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Development of a self-help app for young people with Tourette Syndrome for the management of wellbeing

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 @teens_tics_tech

Tourettes 
action

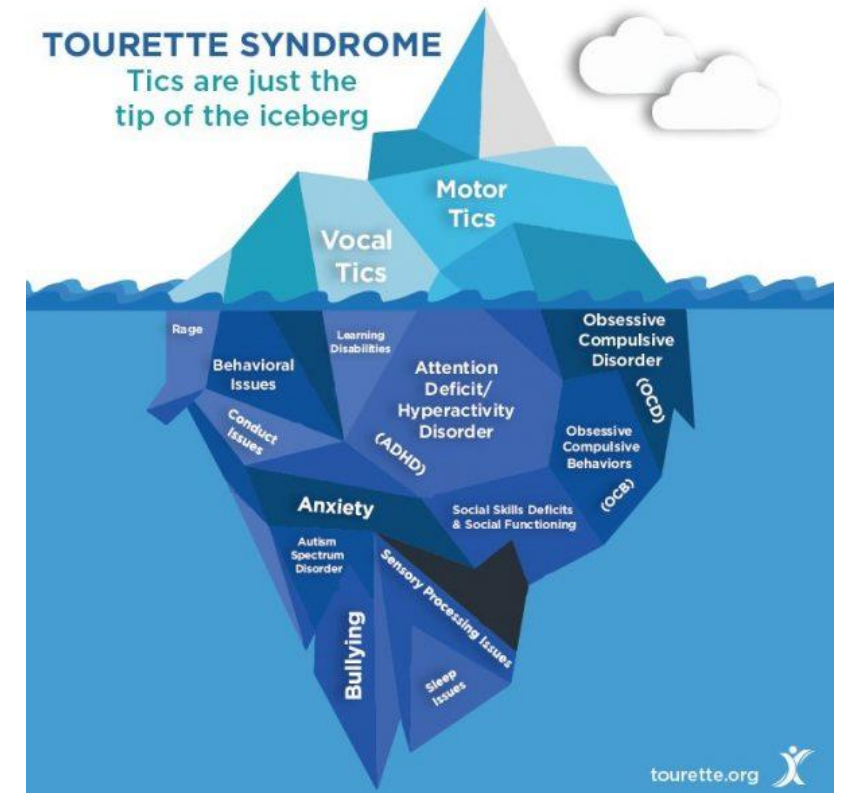


Background: Tourette Syndrome



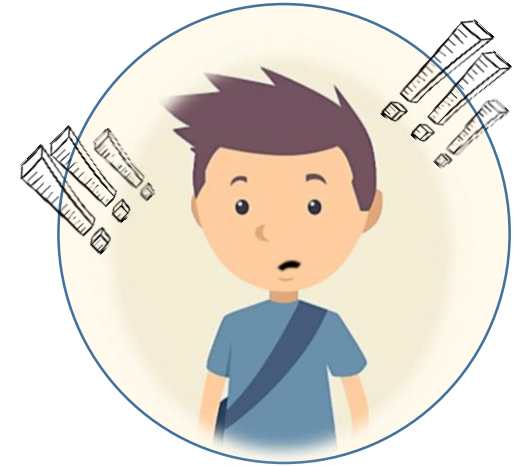
90%

<https://www.youtube.com/watch?v=dXGWwlgvU9M>



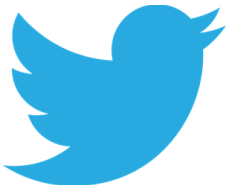
Research Questions

1. What is young people with tics understanding of their wellbeing?
2. What techniques do young people with tics use to improve their wellbeing?
3. What features would young people with tics desire on an app to improve their wellbeing?





