Sleep Detectives:

Co-design with families with 22q11.2 Deletion Syndrome

MAX APPEAL
IMPROVING LIVES OF 22Q11 FAMILIES

Understanding chromosome disorders
Unique

wellcome

UNIVERSITY OF EXETER
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PRIFYSGOL CAERDYDD

bristol neuroscience

What is ‘normal’ sleep?

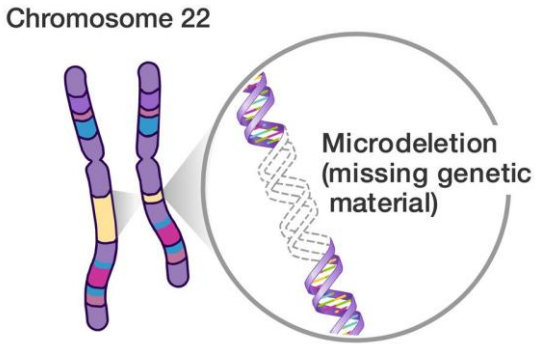
https://www.sleepfoundation.org

School-age	6-12 years old	9-12 hours

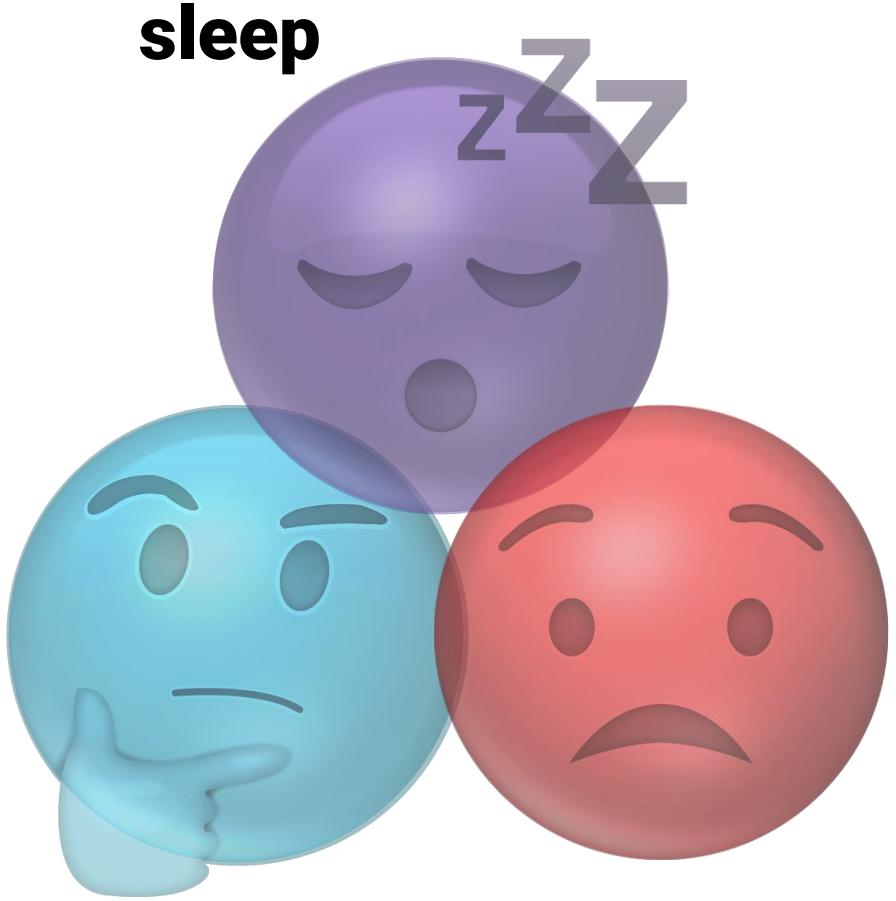
But parents of children with 22q deletion say…

- "We have a **constant battle with sleep**…The next day his window of **tolerance is just so low** - he fights with his sister, kicks cupboards"
- "Oh my god, **the nights are terrible**… she gets so restless, she starts kicking, screaming, like really **aggressive**"
- "When you can't get a proper sleep it's hard to function…she **can't focus in school**"
- "**Sleep is one of the biggest issues…Please help**"

How are sleep, thinking and mental health connected?



