SUMMARY OF RESEARCH FROM DOCTORATE ON THE DEVELOPMENT OF A SELF-HELP TOOL TO SUPPORT WELLBEING IN YOUNG PEOPLE WITH TICS
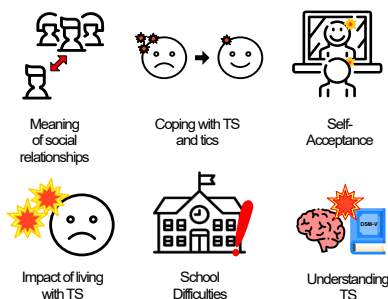
University of Nottingham
UK | CHINA | MALAYSIA

Tourettes action

Study 1: Summary of Interviews with Young People with Tics

KEY
- YP - Young People
- ■ - Young Person
- ■ - Parent/guardian
- ✿ - Tic

RATIONALE

Qualitative Review Findings:

- Meaning of social relationships
- Coping with TS and tics
- Self-Acceptance
- Impact of living with TS
- School Difficulties
- Understanding TS

Previous Research Findings:

No interventions for YP with tics to support wellbeing

Unguided self-help tools for YP with depression, anxiety or social difficulties were effective
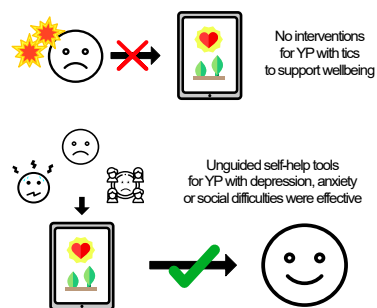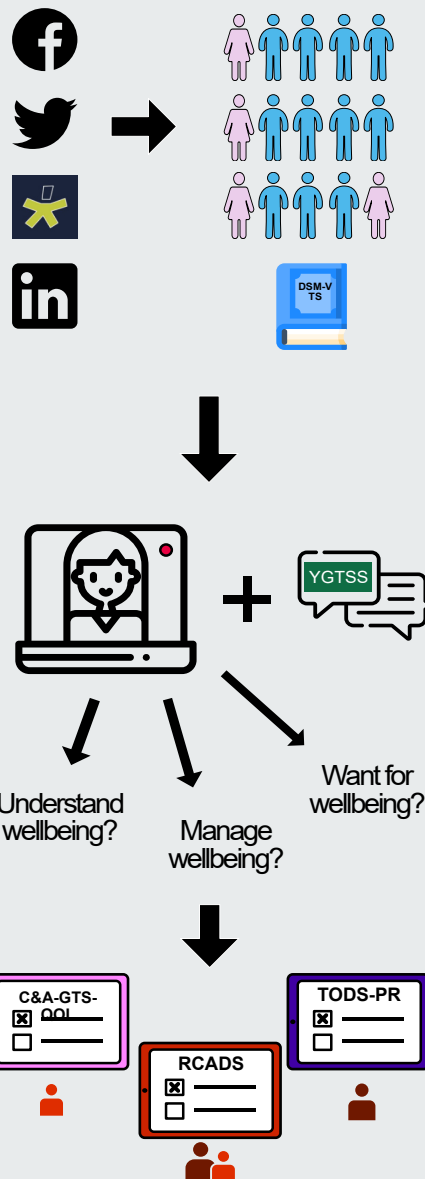
Research Questions

1. How do YP with TS understanding wellbeing?
2. What do YP with TS do to improve their wellbeing?
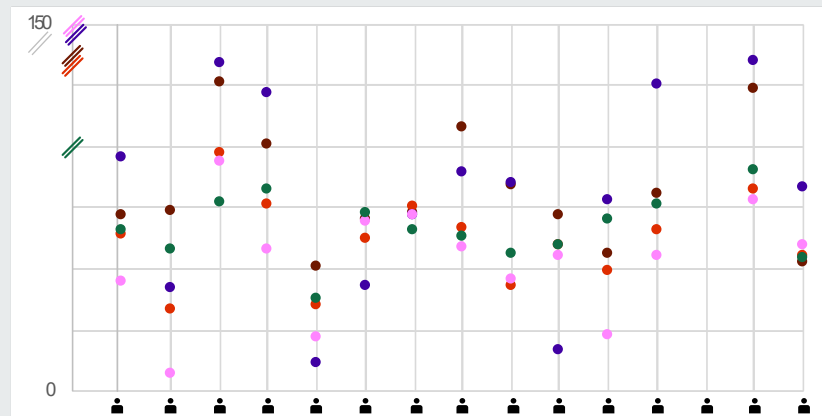3. What would YP with TS find useful in a DHI to improve wellbeing?