Method: Recruitment



Camilla Babbage @Teens_Tics_Tech · Feb 6
"I actually enjoyed it"

One of my favourite bits of feedback from a 14 year old who "actually" enjoyed being part of the research!
If you know someone or think you may actually enjoy it, sign up here:
buff.ly/2COFVWT

#tics #ticdisorders #tourettes #tourettesyndrome

**RESEARCH INTO TOURETTES**
**YOUNG PEOPLE WITH TICS:
DEVELOPMENT OF A SELF-MANAGEMENT TOOL**
We're looking for young people to tell us what they would want in a technology tool to help them with their wellbeing.



We're looking into developing a technology tool to help young people who have tics with their wellbeing.

We want to ask young people about their good days and bad days, to find out what could be incorporated into such a tool to help their mood.



Who is being asked to take part?

We're looking for 9-17 year olds with a diagnosis of Tourette Syndrome or Tic Disorder, who access and use technology.

What would I be asked to do?

- 1) Complete online forms for consent, personal details and to organise a time to chat
- 2) The chat with your child will last around 1-1.5 hours using video-call
- 3) An online form for you and your child will be given to complete after the chat. An



 Search

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**Tourettes action**

**Wellbeing in young people who experience tics:
Development of a self-management tool**



Wellbeing in Young People with Tics: Development of a Self-management Tool

181 views  0  0  SHARE  SAVE ...

 **Camilla Babbage**
Published on Nov 21, 2018

ANALYTICS **EDIT VIDEO**

Please watch with the volume to gain the most information from this video.
This video gives an overview of the process of being a participant in research being conducted at the University of Nottingham and Tourettes Action into Wellbeing in Young People with Tics:
[SHOW MORE](#)