22q11.2 deletion
1q21.1 deletion
16p11.2 duplication



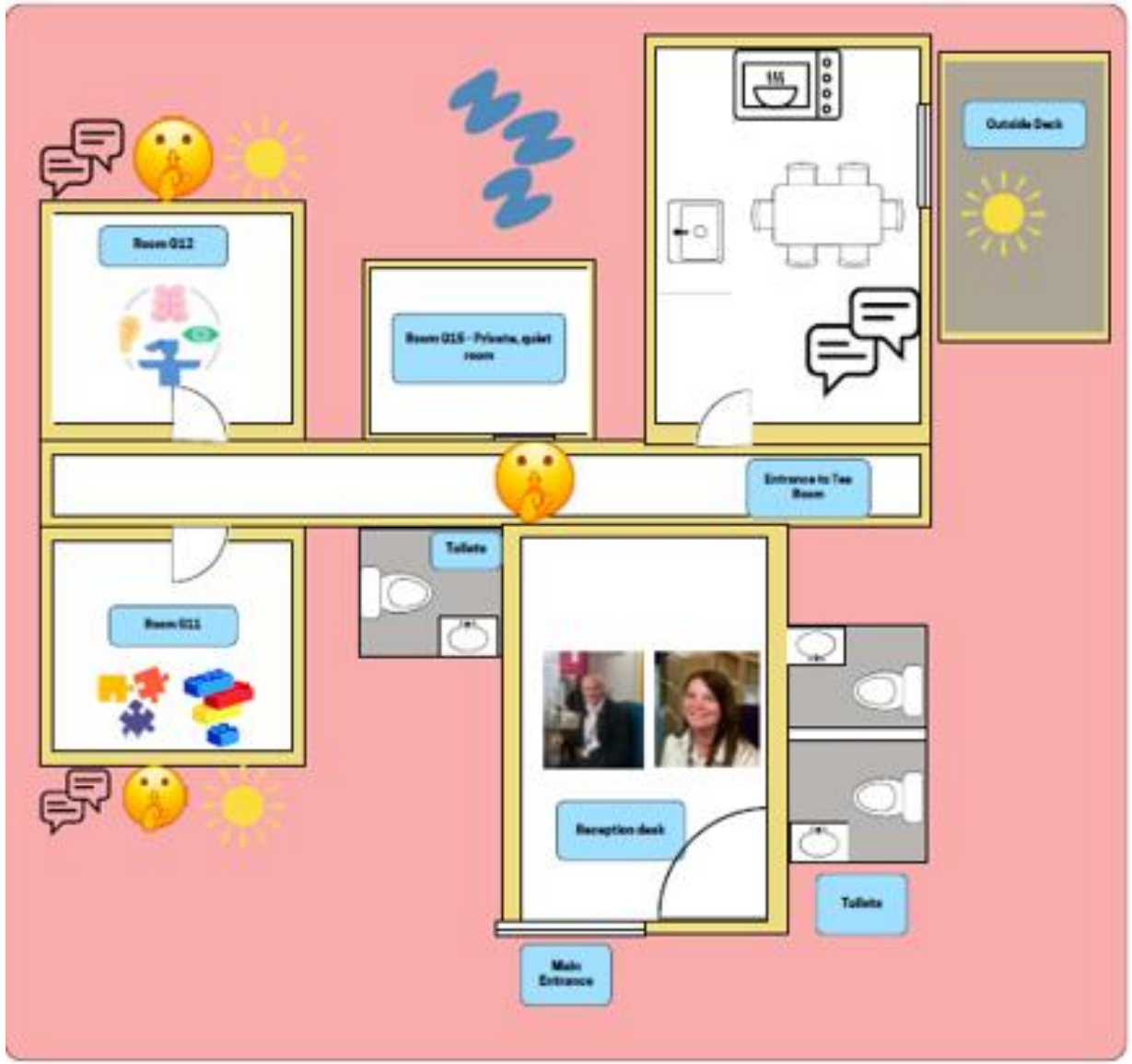
Measuring sleep: nearables, wearables and brain waves (EEG)

