

Barriers and facilitators to integration of care for children with complex care needs across 30 European countries : A MOCHA study

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Models of Child Health Appraised
(A Study of Primary Healthcare in 30 European countries)

Models of Child Health Appraised (MOCHA)

- Large ongoing European Commission Horizon 2020 funded study
- 42 months duration (June 2015 – November 2018)
- Multi-disciplinary scientific team of researchers from 11 European countries, the US and Australia.
- Overall aim: To perform a systematic scientific evaluation of primary health care services for children in 30 EU/EEA member countries.
- Work is spread over 11 different Work Packages (WP)
- This presentation will focus on some of the results from WP2 (specifically Task 2 – Enduring Complex Conditions)



Work package 2: Safe and Efficient Interfaces of Models of Primary Health Care with Secondary, Social and Complex Care.



WP2 lead Dr Maria Brenner (School of Nursing and Midwifery, Trinity College Dublin, Ireland).



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Task 2: Enduring Complex Conditions

- Overall Aim: to provide an updated comprehensive analysis of the current approach to managing the care of children with complex care needs at the acute community / primary care interface within each EU/EEA Member State.
- Exemplar enduring complex conditions
 - Physical conditions: Long term ventilation, Intractable epilepsy and Traumatic Brain
 - Mental health conditions: Autism and ADHD



Why focus on the care of children with complex conditions?

- Medical, surgical & technological advances have led to increasing numbers of children surviving & living with complex care needs (CCN).
- Growth in the recognition that caring for these children in the home/community environment is beneficial for both the child and their family.
- The medical management of children & adolescents with CCN requires input from a wide variety of primary, specialist and allied healthcare professionals.
- Where integration of this care is inadequate parent(s)/guardian(s) are frequently left to coordinate care their children's care.



Methodology

- 30 EU/EEA countries were surveyed using a local Country Agent (CA) who is an expert in child health.
- Each survey consisted of a clinical vignette relating to one of three exemplar physically complex conditions and open and closed-ended questions adapted the Lucile Packard *Standards for Systems of Care for Children and Youth with Special Health Care Needs* and the *Eurobarometer Survey*.
- Categorical data were analysed using descriptive statistics
- Free text data were analysed using thematic network analysis



Methodology (continued)

- The section of the questionnaire adapted from the *Eurobarometer survey* allowed the CAs to consider the integration of care for children with CCN within a wider context of healthcare policy and socio-cultural factors
- CAs were asked to comment on a number of different areas including;
 - The main barriers/facilitators to integration of care for each of the 3 exemplar conditions
 - Significant changes in the integration of care for each of the 3 conditions during the last 5 yrs.
 - Progress towards integration of care for each of the 3 conditions during the last 5 yrs.
 - Strategies used to improved political awareness regarding need for integrated care services for children with CCN.



Main barriers to the integration of care for each condition

Barrier	TBI	LTV	Intractable Epilepsy
Poor care coordination	X	X	X
Lack of clinical expertise and specialist training	X	X	X
Insufficient funding	X	X	X
Absence of standards of care	X	X	X
Absence of clinical pathways to specialist care	X	X	X
Geographical variation in care	X	X	X
Insufficient development of E health	X	X	X
Insufficient access to psychosocial support	X	X	X
Lack of awareness of adolescent needs	X		
Over diagnosis and over treatment		X	



Main facilitators to the integration of care for each condition

Facilitator	TBI	LTV	Intractable epilepsy
Training and retention of skilled healthcare staff	X	X	X
Timely transfers to home and specialist services	X	X	
Increased political awareness		X	
Adolescent specific care	X		
National data base	X	X	
Enhanced family support	X		X
Enhanced school health	X		X
Enhanced technology support		X	
Increased political awareness		X	