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Method: Verbal Assent



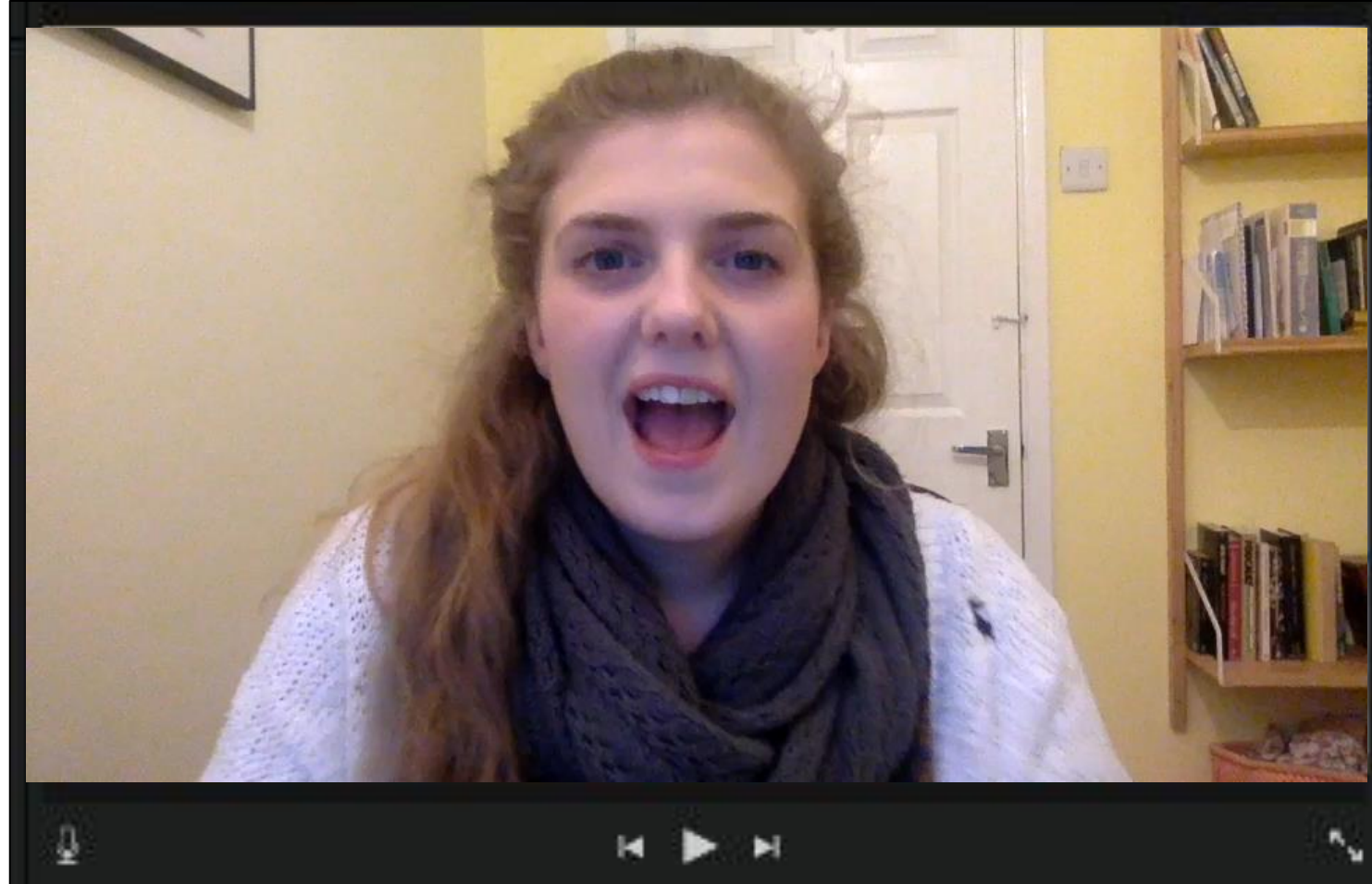


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Method: Familiarisation