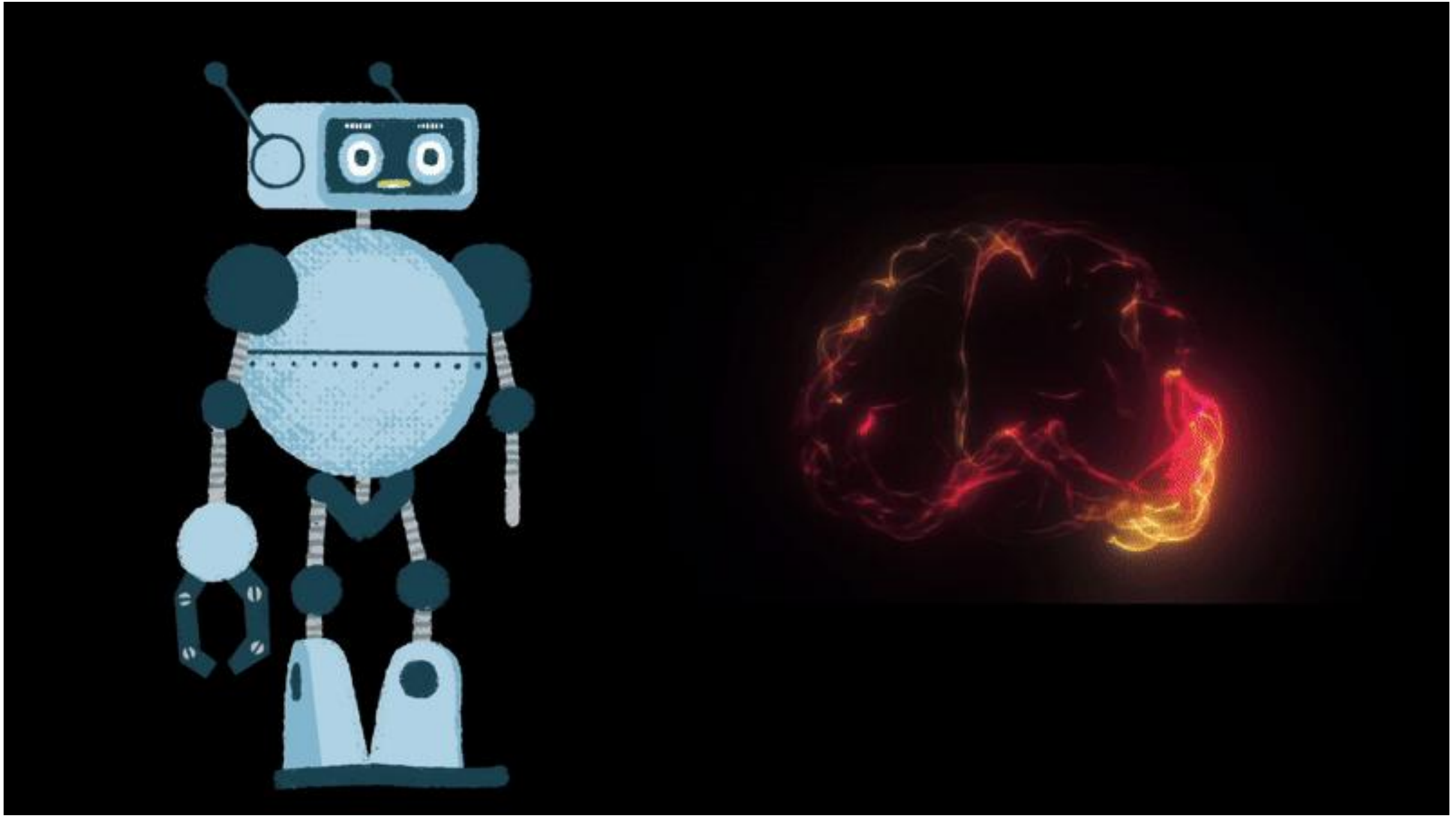
lots of people, long timescales → *few people, 1-2 nights*

20 families (31 children aged 7 to 19), plus 2 charities, 26 staff, students and volunteers, over two weekends, May and June 2024

