

CoIN Study Autumn Newsletter 2021



Hello everyone!



The CoIN Study has now been running for 16 months. As we have completed data collection, we would like to update you on what we have been up to and tell you about our plans for the future. The CoIN Study aims to identify specific challenges facing families of children with rare neurodevelopmental and genetic (hereon 'neurogenetic') disorders, track changes in child behaviour, and examine associations between these and parental mental health during the Covid-19 pandemic. Parents/carers (hereon 'parents') of children with rare neurogenetic disorders were invited to complete a baseline survey, monthly follow-ups, and a final survey. These asked about family life and relationships, access to healthcare and education, overall health and wellbeing, child behaviour, and coping during the Covid-19 pandemic. Information collected in the CoIN Study will be used to identify and provide better support to families of children with rare neurogenetic disorders both now and in the future.

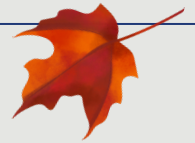


What have we been doing?

We finished circulating the CoIN surveys and collecting data in May 2021, which means that we are now in the process of working through the information we have gathered and planning analyses. We have already looked at some of the information collected in the baseline survey, which you can read more about on the next page. We will be sure to share our findings from the rest of the surveys with you as soon as we can. We have also completed our Community Feedback and Parent/Carer Interview sub-studies. These were invaluable when designing the final CoIN survey, as the responses collected were used to inform the questions that we asked.

Alongside working on the CoIN Study, some of our fantastic team have attended seminars and conferences to present preliminary findings from the CoIN Study to a wider audience. In June, Jess gave a presentation at the 'International Tuberous Sclerosis Complex Research Conference 2021: A Vision for the Future' hosted by the Tuberous Sclerosis Association. She also received an Early Carer Research

award – congratulations Jess! Sarah also gave a presentation on the CoIN Study's preliminary findings at the Centre for ADHD and Neurodevelopmental Disorders Across the Lifespan (CANDAL) seminar series in July, and the Society for the Study of Behavioural Phenotypes (SSBP) international conference in September.

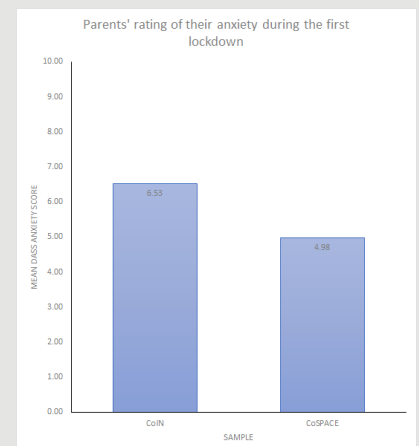


What have we found so far?

We have looked at the survey that was answered during the first lockdown (data collected from May to July 2020). We have created some infographics to report some of the findings from this period, which can be found on our blog (www.coinstudy.co.uk/blog). We also have more in-depth information that is currently being written up into an academic article. While we won't go into as much detail here as we do in the article, here are some of the findings!

Parental mental health

Parents reported, on average, moderate levels of anxiety and severe levels of depression and stress. We compared this to data collected in the Co-SPACE Study, which is a similar study to CoIN but conducted in the wider population. Co-SPACE parents reported only mild anxiety and moderate depression on average, though also experienced severe stress.



Parental anxiety was significantly higher in the CoIN sample than in the Co-SPACE sample.

Child behaviour

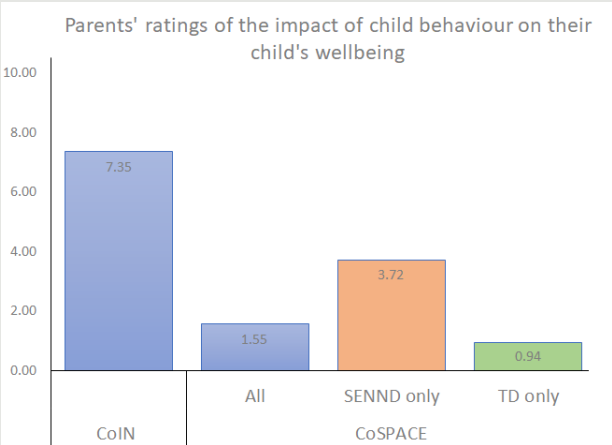
Parents in our sample reported slightly raised levels of externalising child behaviours, such as hyperactivity issues, and high levels of internalising child behaviours, such as emotional problems. We also compared these to the Co-SPACE cohort and found that problematic child behaviours in CoIN were significantly higher than in Co-SPACE.