Video

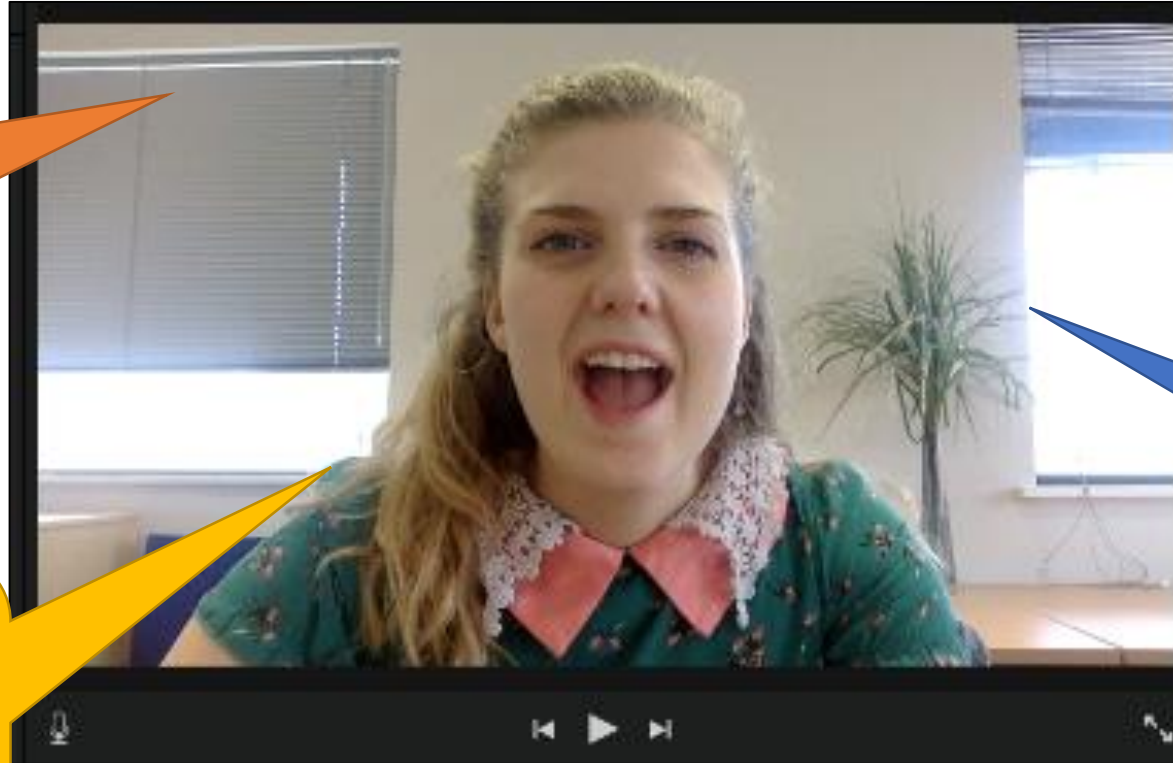




Method: Interview

How do you
feel on good
days/ bad
days?

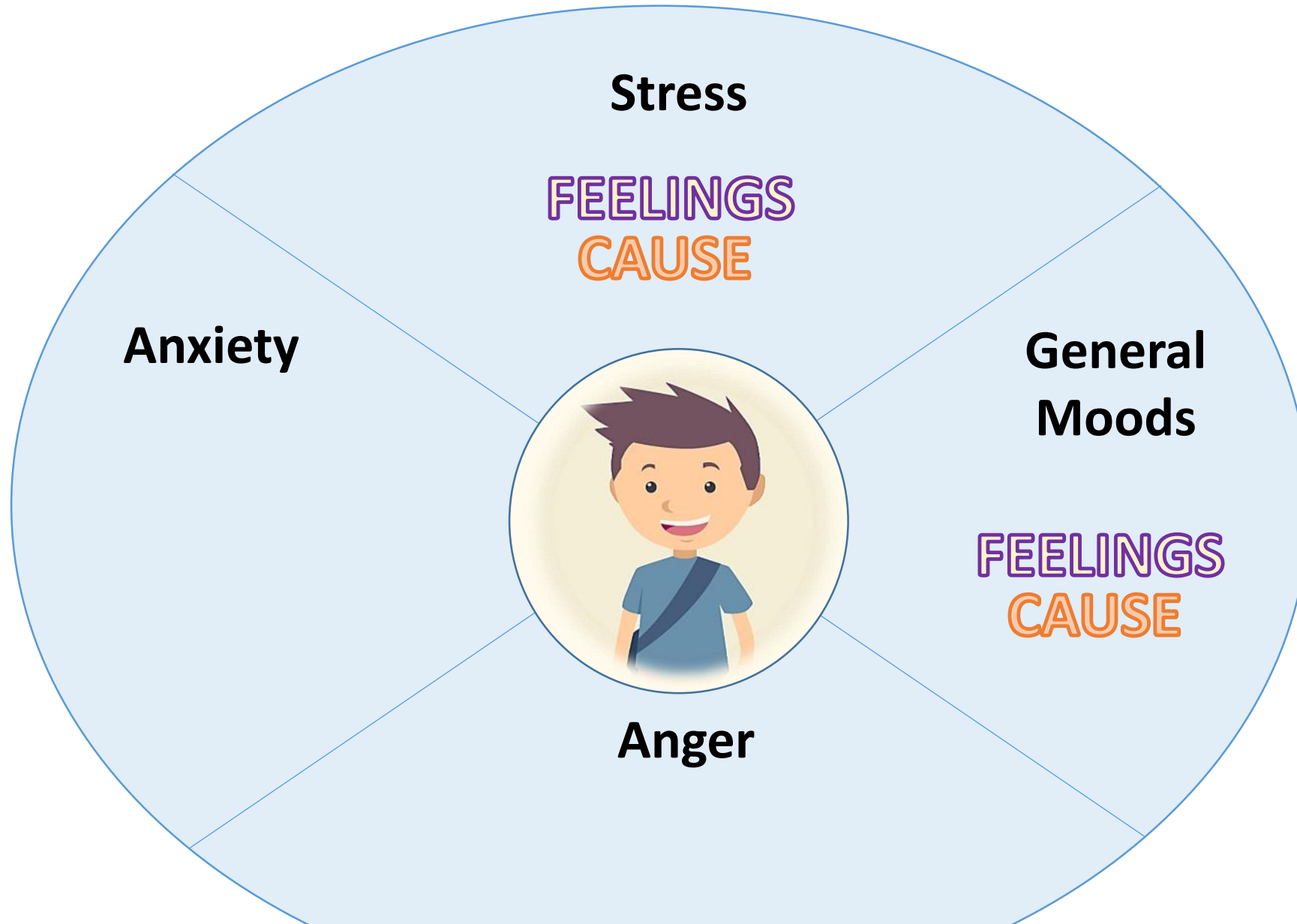
What do you do
when you're
feeling low/up?



