

CHILD and YOUNG PERSON EPILEPSY CONCERNS CHECKLIST – a holistic epilepsy checklist

Since the previous article in 2020 there has been some progress with CHECC.

What is the Epilepsy programme board? What are its aims and what is BACD's role within it?

The UK Paediatric Epilepsy Programme Board was established by the Royal College of Paediatrics and Child Health (RCPCH) as a partnership between epilepsy specialists and stakeholders to develop an overarching strategy to support the development and delivery of national and international projects.

The aim is to provide advice and support to inform paediatric epilepsy research, training and national quality improvement projects.

As a collaboration the board aims to have an influential voice in setting the strategic agenda for paediatric epilepsy and will work together to ensure interests are aligned. The Programme Board is independent from the pharmaceutical industry, commercial sector, single charities or academic institutions, and will provide a unified voice to ensure paediatric epilepsy sits high on the national agenda.

The Board membership includes:

- Chair and Deputy Chair
- British Paediatric Neurology Association (BPNA) representative
- Organisation of Paediatric Epilepsy Networks (OPEN UK) representative
- Royal College of Nursing (RCN) representative
- Mental Health representative (Paediatric Mental Health Association)
- Education representative (Department of Education)
- Allied Health Professions representative (British Association of Childhood Disability, BACD)
- Social Care representative (British Association of Social Workers)
- Children's epilepsy charities (Young Epilepsy representative)
- International League Against Epilepsy (ILAE) representative
- Children and young people (CYP) and parents' representatives
- RCPCH Senior Management representative and RCPCH Coordinator (RCPCH Research and Quality Improvement Division)

The leads of national epilepsy projects present and discuss their work to encourage information sharing and provide a forum for project groups to receive feedback and support from the wide range of specialists and stakeholders represented on the Board (not unlike BACD). The Programme Board will report to the RCPCH Research & Policy (R&P)

Divisional Committee and will provide regular updates to The All Party Parliamentary Group on Epilepsy.

Thus the role of BACD is to provide expert comment and multiagency perspective on documents circulated between meetings as well as advise on project design and delivery, as appropriate; help with stakeholder engagement and dissemination of outputs, using own networks where appropriate and complete actions as proposed and agreed at meeting.

Background

There are particular epilepsy conditions in which there may be a particularly high incidence of neurodevelopmental disorders, such as ASD, ID (LD/GDD), ADHD, DCD/Dyspraxia, specific learning difficulties, e.g. dyslexia.

The Chess study, Gilberg's ESSENCE studies and the Autistica "Embracing Complexity" work highlights that often these factors exist alongside epilepsy and may be under recognised as concerns in their own right. This can be partly due to the focus being on the epilepsy alone or attributing these additional issues to the epilepsy condition or treatment. Additionally, there are some epilepsy conditions in which educational, neurodevelopmental and mental health concerns or disorders are particularly common.

Child and young person Epilepsy Concerns Checklist – CHECC

CHECC is designed to support communication between the family, epilepsy team and education setting with the aim to support the recognition and evaluation of conditions or disorders that may be more common in CYP with epilepsy. Some of these are general issues such as education, behaviour and mental health. Some of these may relate to anxieties about the epilepsy, epilepsy treatment, safety, informing peers or other support needs. There may also be feeding, mobility and posture, self-care and other needs.

CHECC is specifically to identify and support the wider and more general needs of CYP with epilepsy. This is with the aim of a systematic approach whilst attempting to minimise the burden of using a number of tools for each individual.

Development of the CHECC

- Consultation with working group – epilepsy nurse x 2, psychologist, educational psychologist, Paediatric Neuropsychiatrist, tertiary neurologist, paediatricians with epilepsy expertise, parents.