METHODS

DSM-V TS

Understand wellbeing?   Manage wellbeing?   Want for wellbeing?

C&A-GTS-QOL   RCADS   TODS-PR

Measures of tic-related quality of life, depression and anxiety, tic-impairment, behavioural and emotional issues.
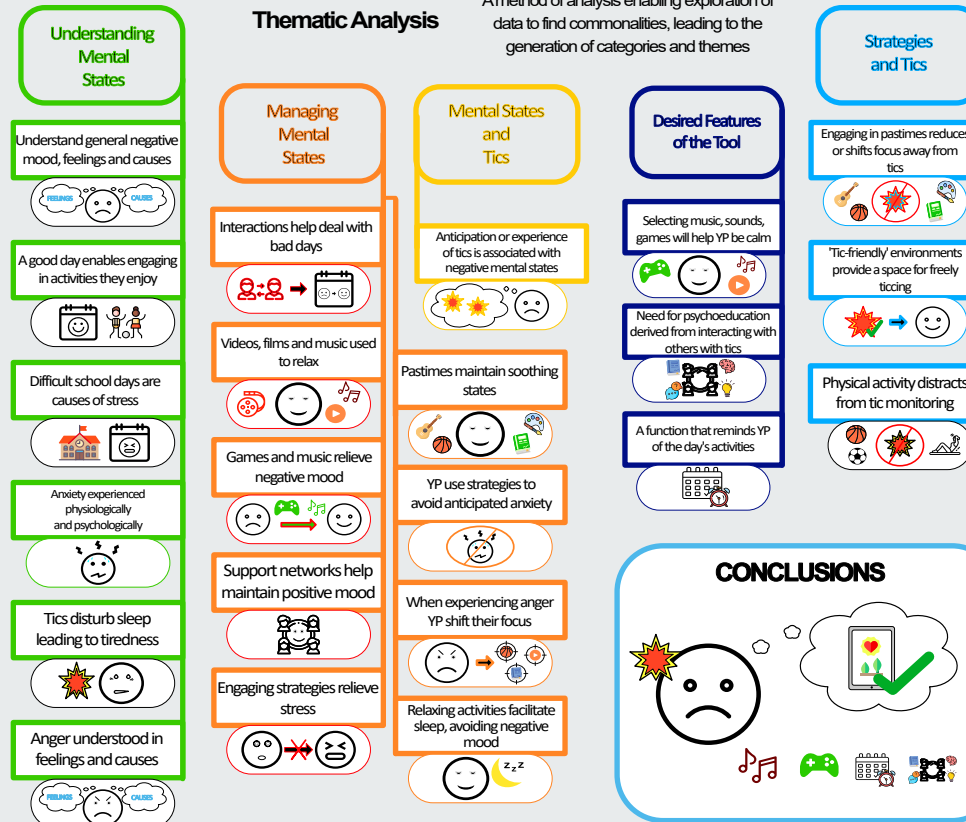
FINDINGS

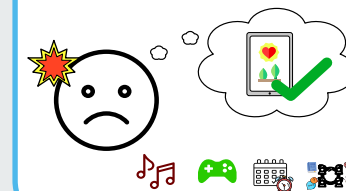Scores from the TODS-PR, RCADS and C&A-GTS-QOL

Thematic Analysis
A method of analysis enabling exploration of data to find commonalities, leading to the generation of categories and themes
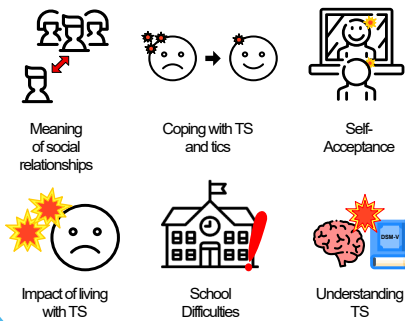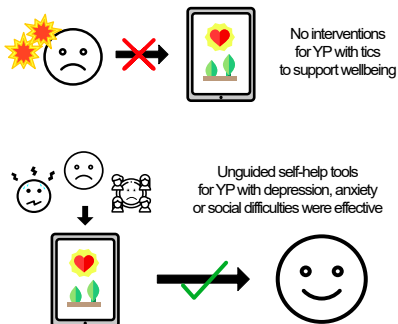
Understanding Mental States
- Understand general negative mood, feelings and causes
- A good day enables engaging in activities they enjoy
- Difficult school days are causes of stress
- Anxiety experienced physiologically and psychologically
- Tics disturb sleep leading to tiredness
- Anger understood in feelings and causes

