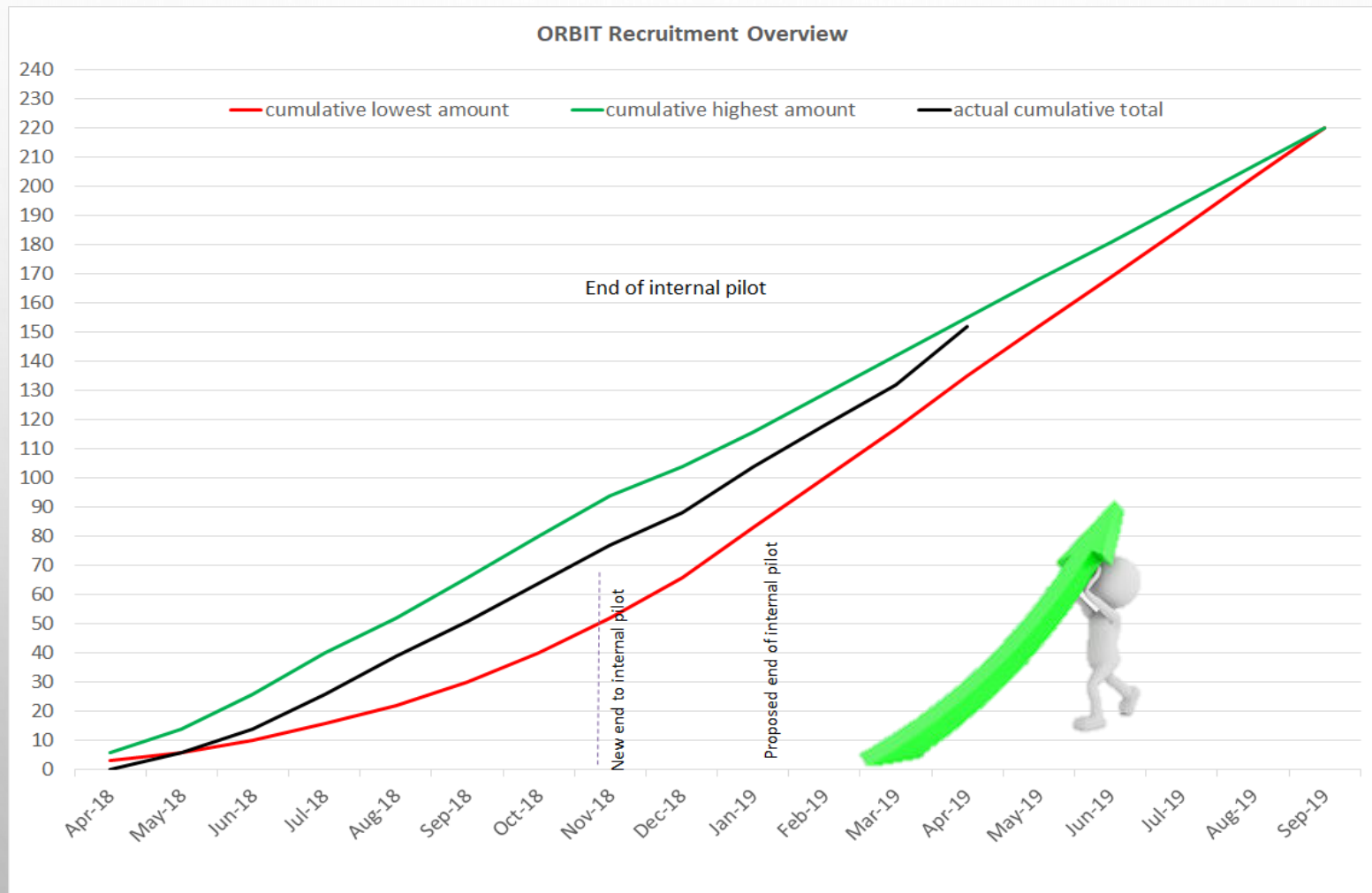
The trial was evaluated 9-months into recruitment by the Trial Steering Committee (TSC).

