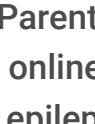


The Brain Development in Early Epilepsy Parent Priorities (BEE-PP) Project

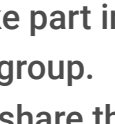
Co-production of research priorities for infant epilepsy

The BEE-PP Project is linked to our wider research programme, the Brain development in Early Epilepsy (BEE) Study, which aims to identify predictors of emerging autistic traits in infants with epilepsy, and to understand shared mechanisms between epilepsy and autism. As researchers, we believe that active collaboration between patients, the public, and researchers in the research process is key to conducting impactful research. Through our BEE-PP project, we set out to document the lived experiences of families with a child with early-onset epilepsy, exploring the impact of epilepsy on child and family wellbeing and identifying priorities for research into early behaviour and development in epilepsy. Our wider goal is to use the information gathered to inform future research initiatives by shining a spotlight on areas of importance to the epilepsy community.



Online Survey

Parents/carers were invited to complete an online survey to understand the impact of epilepsy on family wellbeing and highlight priorities for research in early behaviour and development in epilepsy



Focus group

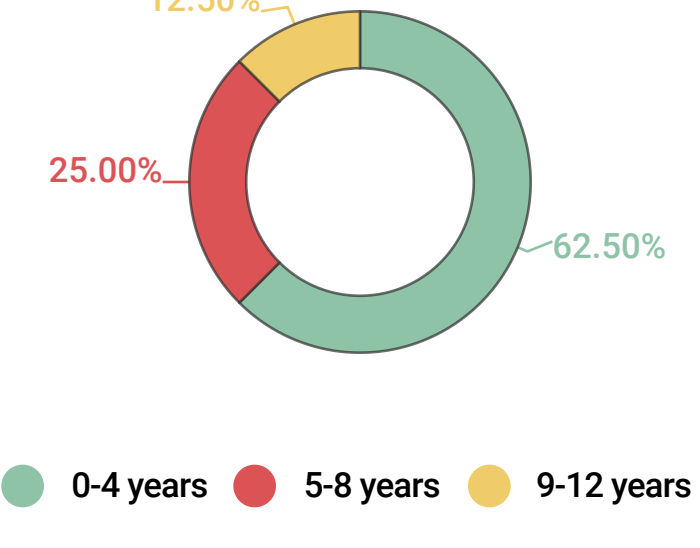
Parents/carers were invited to take part in a 2-hour recorded online focus group. Caregivers had the opportunity to share their thoughts and experiences, and discuss topics covered in the survey

Survey sample

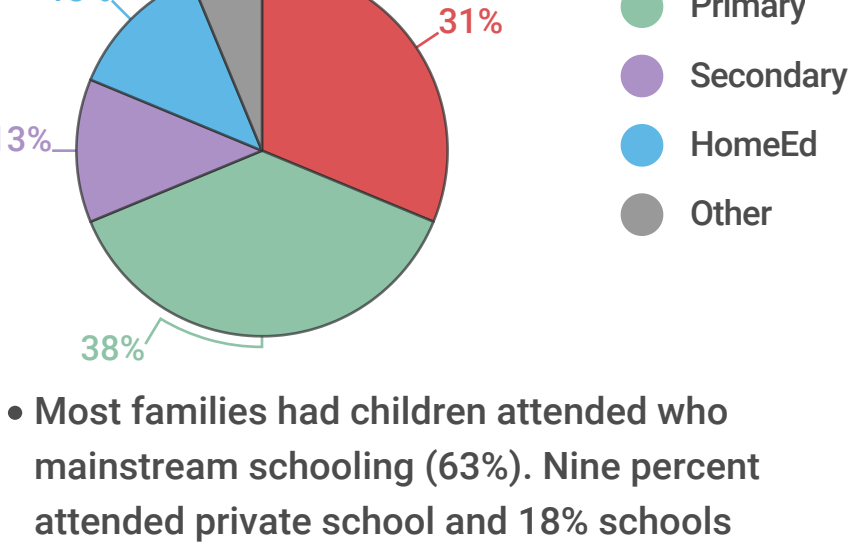
20 parents and carers of children aged between 3 and 16 years of age who were diagnosed before the age of 3

Child age and gender

• Most parents had children below the age of 4.