Managing Mental States
- Interactions help deal with bad days
- Videos, films and music used to relax
- Games and music relieve negative mood
- Support networks help maintain positive mood
- Engaging strategies relieve stress

Mental States and Tics
- Anticipation or experience of tics is associated with negative mental states
- Pastimes maintain soothing states
- YP use strategies to avoid anticipated anxiety
- When experiencing anger YP shift their focus
- Relaxing activities facilitate sleep, avoiding negative mood

Desired Features of the Tool
- Selecting music, sounds, games will help YP be calm
- Need for psychoeducation derived from interacting with others with tics
- A function that reminds YP of the day's activities

Strategies and Tics
- Engaging in pastimes reduces or shifts focus away from tics
- 'Tic-friendly' environments provide a space for freely ticcing
- Physical activity distracts from tic monitoring

CONCLUSIONS

Study 2: Summary of Interviews with Professionals who work with Young People with Tics
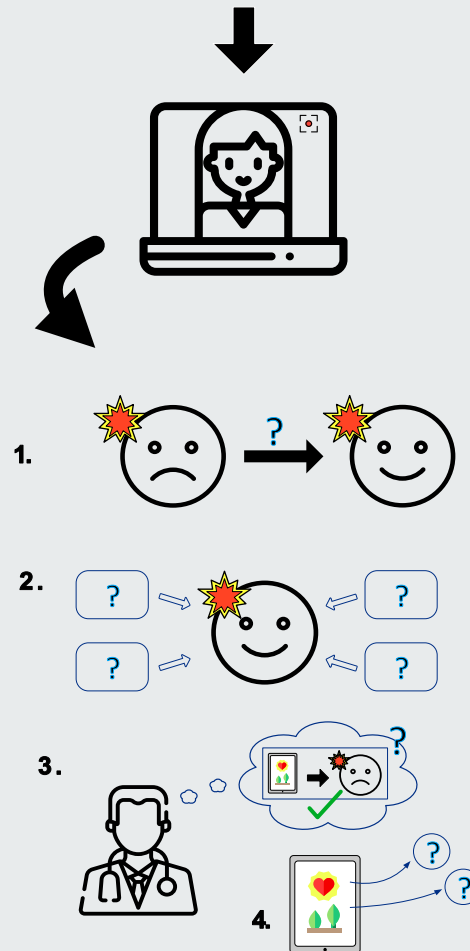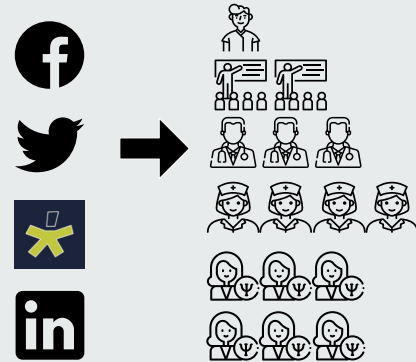
RATIONALE

Qualitative Review Findings:

Meaning of social relationships

Coping with TS and tics

Self-Acceptance

Impact of living with TS

School Difficulties

Understanding TS

Previous Research Findings:

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Unguided self-help tools for YP with depression, anxiety or social difficulties were effective