Can you give me an
example of when
you last felt good/
down?



Findings: Understanding of wellbeing





Findings: Understanding of wellbeing

Stress

FEELINGS

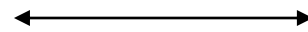
Uhh, I don't know, I'm not stressed not thinking about anything, and it's just, nothing everything's just fine

(Male, 17, TS)

A busy day full of things that, are quite, tiring, or things that aren't, like, your favourite things in the world to do, you know, then umm, I don't know I guess you can't really plan what, what's going to happen on a stressful day, because I know there's always something that you forget or there's something that happens

(Female, 13, TS + OCD)

Relaxed



Stressed

CAUSE

School (N=6)

You have to get up really early, you have to, do this, I, I'm not, like, free to do what I want, so it makes me stressed

(Male, 12, TS + Anxiety + Sensory Processing Disorder)





Findings: Understanding of wellbeing

FEELINGS

A lot of the time, I have like umm I have like bad days and stuff. I just, nothing's happened that's bad... but I don't know why I'm sad, it's just like a down day

(Male, 12, TS + Anxiety + Sensory Processing Disorder)

Umm on good days, I feel really good, excited. I just want to get up and do everything

(Male, 13, TS + Autism + ADHD + SPD)

CAUSE

School (N=8)

Mum: What have we had that's been a good day?

YP: Where we don't go to school at the weekends

(Male, 14, TS + Autism + OCD)

Negative



Positive



General
Moods

Energy (N=3)

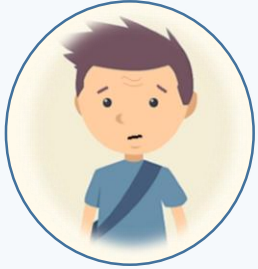
Yeah, like on a good day I'll be so energetic and I'll like be happy and say oh how are you and stuff

(Male, 10, TS + Anxiety + ADHD)



Findings: How do young people manage their wellbeing?

Stress



General Moods



Anger



Anxiety





Findings: How do young people manage their wellbeing?

Engaging Strategies

Physical Activity

Relaxing Strategies

Interaction Strategies

Avoidance Strategies

Yeah, I used to listen to that and it would make me feel more relaxed and it should make me feel really sleepy on them, and make me go to sleep so

Music?

What is it about playing your drums that makes you feel different?