Impact of child behaviour

The CoIN surveys also asked about families' perceptions on the impact that these behaviours were having on their child. CoIN families thought that the behaviours



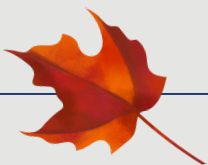
were causing a very high level of impact (7.35 out of 10). This was significantly higher than Co-SPACE families' ratings, even when only considering Co-SPACE families with a child who has special educational needs or a neurodevelopmental disorder (3.72 out of 10). From this, we can clearly see that CoIN families feel that the Covid-19 pandemic may be having a significant impact on their child.



The impact of child behaviour on wellbeing was significantly higher in the CoIN sample than in all sub-sections of the Co-SPACE sample.

While not all effects of the pandemic have been negative (see [here](#)), in our academic article, we advocate for extra help and resources to be given to families like those in the CoIN study to help lessen the perceived impact on their children and to help with parental mental health.

In addition to the surveys, at the start of this year we interviewed 11 parents in the CoIN community to gain a greater insight into their experiences of the Covid-19 pandemic and tap into important elements of their experiences that were not captured by the CoIN questionnaires. These interviews were incredibly insightful, and it was wonderful to be able to truly connect with some of the families in the CoIN community. We are now in the process of analysing the data that we obtained from the interviews. By exploring the similarities and differences between families' experiences, we will be able to provide the best possible support in response to Covid-19 and other future emergency scenarios. Unfortunately, qualitative research demands time and attention to detail such that we are currently unable to provide you with any initial findings. However, we will be sure to share these with you as soon as we can. We are very thankful to everyone who participated in these interviews and shared more of their valuable experiences with us.



What happens next?

Having examined the results from the baseline survey, we will now be looking at some of the longitudinal findings. This means exploring how families' wellbeing has changed over time over the course of the pandemic, by analysing the data

from the follow-up surveys. Once we have some of these results to share with you, we will be sure to post these on our CoIN Study social media accounts and website. Check out our website here (www.coinstudy.co.uk/) to keep up to date with everything that's happening! We will also be asking parents for their feedback on the way we report our findings, to ensure that they are always as accessible to families as possible.

News from the Core CoIN Study Team



Since our last newsletter, we have said goodbye to two team members and hello to two new members! To keep you in the loop, here are some updates on what everyone in the core study team is up to now.

Jess has been a research assistant on the CoIN Study for the past year and is now going on to complete a PhD in medical sciences at the University of Cambridge, focusing on ADHD in children with genetic disorders and intellectual disability. Before leaving KCL, she conducted interviews with families in the CoIN community and is now analysing the data to provide an even richer insight into their experiences during the Covid-19 pandemic. We will miss you Jess!

Katie has been an honorary research assistant on the CoIN Study for the past year and is now returning to the University of Plymouth to complete her final year of her BSc in Psychology. Katie will continue to work with members of the CoIN Study team as she will be exploring some of the data collected in the Early Development in Tuberous Sclerosis (EDiTS) Study, supervised by Charlotte, for her final year research project. Good luck Katie!

Sarah is a post-doctoral researcher who joined the CoIN Study team in April 2021 and is working on analysing and disseminating the data collected from the CoIN Study surveys. Before joining KCL, Sarah obtained a BSc in Psychology from the University of Sheffield and completed a master's degree at Goldsmiths, University of London. She has also recently defended her PhD thesis in Psychology at Coventry University – well done Sarah!

Issy is an undergraduate placement student from the University of Bath where she is studying for a BSc in Psychology. In her first month as part of the CoIN Study



team, Issy has been running the CoIN Study social media accounts and our website. She will be continuing to work with members of the CoIN Study team in the coming year by assisting with data collection in the preschool follow-up phase of the EDiTS Study, supervised by Charlotte.

Abby helped to set up the CoIN Study in the first 2020 lockdown. She has recently graduated and is now an academic junior doctor at the Royal Surrey Hospital – congratulations Abby! Following completing a BSc in Psychology at Loughborough University, Abby stayed in research and works part-time with Charlotte on several research studies investigating mental health and wellbeing in rare genetic conditions.

Charlotte is leading the CoIN Study, alongside a team of UK-wide experts (see our [website](#) for details). She is also launching new studies aiming to chart early development in tuberous sclerosis complex (www.edits-study.org) and early-onset epilepsy (www.beestudy.co.uk). If you're interested, do get in touch to find out more: charlotte.tye@kcl.ac.uk

CoIN Study Team Members



Issy Bowers



Sarah Charles



Jessica Martin



Katie Robertson



Abigail Runicles



Charlotte Tye

Thank you!

With best wishes,

A handwritten signature in black ink, appearing to read 'Charlotte Tye'.

Dr Charlotte Tye & the CoIN Study Team

Contact us: coinstudy@kcl.ac.uk

