

CHECC - Child and Young person Epilepsy Concerns Checklist. A holistic epilepsy and wider needs surveillance tool

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CHECC aims to improve information sharing between health and education services on matters of particular relevance to families and cyp affected by epilepsy..

Carer, young person and school/nursery versions have been developed to include neurodevelopment, emotion and behaviour concerns as well as safety, general health transition and goal setting.

20 children had the CHECC completed by their teachers and or SENCOs. Emotional or behaviour concerns were reported in 8, social interaction and/or communication concerns in 12, attention and concentration and learning concerns were reported in 15.

12 had concerns with the core skills e.g reading, writing, spelling and/or maths and 11 indicated concerns with overall cognitive skills with 8 indicating that further cognitive evaluation would be helpful.

There were no reported concerns re safety, supervision or care plans in general,. All of the 6 respondents who gave feedback on education CHECC, indicated that it was the right length.

This pilot study indicates that the CHECC may be an acceptable and effective tool for collating education professional concerns about the child or young person with epilepsy.

HHFT Epilepsy Padlet resource



"The more people that can use it the quicker the treatment can be accessed..... they can then send the information to the specialist if they are in an area with a long waiting list or very few epilepsy nurses." Parent of child with early onset epilepsy, global delay and asd

"I wish I had this when my child started nursery"
Parent of child with SCN1a epilepsy now a teenager



"We went through CheCC form together. It helped spotlight what were thought to be minor longstanding issues about social anxiety and routines noted from about 4 years which were having a real impact." Parent 15 year old with anxiety and possible features of ASD & ADHD

How parents and voluntary organisations contributed

Discussion with colleagues BPNA 2020 –evaluation tool for children with wider needs in the context of epilepsy

Combined Tool developed based on TAND in consultation and shared with local working group – epilepsy nurse x 2, psychologist, educational psychologist

Contact with EP Colin Reilly (Chess study) suggest tool such as CHECC could be used at initial clinic meeting or even pre clinic for established epilepsy and then further screening /information gathering tools

Shared with Dravet UK, – supportive though commented that some families may prefer to discuss family /parental stress of parental mental health with gp rather than paediatrician.

Shared with BACD and BACCH

Feedback from Young Epilepsy group

Feedback from RCPCH &Us/Experts by experience and epilepsy programme board parent/care reps, as well as schools and parents

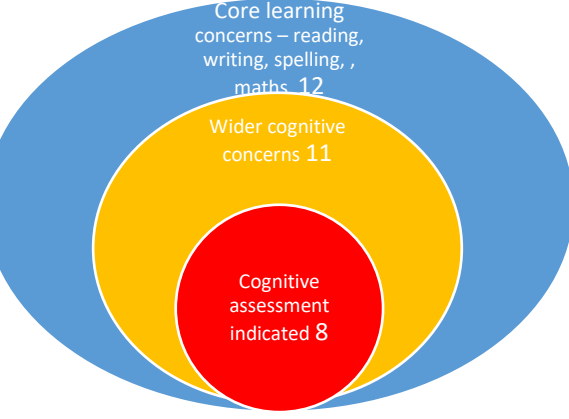
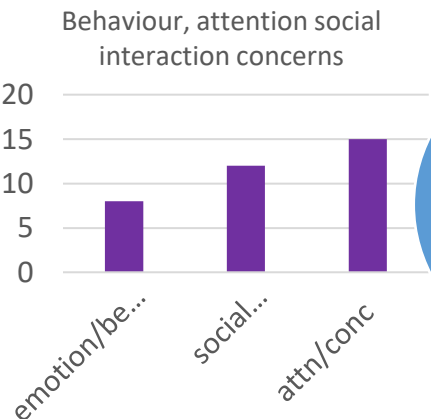
Pilot tools refined following initial feedback with development of separate schools version, young person's version, parents version

Ongoing feedback

With thanks to:

- Dr Ashley Liew – Consultant Neuropsychiatrist Evelina/GSTT
- DR Elaine Hughes – Consultant Paediatric Neurologist Evelina /GSTT ans SETPEG chair
- Dr Dionysious Grigoratas – Consultant paediatrician spec interest in epilepsy
- Helen Evans - Dravet Syndrome UK
- Amy Muggeridge - Young Epilepsy Medicines in schools alliance
- Experts by experience (RCPCH & Us) – Emma Sparrow and parent representative Venner Turner

- Sharon Seton CCN sister and Paediatric Epilepsy nurse specialist HHFT
- Dr Brigitte Vollmer Consultant Paediatric Neurologist Neonatal neurologist University Hospitals Southampton (UHS)
- Dr Alice Lording Consultant Paediatric Neurologist –UHS
- Dr Danielle McLymont – Principal Clinical Psychologist HHFT
- Rebecca Case Epilepsy Nurse specialist – Portsmouth HFT
- Melissa Dean SALT – Hampshire HHFT



Clinical characteristics

- 12 males; 8 females
- Age range 5 -16 years
- One – Hemi cerebral palsy + West syndrome
- 3 genetic confirmed (SCN1A – GEFS +), NF1, Rhobtb2
- 2 In special school
- 8 SEN/EHCP applied for
- 2 Confirmed EHCP
- All well controlled/very infrequent
- 2 Prior diagnosis ADHD
- 2 SLD (special school)
- 2 ASD subsequently diagnosed
- 8 - Sets Conners (ADHD questionnaires) 3 indicative of ADD/ADHD
- 7 Sets ASD screening (NICE ASD guidance appendix - signs and symptoms ASD). 5 on ASD assessment pathway
- 1- DCD (new diagnosis)