

## CONFERENCE ABSTRACT

# The integration of care at the acute/ community/ primary care interface for children with complex health needs in 30 European Countries: A MOCHA study

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**Introduction:** Internationally, there are wide variations across the systems in place to care for children with complex care needs. The aim of this study is to provide an up-to-date account of the current approaches to the integration of care at the acute/community interface for these children across 30 European countries. This work is part of a large ongoing European Commission Horizon 2020 funded project – Models of Child Health Appraised (MOCHA).

**Methods:** In this non-experimental descriptive study, utilising a sequential explanatory mixed-methods design, we surveyed in each country, using a local agent, a paediatric health expert. The 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, and the Eurobarometer Survey. Vignettes were developed based on three clinical exemplars: Long-term Ventilation (LTV), Intractable Epilepsy, and Traumatic Brain Injury (TBI). Data were analysed to-date using descriptive statistics; thematic analysis of the qualitative data is ongoing. The final results for this study are expected July 2017. This presentation focuses on the early results of the LTV data.

**Results:** There was a response rate of 76% (n=23), of which 22 (73.3%) could be analysed as one of the countries did not offer community care for children on LTV. There are significant gaps in the integration of care for children on LTV across Europe. Forty-five percent (n=10) of the countries surveyed have no policies/ procedures in place to support care coordination for children on LTV, while just over one third (36.4%, n=8) have a discharge planning coordinator in place to oversee the transfer of a child on LTV to home. However, the majority of respondents (63.6%, n= 14) indicated that their country had a process in place to facilitate direct access to and/or from a paediatric intensive care unit.

**Conclusions:** The preliminary results suggest that there are limited structures and processes in place to support integrated care delivery to the child on LTV and their family across 22 European countries.

**Discussion:** It is anticipated that the ongoing analysis of the qualitative data will help to contextualise the results to-date, within the socio-political landscape of each country. Further analysis will explore optimum facilitators of integration of care for these children and their families.

**Lessons learned:** The development of a glossary of terms, with wide consultation across Europe, afforded clarity for data collection. The inclusion of this glossary with each survey facilitated comprehension of the concepts and the questions being asked.

**Limitations:** There was a designated person assigned to respond to the surveys in each participating country. To-date the response rate is below 80%. This may be due to the fact that this was a lengthy survey, reflecting the level of detail required to build a comprehensive picture of the integration of care for this group of children and their families.

**Suggestions for future research:** Further research is important to explore regional variations and equity of provision of integrated care for children with complex care needs.

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**Keywords:** children; complex health needs; integration; europe

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