Research Questions

1. How do professionals perceive wellbeing in YP with tics?
2. What do professionals think determines wellbeing in YP with tics?
3. What strategies do professionals think would be useful for YP to manage wellbeing?
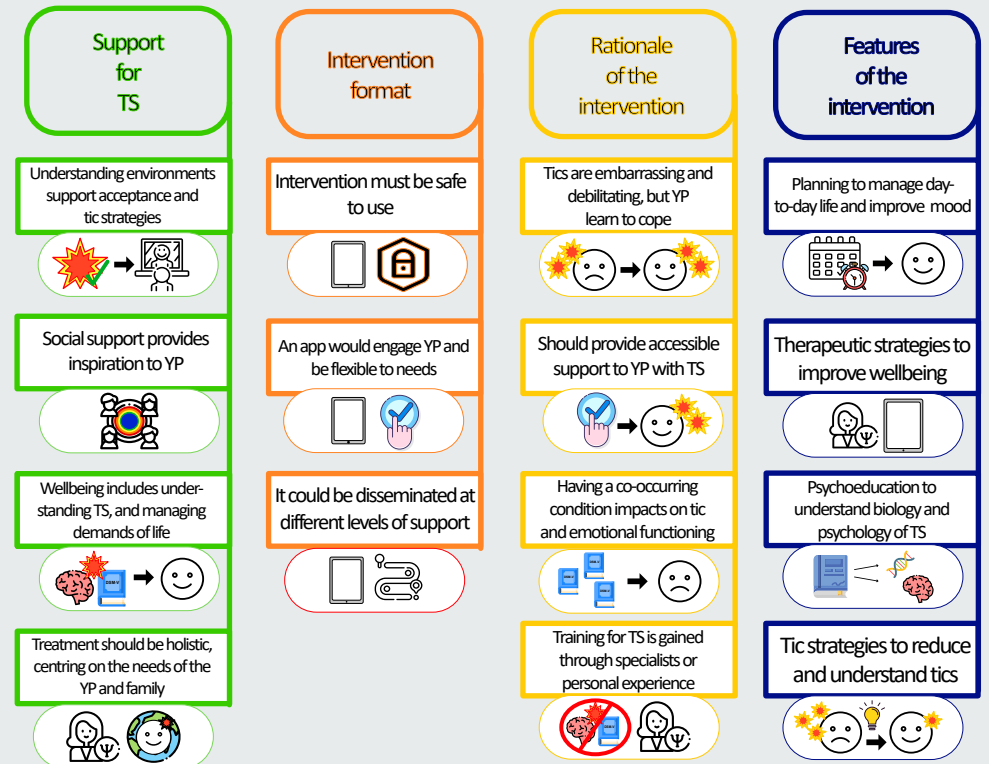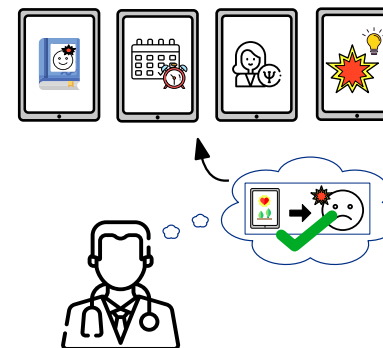4. What would be important in determining whether a DHI is acceptable for professionals?
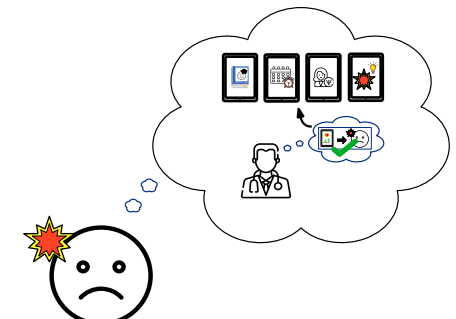
METHODS

1.

2.

3.

4.

FINDINGS

Thematic Analysis

A method of analysis enabling exploration of data to find commonalities, leading to the generation of categories and themes

Support for TS

- Understanding environments support acceptance and tic strategies
- Social support provides inspiration to YP
- Wellbeing includes understanding TS, and managing demands of life
- Treatment should be holistic, centring on the needs of the YP and family

Intervention format

- Intervention must be safe to use
- An app would engage YP and be flexible to needs
- It could be disseminated at different levels of support

Rationale of the intervention

- Tics are embarrassing and debilitating, but YP learn to cope
- Should provide accessible support to YP with TS
- Having a co-occurring condition impacts on tic and emotional functioning
- Training for TS is gained through specialists or personal experience

Features of the intervention

- Planning to manage day-to-day life and improve mood
- Therapeutic strategies to improve wellbeing
- Psychoeducation to understand biology and psychology of TS
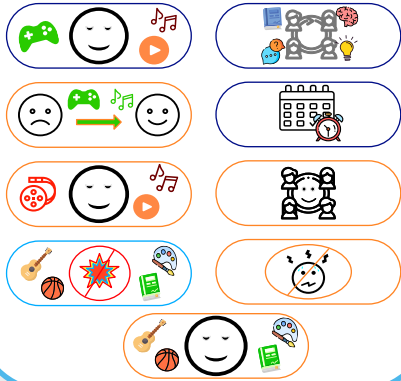- Tic strategies to reduce and understand tics