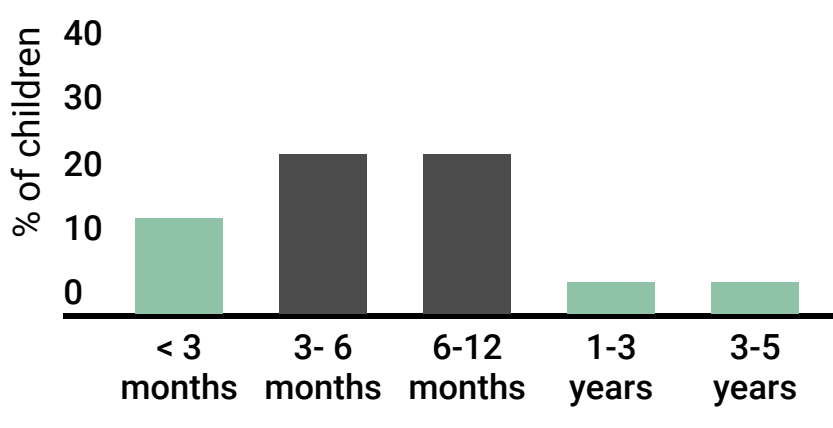
Child education



• Most families had children attended who mainstream schooling (63%). Nine percent attended private school and 18% schools supporting Special Educational Needs.