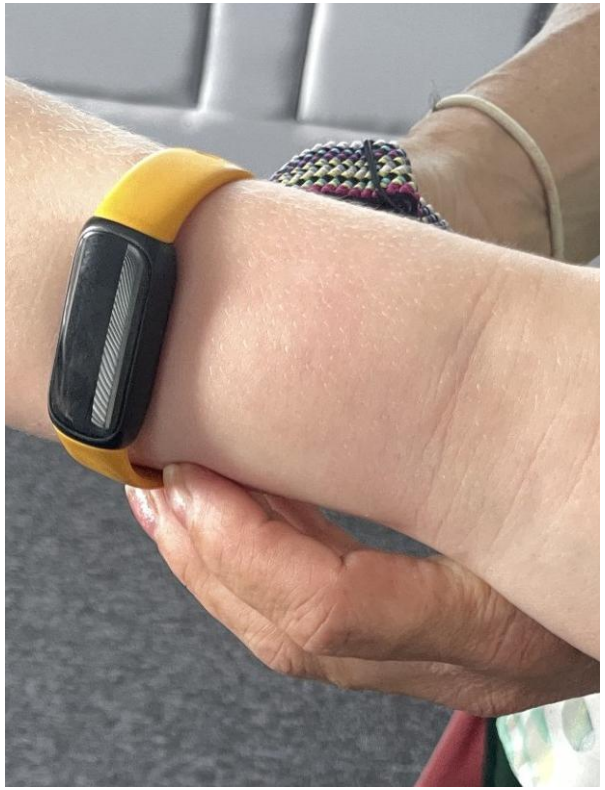
The Sleep Detectives: Workshop preparation

Lived Experience Advisory Panel
9 parents / carers
1-4 young people (occasionally)
2 charities (MaxAppeal, UNIQUE)
6 researchers