Because of the loud noise

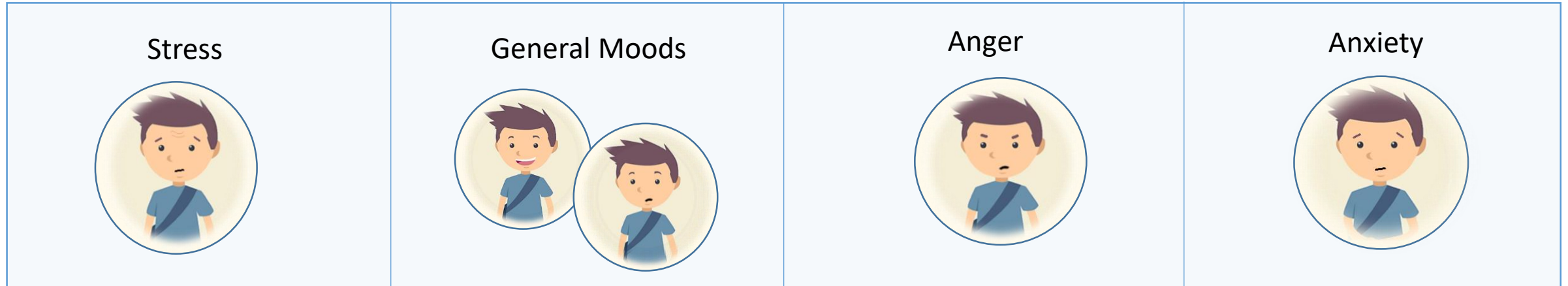
Before the walk I'm probably just feeling not good but after the walk I feel really nice and calm and chilled

Physical Activity?

What are you thinking [when riding your bike]?

Sometimes I'm thinking goes from don't crash to oh that was sketchy, to oh that's fun, and alright, I can't believe I did that she's gonna kill me

Findings: How do young people manage their wellbeing?



Stressed

Engaging Strategies (N=5)

Relaxed

Engaging Strategies (N=7)
Relaxing Strategies (N=13)

Positive

Engaging Strategies (N=12)
Interaction Strategies (N=9)

Negative

Relaxing Strategies (N=7)
Interaction Strategies (N=7)

Engaging Strategies (N=3)

Interaction Strategies (N=3)

Relaxing Strategies (N=3)

Escape Avoidance (N=5)

Relaxing Strategies (N=6)



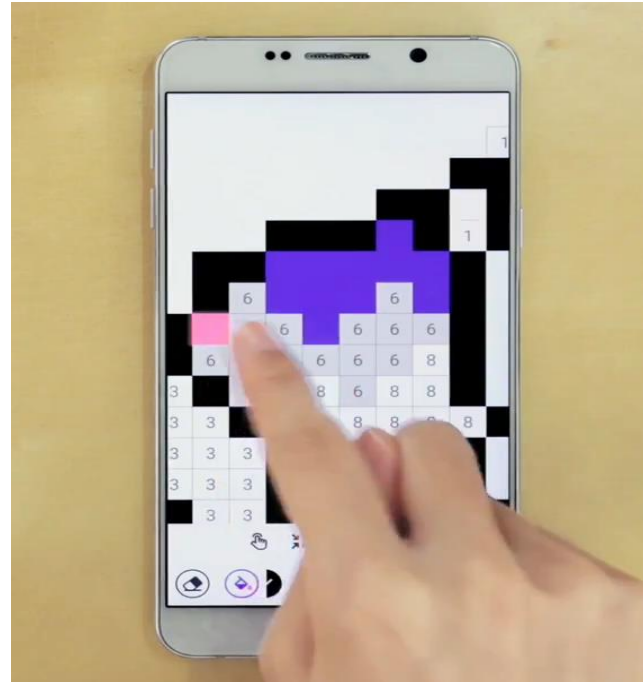
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Findings: How do young people manage their wellbeing?

Stress



Relaxing Strategies (N=13)



Videos (N=4)

Art (N=5)

Music and sounds (N=7)



Findings: How do young people manage their wellbeing?