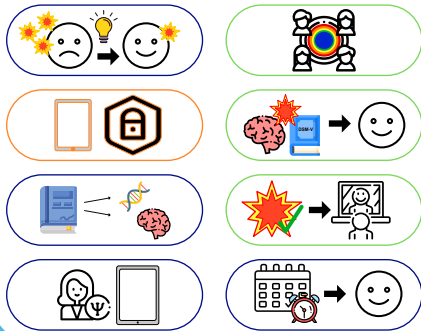## CONCLUSIONS

Future Research

Study 3: Summary of Focus Groups with Young People with Tics and their Parents

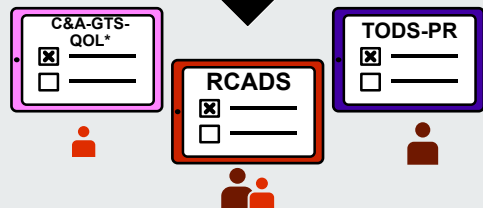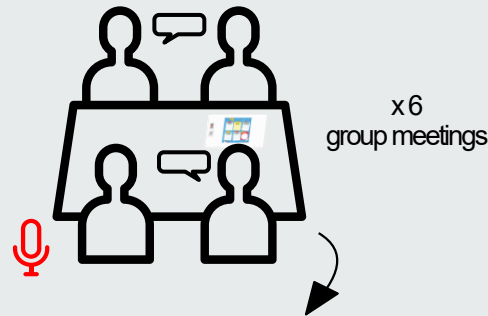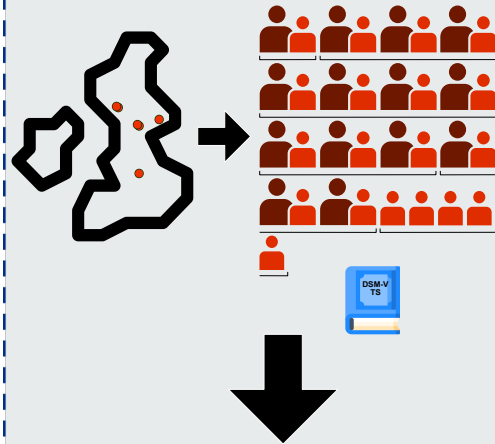## RATIONALE

YP Interview Findings

Mental Health Professional Interview Findings

Research Questions

1. Do YP and parents support the previously proposed features?

2. How do YP and parents think the features should look?

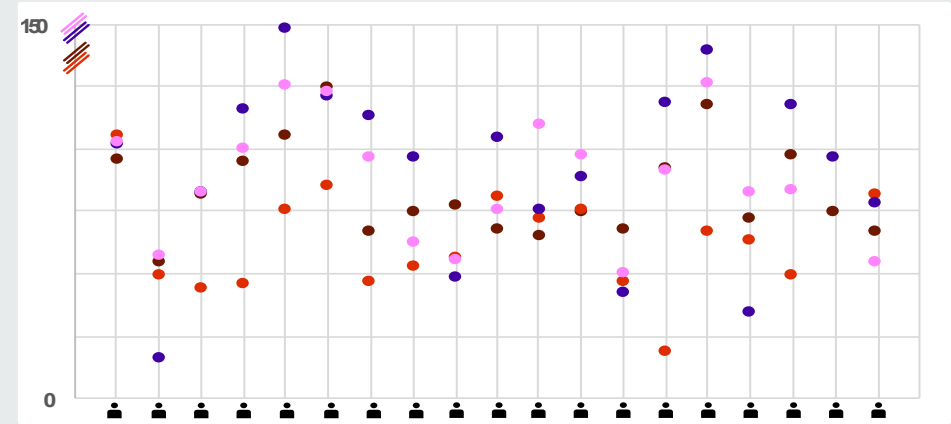3. What are YP and parents experiences of living with tics?

METHODS

x6 group meetings

C&A-GTS-QOL*	RCADS	TODS-PR

Measures of tic-related quality of life, depression and anxiety, tic-impairment, behavioural and emotional issues.
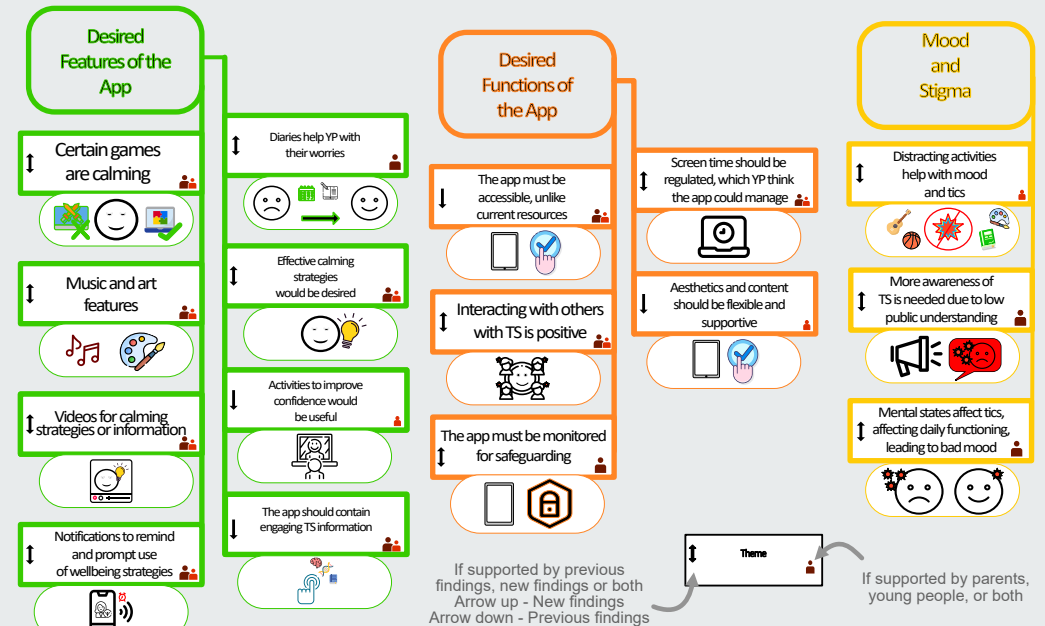
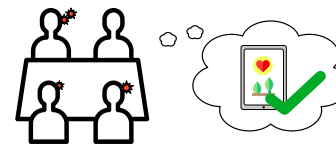## FINDINGS