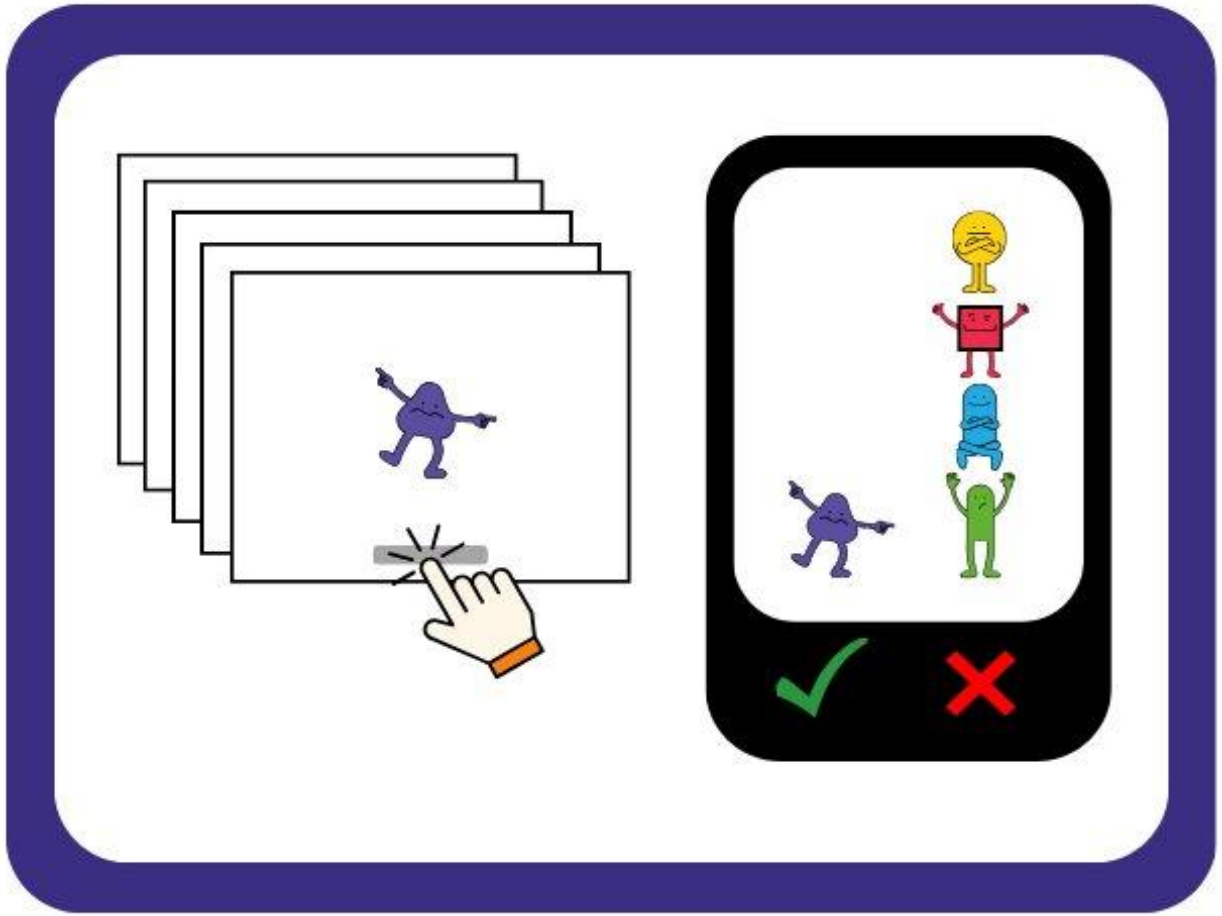
Trying on equipment



Feedback on the iPad tasks

The Sleep Detectives: Customising cognitive tests

Try out our tasks...



... just for fun.

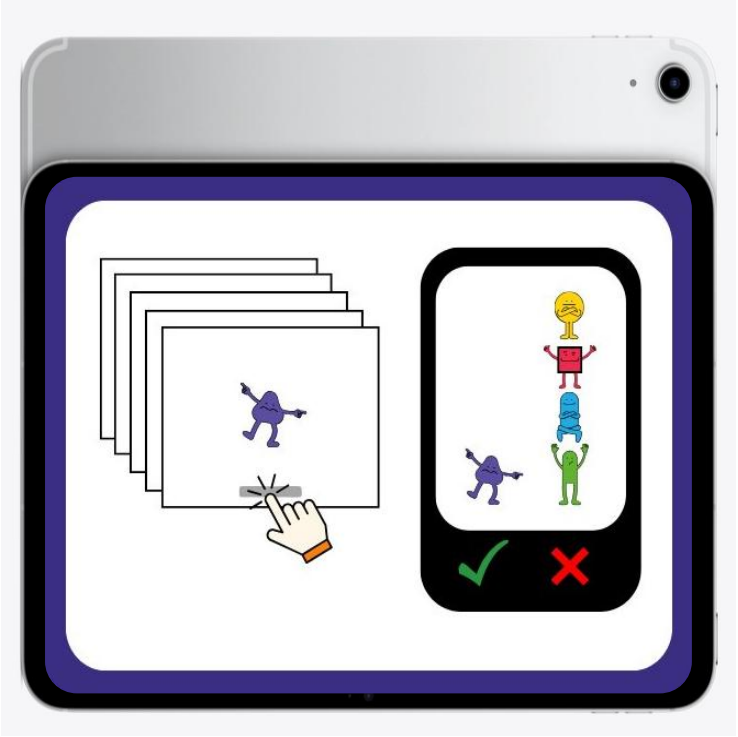
Track your progress...

Our co-designed Sleep Detectives toolkit

actigraphy and heart rate

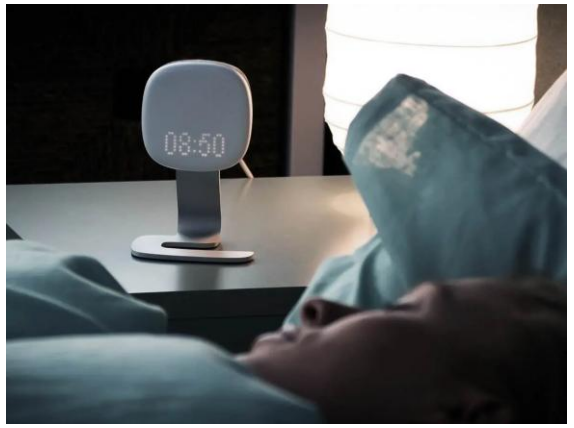
Fitbit® Inspire 3
worn continuously for 7 days & nights

diaries and cognition



iPad® for sleep diary, activity log, daily cognitive games

sleep behaviour and EEG



Somnofy®
bedside radar

Clic EEG®
F7-F8 patch

Reducing the burden on families

- Shorter cognitive tasks (less than 15 mins morning or evening)
- Allow a first-night test run
- Allow up to 14 days data collection
- Provide a report to help families access services