The study needed to have:

1. Recruited 66 patients by January 2019 – met pilot end of October 2018.
2. At least 60% of participants need to have completed the interventions.
3. 80% of participants need to have completed the primary outcome measure (Tic questionnaire) at the primary end point (3-months).



PROGRESS...



Recruitment (Notts & GOSH) 180/220

Therapy completion

92% 8.1/10 chapters



Midpoint measures 3 & 5 weeks - online

3 weeks – YP = 89% & S = 93%

5 Weeks – YP = 87% & S 89%



Primary Endpoint (3mnths) & 6 month follow up

3mnths– YP & S = 90%

6 mnths – YP & S = 83%

*Figures are constantly updating and do not include participants who are booked in and awaiting follow up appointments or secondary measure rates
12 Month follow up appointments have only just begun
18 Month follow up appointments begin in October 2019

CURRENT ISSUES

- REFERRALS

- lots of clinic referrals.
- evidence of greater complexity (e.g. behavioural problems/coexisting diagnoses/risk). tics not always the primary concern.
- not always apparent how complex until baseline assessment (affects retention rates)
- **SOLUTIONS**
- Encouraging direct referrals from ta – tics usually primary issue
- thorough screening to assess primary concerns/needs from those referred from clinics
- **Keeping in touch:** rapport, support between follow ups, referrals back to GP/CAMHS. Checking in periodically, personal thank you messages after follow ups etc.



Patient and Public Involvement



When we talk about 'involvement' we mean getting actively involved in the research process itself rather than being the participants or subjects of the research.

Public involvement in research is defined as research that is done with or by the public and not to, about, or for them (Involve www.invo.org.uk).



ORBIT Team



*National Institute for
Health Research*

Chief investigator: Prof Chris Hollis

Nottingham (Trust)

- Joe Kilgariff
- Liam Chamberlain
- Caitlin Hand
- Angela Summerfield

Nottingham (University)

- Dr Charlotte Hall
- Dr Bethan Davies
- Dr Beverley J Brown
- Prof Cris Glazebrook
- Dr Jen Martin
- Dr Sue Brown
- Dr Michael Craven
- Kareem Khan

Great Ormond Street Hospital

- Dr Tara Murphy
- Dr Sophie Bennett
- Dr Charlotte Sanderson
- Amber Evans
- Natalie Kouzoupi
- Dr Isobel Heyman

Priment (UCL)

- Prof Elizabeth Murray
- Anne Marie Downey
- Dr Natalia Lago
- Dr Louise Marston
- Rebecca Jones
- Rachel Hunter

Karolinska Institutet

- Per Andrén
- Prof David Mataix-Cols
- Prof Eva Serlachius

Trial Steering Committee:

Chaired by Prof Edmund Sonuga-Barke

**Data Monitoring and Ethics
Committee:**

Chaired by Prof Stephen Scott

ACKNOWLEDGEMENTS

A horizontal bar composed of several colored segments: green, dark green, orange, purple, red, and blue.

Thank you to the organisers of the CANDAL conference and for inviting us to deliver a talk on our research today!

This research was funded by the NIHR Health Technology Assessment (ref 16/19/02). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

Thank you to all those involved in the ORBIT research – families, colleagues, TA, PPI committee, Priment CTU, and the NIHR and the Karolinska Institute

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Thank you for listening



ADDENDUM: ADDITIONAL INFO ON SECONDARY MEASURES



Secondary outcome measures: *(researcher rated, parent rated and young person rated)*

- Parent tic questionnaire
- Global measures of functioning (CGAS and CGI)
- Various questionnaires to assess - Moods and Feelings, Child Anxiety, Quality of life, Treatment credibility and satisfaction
- Concomitant interventions (changes in treatments)
- Side effects
- Service resource use (e.g. visits to healthcare professionals etc)