Scores from the TODS-PR, RCADS and C&A-GTS-QOL

Hybrid Thematic Analysis

A method of analysis which integrates previous findings with new findings, so that commonalities can be identified
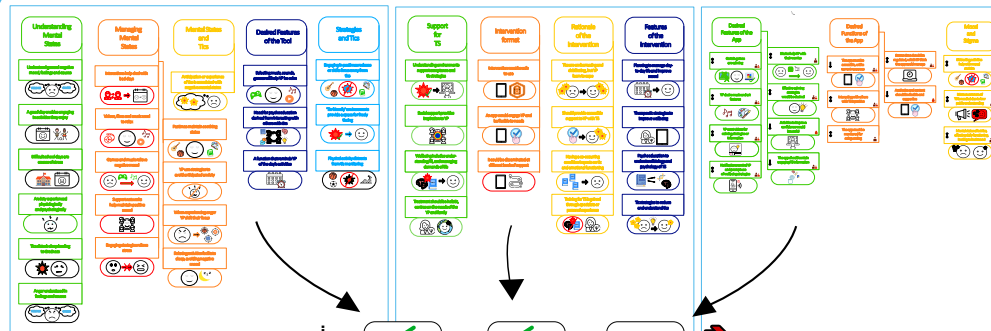
Desired Features of the App

- Certain games are calming
- Music and art features
- Videos for calming strategies or information
- Notifications to remind and prompt use of wellbeing strategies
- Diaries help YP with their worries
- Effective calming strategies would be desired
- Activities to improve confidence would be useful
- The app should contain engaging TS information

Desired Functions of the App

- The app must be accessible, unlike current resources
- Interacting with others with TS is positive
- The app must be monitored for safeguarding
- Screen time should be regulated, which YP think the app could manage
- Aesthetics and content should be flexible and supportive

Mood and Stigma

- Distracting activities help with mood and tics
- More awareness of TS is needed due to low public understanding
- Mental states affect tics, affecting daily functioning, leading to bad mood

If supported by previous findings, new findings or both
Arrow up - New findings
Arrow down - Previous findings

Theme

If supported by parents, young people, or both

CONCLUSIONS

Study 4: Summary of Online Focus Groups with Young People with Tics and their Prents

