**Title**: Additional Sleep Interview for Kids: A qualitative approach to investigating UK access to sleep services

**Authors:** Lauren Walters 1, Aamina Khan 1, Kelan Todd 1, Prof Caroline Richards 1, Dr Georgie Agar 2, Prof Richard Hastings 1, Prof Petrus de Vries 3, Prof Andrew Bagshaw 1, Dr Catherine Hill 4, Dr Stacey Bissell 1

**Background:** Children with intellectual disabilities are more likely to experience poor sleep, including early morning waking and frequent night wakings. The need for overnight care is further exacerbated by the high prevalence of complex health conditions often associated with intellectual disabilities, such as nocturnal seizures. While existing literature addresses caregiver stress and sleep deprivation, the psychosocial impact on same-household siblings remains significantly under-researched. This study aims to investigate the wider familial context relating to sleep, provision of support and sibling experience by utilizing Patient and Public Involvement (PPI) to co-develop both the study design and interview content.

**Method:** A semi-structured interview schedule was developed to explore the perspectives of caregivers of children with intellectual disabilities and complex health needs. To ensure the sensitivity, relevance, and appropriateness of the interview design, the schedule was piloted with a Patient and Public Involvement (PPI) group comprising older adult siblings of individuals with intellectual disabilities. Participants in this PPI group were recruited through Sibs, a sibling support network, and syndrome-specific support groups. Participants provided feedback on various aspects of the study design, including the sensitivity and relevance of the questions. This focus group session was recorded, transcribed verbatim, and analyzed using thematic analysis to identify key areas for revision. The thematic analysis was conducted with NVivo software to facilitate coding and theme generation.

**Results:** The analysis of the PPI feedback revealed several key areas for improvement, prompting revisions to the interview schedule based on these insights. Following revisions, the updated interview schedule was reviewed by a focus group comprising eight clinicians and researchers specializing in intellectual disabilities, neurodevelopmental conditions, and caregiver support. This second focus group took place in person, allowing for further refinement of the interview questions based on expert opinion and experience. The finalized interview schedule was subsequently administered to caregivers of children aged 4–15 years with intellectual disabilities and complex health needs and a same-household sibling without a neurodevelopmental condition. Interviews were conducted online via Zoom with families from the UK and Ireland. Transcribed interviews analyzed via thematic analysis revealed significant impacts of caring for a child with complex health needs on same-household siblings, particularly regarding sleep disturbances, societal consideration in relation to schooling and friendships, and mental health challenges.

**Discussion:** The study underscores the value of Patient and Public Involvement (PPI) in shaping research that is both informed and impactful, demonstrating the benefit of integrating lived experiences with clinical and research expertise when addressing sensitive lived experiences. Findings suggest potential areas for intervention, such as school-based support for siblings experiencing sleep disruption and targeted sibling support. This research provides valuable insights for policymakers and service providers in developing guidelines that better address the specific unmet needs of young carers.

 University of Birmingham

2 Aston University

3 University of Cape Town

4 University of South Hampton