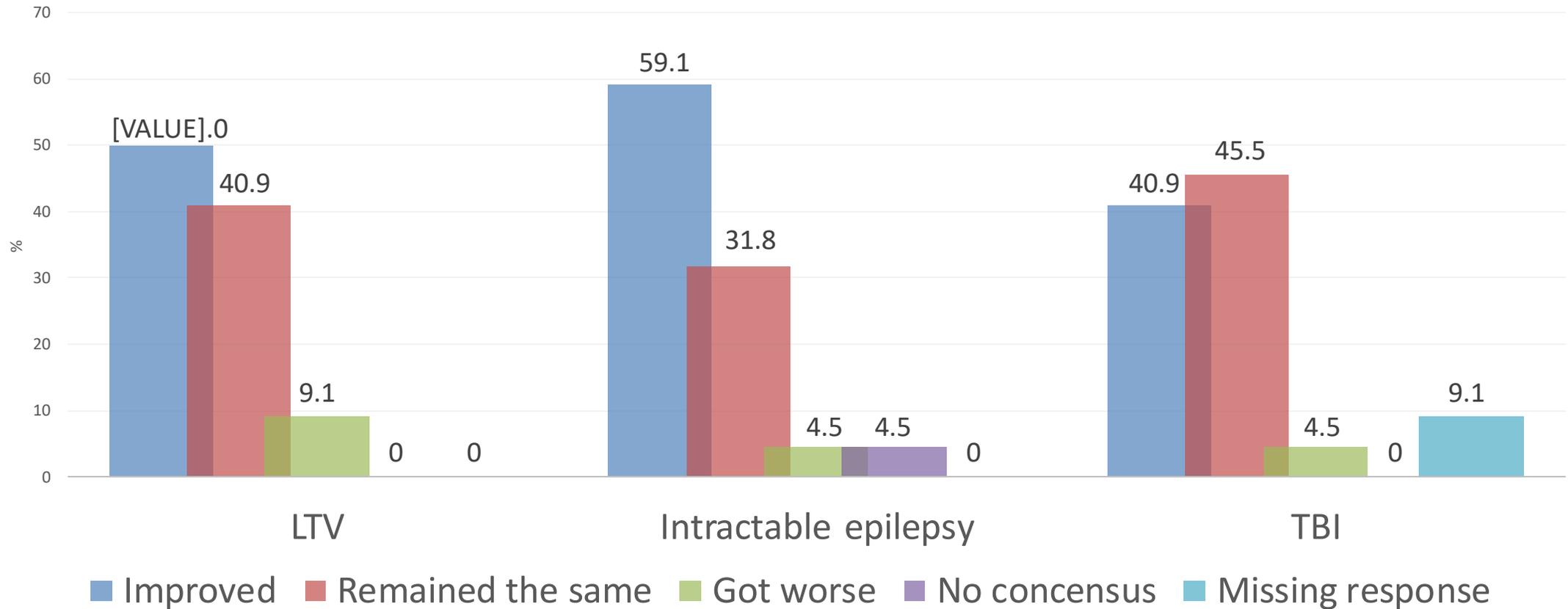


Significant changes in the integration of care in the last 5 yrs

Significant changes in the integration of care in the last 5 yrs.	TBI	LTV	Intractable Epilepsy
Enhanced care coordination	X	X	X
Establishment of integrated care programmes	X	X	X
Establishment of specialist centres and care pathways	X		X
Specialised training for school teachers	X		
Enhanced rehabilitation	X		
Enhanced adolescent care	X		
Availability of written information	X		
Use of electronic health records	X		
Reduction in funding		X	
Establishing expertise in clinical care		X	
Discussion on limits of care		X	
Introduction of digital prescriptions		X	
Introduction of a palliative care strategy		X	
Establishment of advocacy groups			X
Increased participation in care delivery			X
Development of the role of Advanced Nurse Practitioners			X
Increased awareness of needs of siblings			X



Progress in the integration of care in the last 5 yrs



Strategies used to improve political awareness and government recognition of the need for integrated care for children with CCN

Strategy	TBI	LTV	Intractable epilepsy
Media campaigns	X	X	X
Parent lobby groups	X	X	X
Conference debates	X	X	X
Increase in NGOs		X	
EU campaigns			X
Medical expert lobby group			X



Discussion/Conclusion

- The results suggest that there are a variety of processes and structures that act as barriers and facilitators to the integration of care for children with CNN across Europe.
- Although commonalities exist across the results presented, there may be individual critical junctures in care delivery that will demand care provisions that are specific to particular cohorts of children with different complex conditions.
- Future research should be considered exploring innovative ways of minimising the barriers to integration of care for children with CCN



Information and acknowledgments

- More information regarding the MOCHA project including reports may be found at: <http://www.childhealthservicemodels.eu/>
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