Secrets of success

Relaxation and fun activities

Volunteer buddies for each family

What families told us

We had no anxieties that weekend and that played a huge part in getting the best out of us and, I'm sure, other families.

We felt listened to, understood, catered to, and connected to others taking part.

We are immensely proud to be part of this important study, with the other amazing families. Any advance in understanding and coping with our children's medical needs will always be beneficial.

And the research team said…

The best part about being involved… was witnessing the shift, from families feeling unheard to becoming central voices in shaping research.

The generosity of the families to give their time and discuss the realities of their experiences was genuinely eye opening.

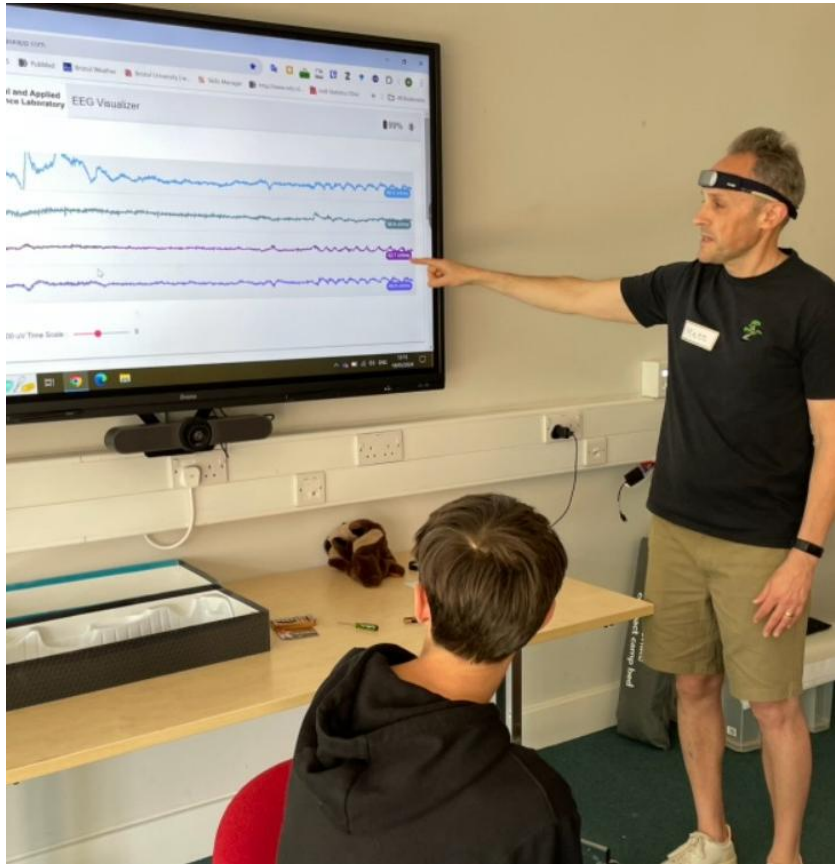
Seeing parents and young people light up when their insights were reflected in materials and outcomes, reminded me why codesign matters… it was about making individuals feel empowered.

Future: longitudinal studies

- Find out if the unusual sleep patterns can help explain the mechanisms leading to mental health conditions in 22q11.2 DS.
- These longitudinal studies with children and young people probably would not work unless co-designed.
- Sleep gadgets are great but rarely validated with children and young people.

Co-working with lived experience experts isn't only necessary – it's wonderful!

(Professor Matt Jones)



Thank you!

Please get in touch

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Who can become a sleep detective?
Young people aged 6-21 with a copy number variation and their siblings.

For more information scan the QR code!