General Moods



Positive

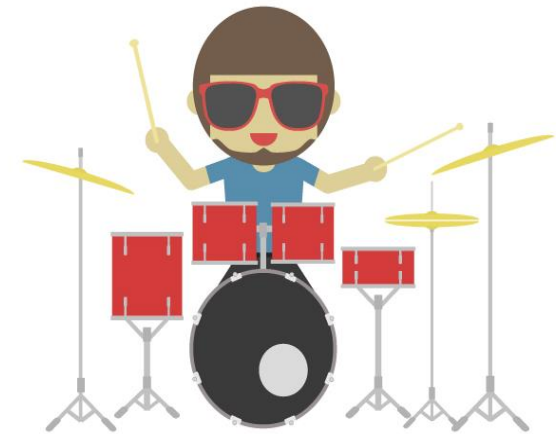
Interaction Strategies
(N=9)

Peers (N=9)



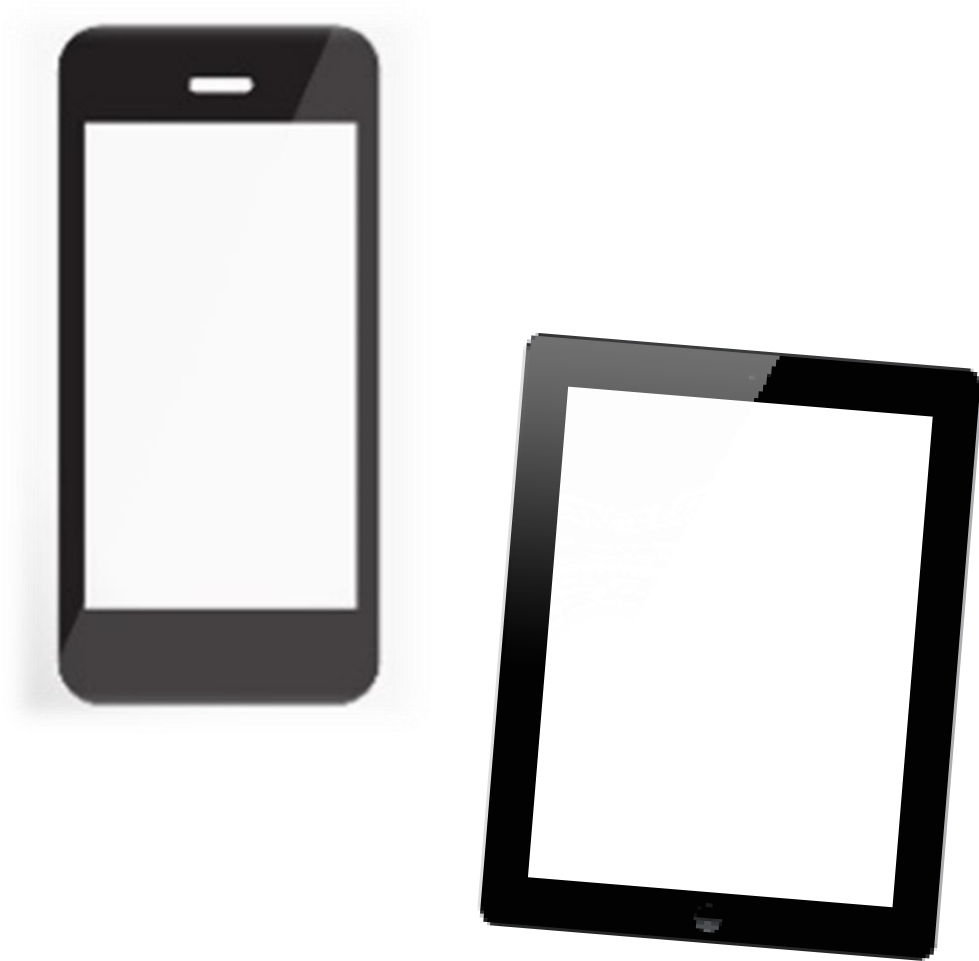
Engaging Strategies
(N=12)

Music (N=7)





