Introduction: Children and adolescents with complex care needs CNN living in the community require the care of a variety of primary and secondary healthcare service providers. Conducted as part of a large ongoing EU Horizon 2020 funded project Models of Child Health Appraised MOCHA, the aim of this study was to provide a contemporary account of the approaches to the integration of care at the acute/community interface for children with CNN.

Methods: Utilising a mixed-methods design, 30 European countries were surveyed, using a local country agent – an expert in child health. Each survey consisted of a vignette and open and closed-ended questions adapted from the Standards for Systems of Care for Children and Youth with Special Health Care Needs 1 and the Eurobarometer Survey 2. Vignettes were developed based on three clinical exemplars: Long-term Ventilation LTV, Intractable Epilepsy, and Traumatic Brain Injury TBI. Categorical data were analysed using descriptive statistics. Textual data were analysed using thematic network analysis 3. This abstract presents a comparison of the key quantitative findings pertaining to care coordination across the three exemplar conditions.

Results: Twenty-three countries 76.7% provided categorical data that could be analysed in relation to care coordination for all three exemplars. Of these countries, ten 43.5% reported they had no mechanisms policies and/or procedures to promote care coordination for children assisted with LTV. A smaller proportion of countries 39.1%, n=9 indicated that they did not have care coordination mechanisms for children with intractable epilepsy or adolescents with TBI. Personalised care plans are developed in consultation with parents/guardians of children assisted with LTV 82.6%, n=19 or with intractable epilepsy 73.9%, n=17 in the majority of countries. The parents/guardians of adolescents with TBI were included in the development of personalised care plans in a smaller proportion of countries 52.2%, n=12.

Discussion: It is likely that there is no "one-size-fits-all" approach to facilitating optimum care for children with CCN, given the diverse nature of conditions represented within this cohort. Complex conditions with a higher prevalence may have specific facilitators at the acute/community interface that are not reflective of rarer conditions.
Conclusions: The results suggest that there are limited mechanisms in place to support the provision of coordinated care for children/adolescents with the three exemplar conditions across 23 European countries.

Lessons learned: This study was reliant on data from a large number of informants being collated by local agents across the 30 MOCHA countries. This process was assisted by the development and utilisation of a glossary of terms in each survey, which ensured uniform comprehension of the included terms.

Limitations: The response rate for returning surveys pertaining to all three exemplar conditions was 76.7%, which was lower than expected. This may have been due to the comparative length of each survey, which was required to build a comprehensive representation of care for children with the three exemplar conditions at the acute/community interface.

Suggestions for future research: Further research should consider geographical variations in the integration of care for children with CCN within countries.

Keywords: children; complex healthcare needs; care coordination; europe