RATIONALE

Previous Findings
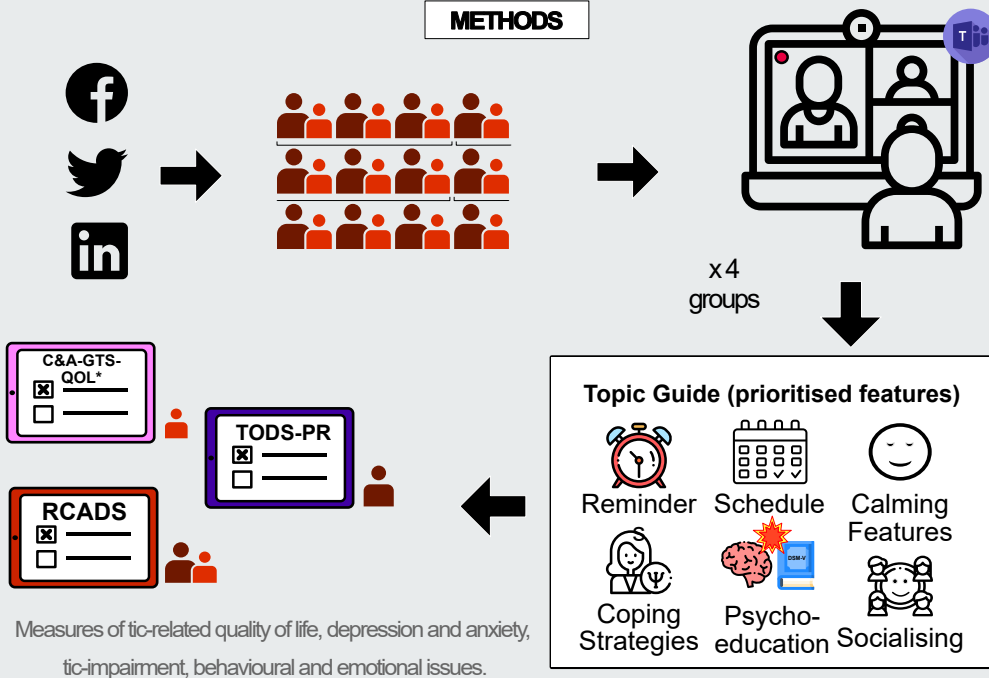

Prioritsation

i. ✔ ✔ ⬜ ➡
ii. ⬜ ⬜ ✔ ➡
iii. ✔ ⬜ ✔ ➡
iii. ✔ ✘ ⬜ ✘

If similar themes were found to support features across methods, they were explored further in the next study
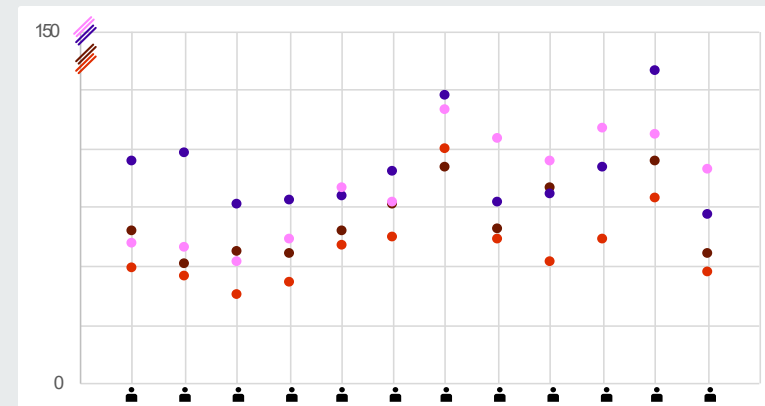
Research Questions

1. What features are most important?
2. What types of features are most important?
3. How should desired features look and function?

METHODS

x 4 groups

C&A-GTS-QOL*

TODS-PR

RCADS

Measures of tic-related quality of life, depression and anxiety, tic-impairment, behavioural and emotional issues.

Topic Guide (prioritised features)

Reminders · Schedule · Calming Features
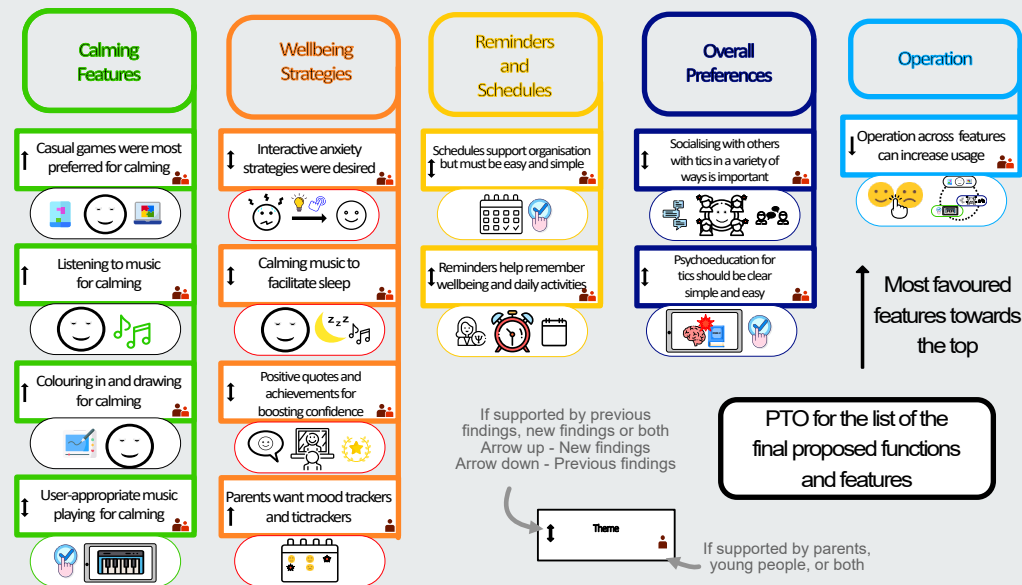Coping Strategies · Psycho-education · Socialising