- Presented to RCPCH epilepsy programme board (includes stakeholders RCPCH, OPEN UK, ILAE UK chapter, Epilepsy 12, young epilepsy, parents and cyp, RCPCH experts by experience.
- Shared with Dravet UK, Support from NYCPE – Young epilepsy regarding the young person version.
- Shared with BACD and BACCH – for input and comments.
- Presented as poster at BPNA 2022, BACCH 2022, EPNS 2023
- Refinement of the checklists. School/nursery version, Young person version, parents version.

- There were no reported concerns re safety, supervision or care plans in general. All of the 12 respondents who gave feedback on education CHECC, indicated that it was potentially helpful. 2 were unclear – though this was an earlier version of the checklist

Following or accompanying the CHECC, more focussed information gathering and evaluations were completed. These were associated with the following outcomes: 5 formal cognitive assessments confirming LD and 2 awaiting outcome; 5 ASD, confirmed, 2 in progress. 6 individuals diagnosed ADHD/ADD and 2 individuals diagnosed with DCD.

Three different versions of the checklist have created (parent/carer, education, and young person version). Different questions were included in each version.

Nursery/School CHECC

- Early Years
- National Curriculum attainment
- Reasonable adjustments

Parent/Carer CHECC

- Milestones
- Emotional well-being
- Medication side effects
- Sleeping issues

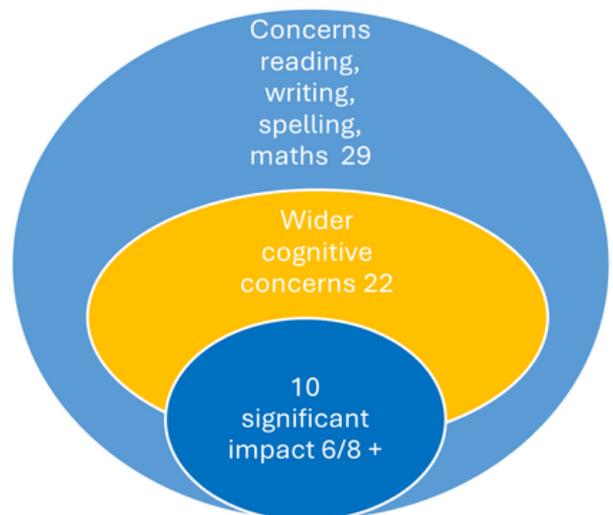
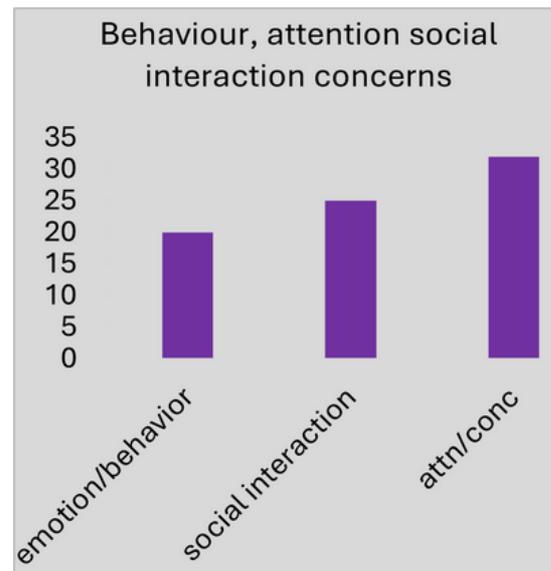
Young Person CHECC

- Transition to adult services
- Lifestyle concerns
- Barriers regarding driving and employment

The evaluation was based on checklists were received from education professionals.