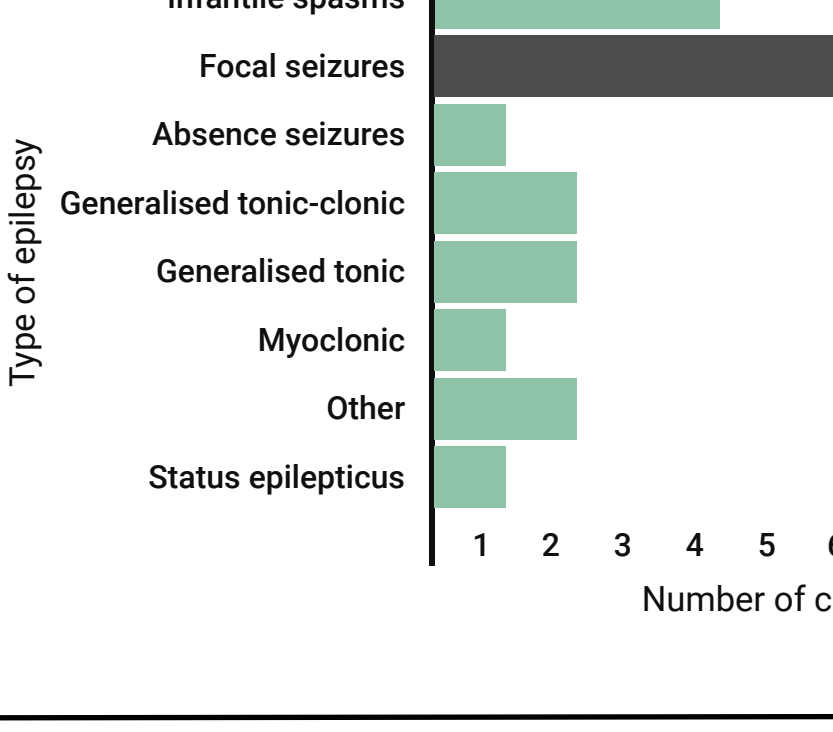
Survey results

Child age at diagnosis



• Most children were diagnosed with epilepsy between 3 and 12 months of age

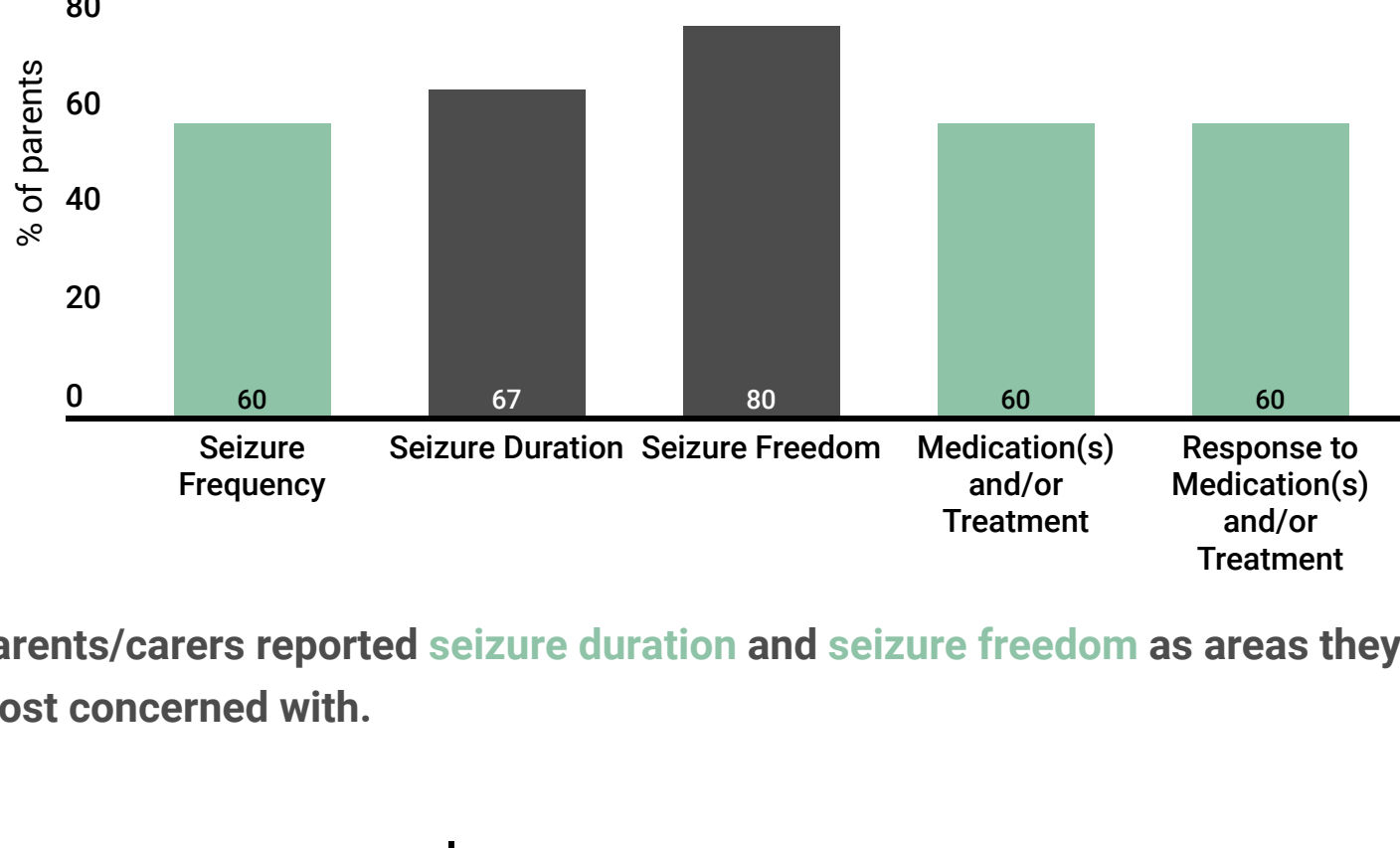
Type of epilepsy



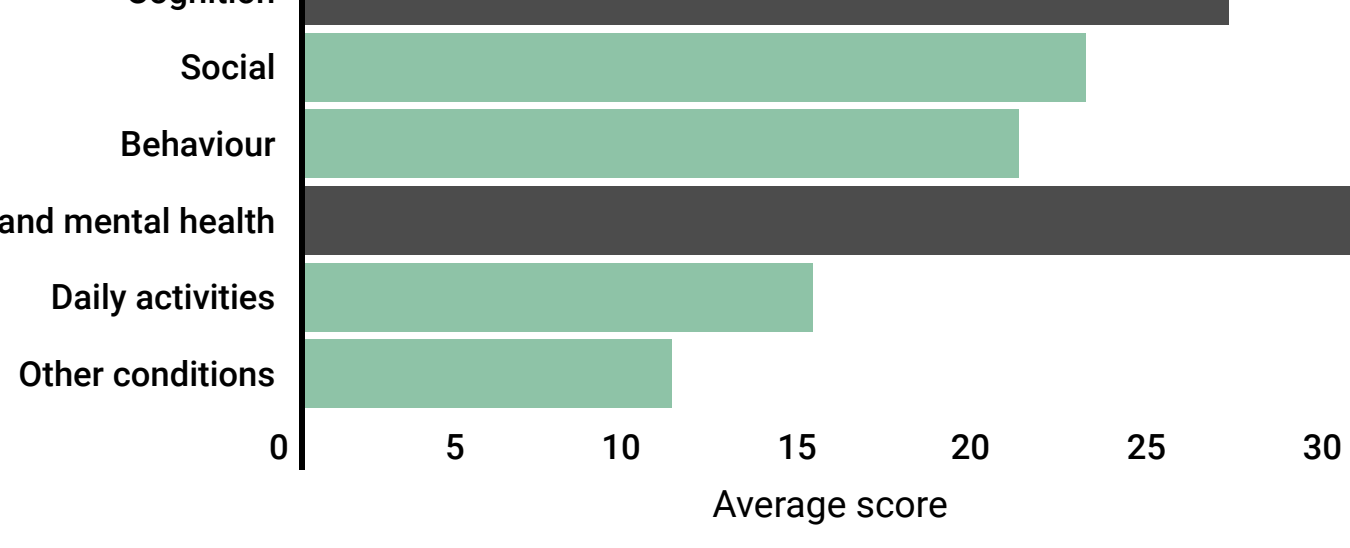
• Of the sample, 47% had been diagnosed with a genetic disorder, 14% with a neurodevelopmental disorder