FINDINGS

Scores from the TODS-PR, RCADS and C&A-GTS-QOL

Hybrid Thematic Analysis

A method of analysis which integrates previous findings with new findings, so that commonalities can be identified

Calming Features
- ↑ Casual games were most preferred for calming
- ↑ Listening to music for calming
- ↑ Colouring in and drawing for calming
- ↓ User-appropriate music playing for calming

Wellbeing Strategies
- Interactive anxiety strategies were desired
- Calming music to facilitate sleep
- Positive quotes and achievements for boosting confidence
- Parents want mood trackers and tictrackers

Reminders and Schedules
- Schedules support organisation but must be easy and simple
- ↑ Reminders help remember wellbeing and daily activities

Overall Preferences
- Socialising with others with tics in a variety of ways is important
- Psychoeducation for tics should be clear simple and easy

Operation
- ↓ Operation across features can increase usage

↑ Most favoured features towards the top

If supported by previous findings, new findings or both
Arrow up - New findings
Arrow down - Previous findings

PTO for the list of the final proposed functions and features

↕ Theme

If supported by parents, young people, or both

CONCLUSIONS

The proposed features have been supported across methods, by YP and parents. The proposed functions identify ways the intervention should work to keep YP with tics safe and to increase the accessibility of the intervention. Combined with behavioural theory, these findings will lead to the development of guiding principles which are theory, evidence and person-based, to support the development of an intervention that will support YP with tic's wellbeing.

Final proposed functions and features of an app top support wellbeing in YP with TS

Proposed Functions
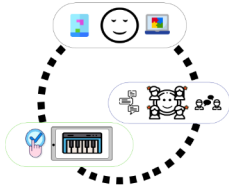
Features should link between each other

Features should be accessible

The app should be personalised

The app should be safe

The app should monitor screentime

Proposed Features

Schedules and reminders help with daily activities

Learning about TS via animation videos would be helpful

Music supports as a sleep facilitating activity

Socialising with others with TS helps to normalise experiences and share perspectives

Casual games and music act as calming strategies

Learning about TS from others with TS would be helpful

The app should include strategies for anxiety

If you would like to have an online copy of this, ask any more questions about the research, or view the thesis, please don't hesitate to get in touch with me at my email: Camilla.Babbage@nottingham.ac.uk.

Finally, I would like to share the acknowledgements section of my thesis, to thank those who have been so wonderful in supporting me over throughout this research.

Acknowledgements

Firstly, I would like to thank my supervisors, Elena and Georgina, for dedicating their time and giving me the opportunity to complete this PhD. We could never have anticipated this last year, but I am so grateful for your ongoing encouragement and have valued learning from you both. Secondly, to the ESRC, who have provided me with resources, training and helped to make me feel part of a research community. Further, to Tourette's Action, who have been so supportive and welcomed me open-armed. I am so thankful to have had the opportunity to work with you, have adored attending your events, especially TicFest, and wholeheartedly hope this research can be of benefit to the aims of the charity.

I would like to dedicate this PhD to the tic-community, who are at the very centre of this project. I have been humbled by those who have accepted me into their groups, who reached out to me at various points, and who have shown interest in this work. When times were tough, it was you guys who spurred me on. A special thanks to the Group Leaders and friends, Kim, Bev, Tracy, Carole, Linden and David, your support meant so much. I'd also like to thank all the participants who were involved in the research, who gave their time and effort because you saw value in this research area.

Special thanks go to the MindTech team, who's inspiring and upbeat attitude never went amiss. In particular, to Bethan Davies, who has been a real mentor to me throughout, thank you. I am also grateful to Ellen Simpson and Madeleine Roche for their assistance in the research projects. I also can't forget those at the Institute of Mental Health, my wonderful IMH ADAPT group and colleagues there, who have all brought me such camaraderie, joy and understanding throughout the PhD, you guys always gave me the boost I needed.

Finally, some personal notes, I would like to thank my wonderful friends, who have seen me journey through one part of education or another..! I am so privileged to have had these opportunities to learn, but who'd have thought the greater privilege would be meeting you all. Thank you for sticking through with me. A huge shout out to my family and those lost along the way, I really hope to make you proud and love you all very much. Last, but definitely not least, thank you to Craig Scott (and Bembe Babbage). You've been the best workmates I could have asked for, even before lockdown. I couldn't have done it without you, thank you for helping me see it through, ensuring I mostly keep my eyebrows, and I can't wait to be doctors together.