



**Young
Epilepsy**

Child and young person Epilepsy Concerns Checklist (CHECC) Feedback

17.10.203

Method

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?

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.

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

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

Q5. What are your expectations after completing this?

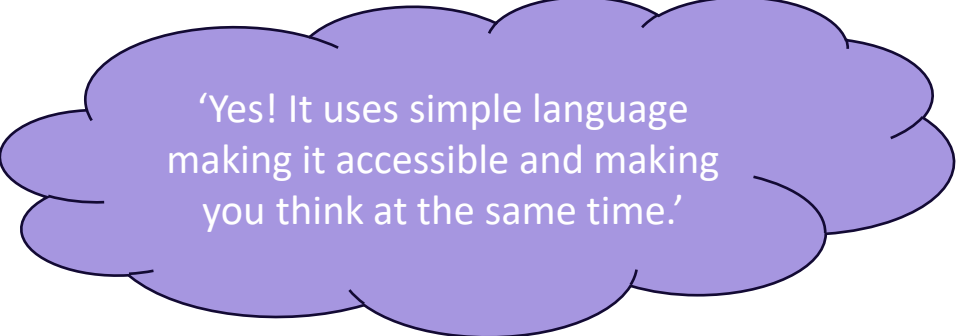
Q6. Do you have any other comments to help us develop this further?



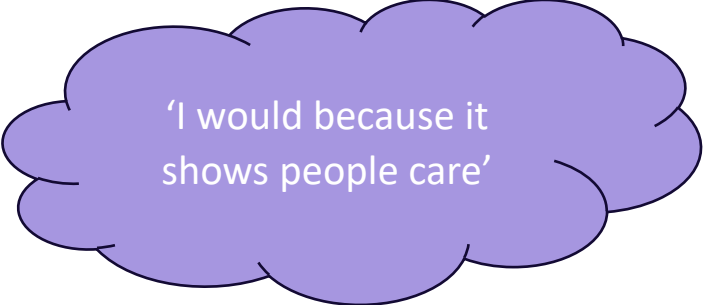
Q1 - 2

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.



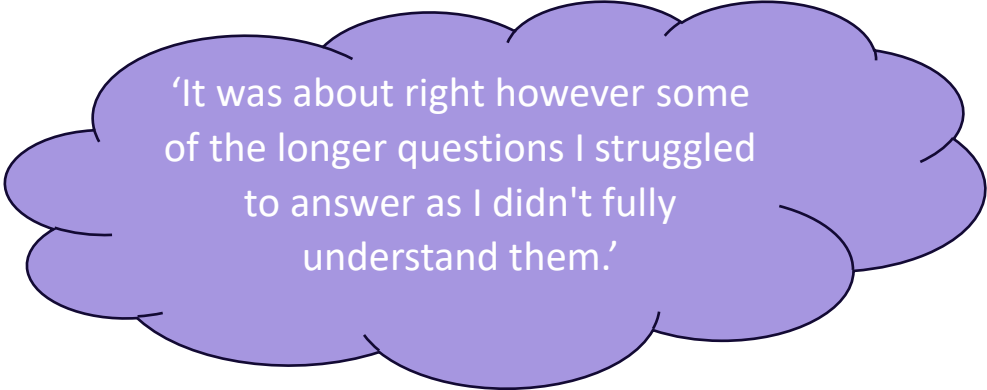
'Before clinic appointments as there is less pressure and more time to complete. I feel for school and between appointments it should have alterations.'



Q3 - 4

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

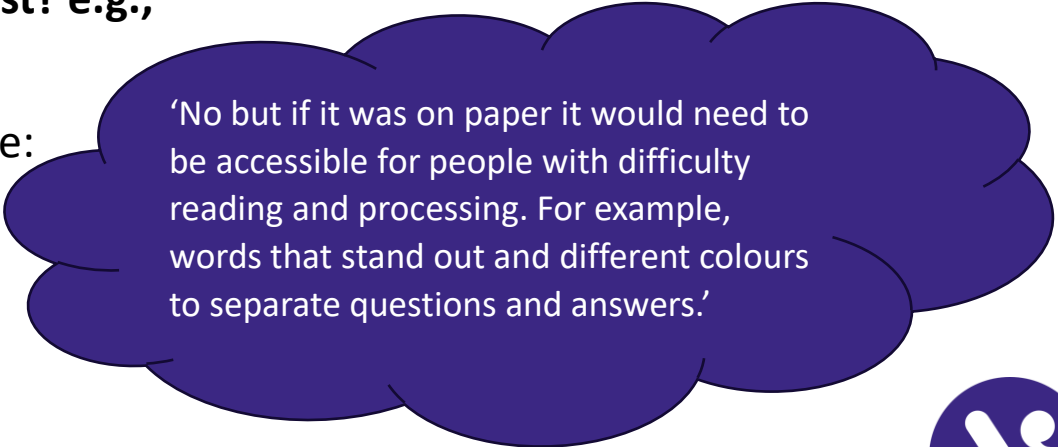
All participants (n = 8) reported that it was the right length. However, note:



'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

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

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 quite 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!'