Implications for App



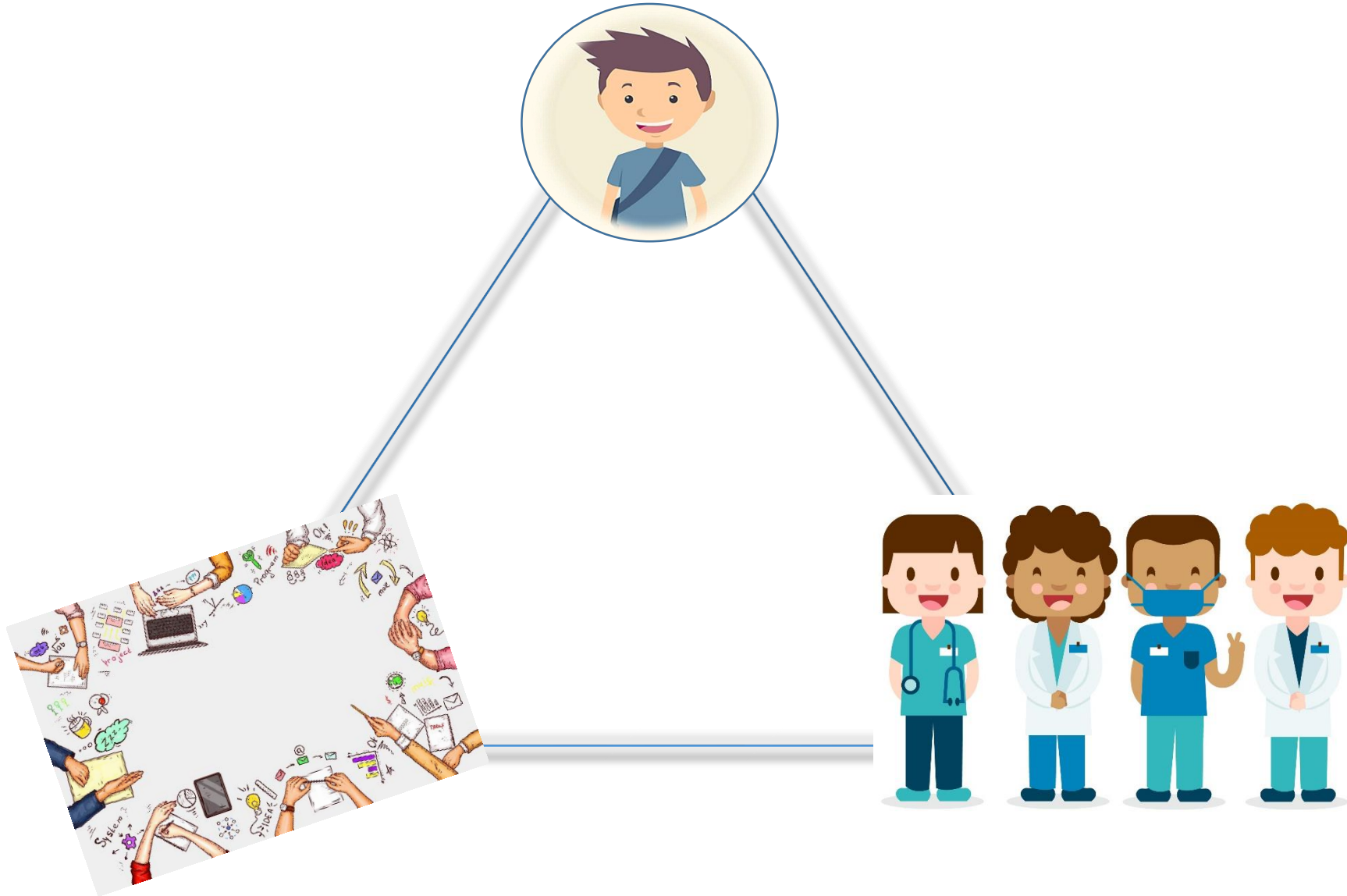
- Psychoeducation based on young people's needs
- Management techniques can be incorporated based on what young people like to use
- Strategies introduced that young people don't use



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Future Directions





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Thank you for listening!

Thank you also to

Dr Elena Nixon & Prof. Georgina Jackson



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