Results:

- 41 children had the CHECC completed by their teachers and or SENCOs
- Emotional or behaviour concerns were reported in 20,
- social interaction and/or communication concerns in 25
- attention and concentration 32 and Special Educational Needs in 16
- 29 had concerns with the core skills e.g. reading, writing, spelling and/or maths and 22 indicated concerns with overall cognitive skills with 8 indicating that further cognitive evaluation would be helpful



We created an in house resource to support families and young people as well as other professionals ([HHFT Padlet epilepsy resource](#))



Parents comments on using CHECC

"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 of 15 year old with anxiety and possible features of ASD & ADHD

"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

NCYPE - Child and young person Epilepsy Concerns Checklist (CHECC) Feedback (17.10.2003)

- 8 participants completed the Child and young person Epilepsy Concerns Checklist (CHECC) and provided feedback.
- Participants ranged in age from 15-25 years (M = 18.63, SD = 3.11).

All participants were asked to complete the CHECC and were then asked five questions on how they found the tool:

Q1. As this is a draft tool we would love to know whether you would find this helpful and how?

All participants (n = 8) reported that they would find it helpful.

'Yes! It uses simple language making it accessible and making you think at the same time.'

'I would because it shows people care'

Q2. When do you feel is the best time to complete this?

For example, before the clinic appointment, in the waiting room, after meetings with school, concerns in between appointments.

The majority of participants (n =6) reported they would prefer to complete it before the appointment as there would be less pressure.

'Before clinic appointments as there is less pressure and more time to complete. I feel for and between appointments it should have alterations.'

Q3. Was this about right or too short or too lengthy to complete?

All participants (n = 8) reported that it was the right length. However, note:

'It was about right however some of the longer questions I struggled to answer as I didn't fully understand them.'

Q4. Is there any way you would prefer to complete this checklist?, e.g. on paper.

No participants reported a preference either way. However, note:

'No but if it was on paper it would need to be accessible for people with difficulty reading and processing. For example, words that stand out and different colours to separate questions and answers.'

Q5. What are your expectations after completing this?

All participants (n = 8) brought up a similar theme of referrals being put into place:

'If it was completed in the setting of a hospital or school. I would expect there to be a plan for the answers not just a checklist. For example, tailored support, more appointments, referrals, etc.'

Additionally, this respondent refers to a more holistic approach to treating epilepsy:

'That other areas of my health are considered as epilepsy can be a ball of knotted string and in order to get to the big Knot we have to undo all the other ones on the way'

Q6. Do you have any other comments to help us develop this further?

'I feel that within my appointments, my doctor doesn't take my epilepsy seriously or consider that because of it I have no friends and had to quit college so the least that could happen is that my options are taken seriously.'

'This is exciting! I'd love to know if this is an example for all settings or is a base to be tailored!'

How to use CHECC in practice

After meeting or otherwise contacting the family – usually the first appointment, send the CHECC parent/carers version. If the child/young person is in secondary school and able to understand the child/young person version then consider sending this too. If consent has been obtained the nursery /school version of the CHECC can be sent along with any care plan or other information.

The epilepsy team analysed the responses; for instance if neurodevelopmental concerns were raised, further questionnaires as appropriate, e.g. SDQ, were sent. NICE signs and symptoms of possible ASD (pre-school/primary/secondary school age, DCD-Q, Connors questionnaires/SWAN, SNAP, etc. with further assessment/referrals as appropriate.

If there were mood or behaviour difficulties reported then appropriate behaviour support, counselling or CAMHS.

If the concerns relate to academic learning difficulties, then attempt to facilitate assessment as appropriate, e.g. educational psychology, clinical psychology/neuropsychology.

If the concerns relate to physical issues, such as sleep appetite, possible side effects, safety and care plan then this should be addressed by the epilepsy team.

How can you contribute by sharing feedback on this tool?

Please trial this with 5-10 of your epilepsy patients and complete the feedback form on the last page for each one, anonymise and send to me. This includes any comment about whether the tool was helpful in identifying these concerns.

Dr GABRIEL WHITLINGUM

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If you have any questions or want to know more about CHECC, email Gabriel.Whitlingum@hhft.nhs.uk

With thanks to:

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**RCPCH EQIP**
Epilepsy quality improvement programme

**RCPCH &Us**
The voice of children,
young people and families

 **Young Epilepsy**