Concerns about child's epilepsy

Early Childhood Epilepsy Severity Scale (ECESS)



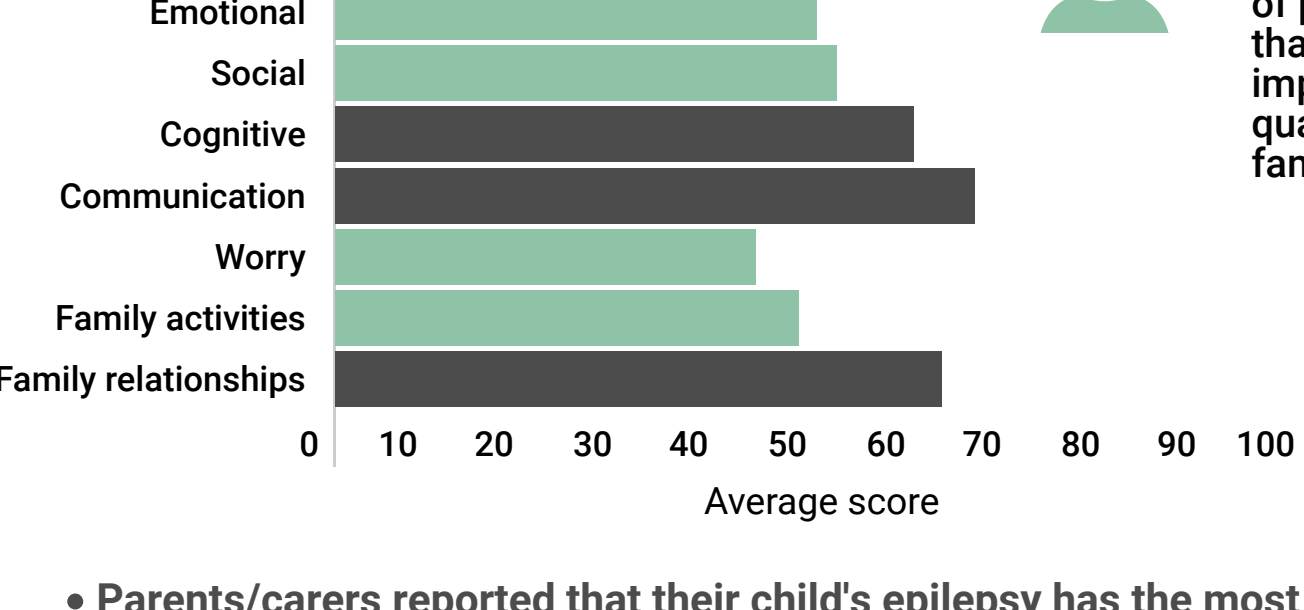
• Parents/carers reported seizure duration and seizure freedom as areas they were most concerned with.



• Parents/carers also reported they were most concerned with their child's sleep and motor functioning, cognitive functioning and emotions and mental health.

Impact on family life and wellbeing

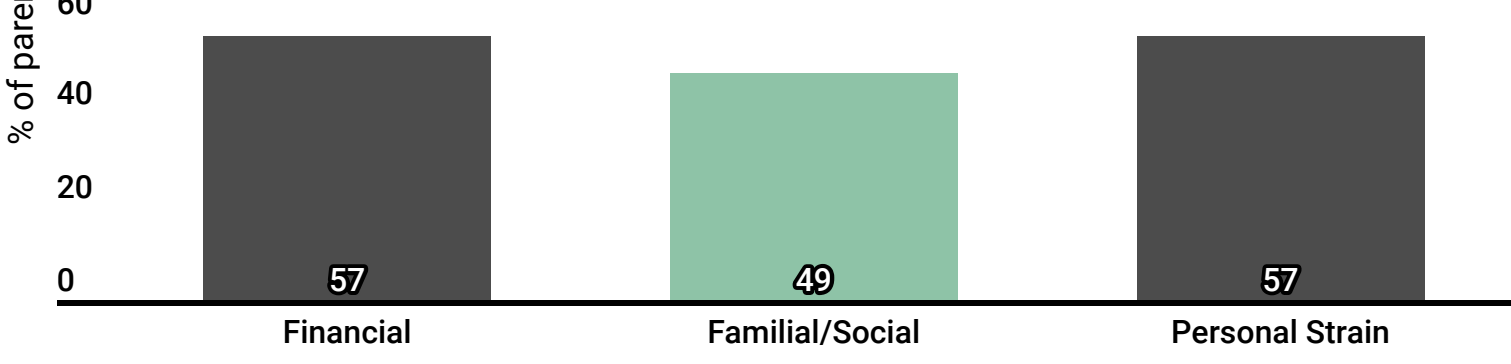
PEDSQoL: Family Impact Module



50% of parents/carers reported that epilepsy had a high impact on their child's quality of life and their family

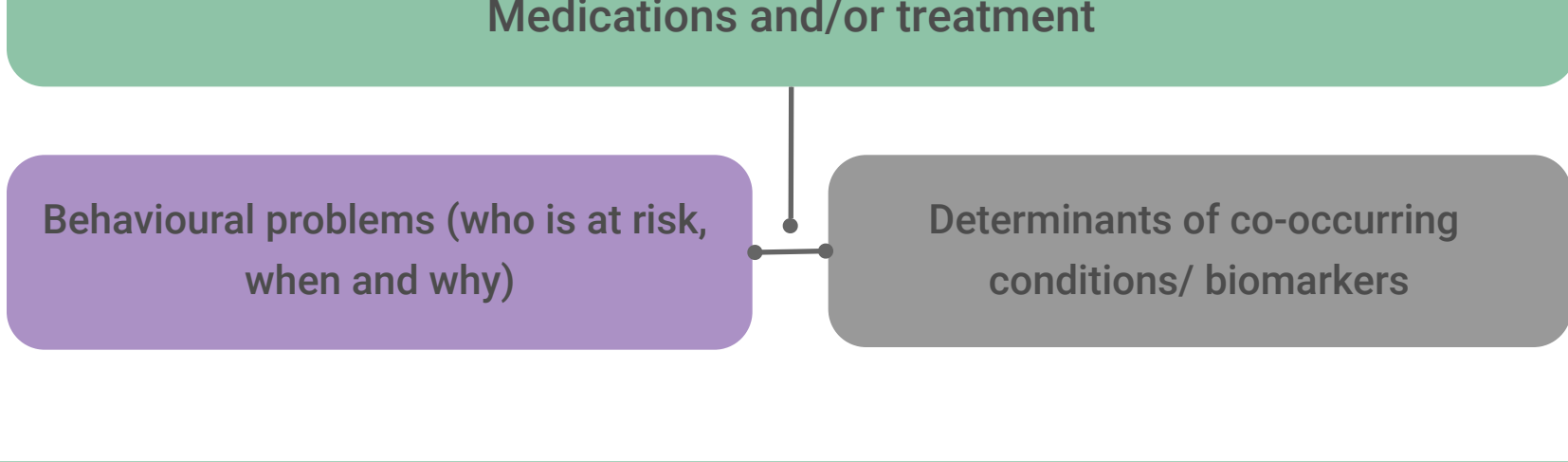
• Parents/carers reported that their child's epilepsy has the most impact on their own cognitive functioning, communication, and family relationships.

Impact on Family Rating Scale



• 57% of parents agreed/strongly agreed that their child's epilepsy had impacted their finances and had placed a psychological burden on them (personal strain).

Top 3 priorities for research



Focus group: Main themes

The goal of the focus group was to provide a safe and open space for parents and carers to share their personal experiences, thoughts and opinions. This allowed us to gain a clearer insight into the impact of childhood epilepsy on family wellbeing and identify priorities for research.

Value of Co-production

How we live and how we feel about what we go through with our children must be integral to anything that you're going to research.

Parents are an important collaborative source.

Parents need to feel that researchers are listening and look at what's actually important to families.

Impact on family and wellbeing

That constant state of anxiety in the back of your mind the whole time, is so exhausting.

I think long term it's still affected our family dynamics. It has changed how we see her and how her siblings see her.

This constant worry is working its way into all aspects of our lives, from planning family trips or activities, to future jobs or job opportunities.

Research priorities

Trajectories related to treatment pathways

Psychological wellbeing and behaviour

Additional needs (e.g., learning difficulties)

Summary

The BEE-PP study findings highlight some of the key areas in which having a child with epilepsy impacts early development and behaviour, the family and overall wellbeing. By creating accessible opportunities for those experiencing and affected by epilepsy to take part in research, we are able to use views from the community to shape future research into early-onset epilepsy.