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

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Models of Child Health Appraised (MOCHA)

6.8m Euro project funded by EU Commission Horizon 2020 Programme: June 2015 – December 2018.

19 scientific partners from 11 European countries plus US, Switzerland and Australia encompassing medicine, nursing, economics, informatics, sociology and policy management.

30 countries involved via Country Agents to answer questions about a number of work streams.
Aims

Categorise models of primary care incorporating school health and adolescent services.

Develop innovative measures of quality, outcomes and cost.

Assess effects on equality, and on continuity of care with secondary care.

Systematically obtain stakeholder views.

Indicate optimal future patterns to optimise operation of the model(s).

Demonstrate the optimal model(s) of children’s primary care with an analysis of factors (including cultural) which might facilitate adoption, and indications for policy makers of both the health and economic gains possible.
Identification of Models of Children’s Primary Health Care
Prof M Blair, ICL

Interfaces of Models of Primary Health Care with Secondary, Social and Complex Care
Prof M Brenner, TCD

Effective Models of School Health Services and Adolescent Health Services
Dr D Jansen, NL

Identification & Application of Innovative Measures of Quality & Outcome
Dr N Minicuci, CNR

Identification & Use of Derivatives of Large Data Sets and Systems to Measure Quality
Prof S de Lusignan, Surrey

Economic & Skill Set Evaluation & Analysis of Models
Prof H Gage, Surrey

Equity Across Socio-economic, Ethnic and Cultural Divides
Prof A Hjern, Karolinska

The Role of Electronic Records and Data to Support Safe and Efficient Models
Prof M Rigby, ICL

Validated Optimal Models of Children’s Prevention-Orientated Primary Health Care
Dr P Kocken, TNO
Work Package 2: Safe and Efficient Interfaces of Models of Primary Health Care with Secondary Social and Complex Care
Improvements in neonatal and paediatric care.

Challenges on healthcare delivery in the community.

Small proportion of the population but high cost - as much as one-third of healthcare spending for all children.

Provision of care closer to home for such children is a policy objective internationally.

Integration of health services is insufficient with wide variation in systems of care for these children internationally.
Aim

To examine the primary physician/specialist interface, the interface between primary and secondary care for children with enduring health issues and the social care interface with families of children who have complex health needs, leading to the development of a model of complex care delivery.
Objectives

- Identify ‘in-principle’ complex health issues that would be representative of population trends across childhood.

- Adapt tools to gather data on systems of care for children with complex healthcare needs.

- Explore the structures and processes of care in place for children with complex healthcare needs, identifying those which are part of primary care services.

- Identify facilitators and barriers of optimum integration of care at the acute community interface for children with complex healthcare needs.
Referral / Discharge Interface
Enduring Complex Conditions
Social Care Interface
Nursing and Skills
Patient and Family Experience
Business Model of Continuity of Complex Care

Reviews, case studies, surveys, document analysis, interviews

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 634201
Methods

Challenge: develop a research approach that could help facilitate comparative research, by providing a data collection method that could be used across 30 states.

Non-experimental descriptive study with a qualitative element – a pragmatic and pluralist approach.

Development of vignettes and survey.
Vignette 1

Max is an eighteen month old boy with a diagnosis of chronic lung disease due to bronchopulmonary dysplasia. Max was born at 26 weeks gestation weighing less than 1kg. He had a diaphragmatic hernia, a gastrostomy tube placement at three months of age, and a Grade IV intraventricular haemorrhage requiring a cerebrospinal fluid ventricular shunt. Max has been ventilator dependent since he was born and is considered to have a life-threatening condition. A tracheostomy tube was placed at six weeks of age due to the need for ongoing ventilation. Max spent the first three months of his life in intensive care, followed by four months in a step-down/transitional care unit. At present Max has the following: impaired pulmonary function, developmental delay in fine and gross motor skills, and speech and language difficulties. His prognosis for weaning off the ventilator does not seem favourable at the moment and ideally he requires the healthcare input of the following healthcare professionals: community nurses, specialist consultants (respiratory, paediatrician, neurology), community general practitioner, pharmacist, speech and language therapist, physiotherapist, occupational therapist, social worker, dentist, home care nursing team and respite care services. He lives with his two sisters, aged 5 and 7 years, and his mother and father. He lives 120kms from the main children’s hospital and 40kms from his nearest regional hospital which has a small paediatric unit.
Vignette 2

Lara is a 7 year old girl who lives at home with her mum, dad, and younger brother, aged 18 months. Lara has developmental delay and initially presented with infantile spasms. The infantile spasms resolved with treatment, however, Lara has been presenting with generalised seizures for the last three years and has intractable epilepsy. She is currently on a ketogenic diet administered through a gastrostomy tube but is not responding to it. She is waiting surgery for insertion of a vagal nerve stimulator. Lara has seizures at least three times a day and has presented in the Emergency Department more than 20 times in the last year. She is confined to a wheelchair and has significant physical and emotional care needs and requires the input of the following: epilepsy specialist nurses (inpatient and community), community nurses, specialist consultants (neurology, paediatrician), community general practitioner, pharmacist, speech and language therapist, physiotherapist, psychologist, occupational therapist, and social worker. Lara’s parents are non-EU migrants who settled in your country 9 years ago. Her Dad only speaks his native language while her Mum has basic knowledge of the official language of your country.
Vignette 3

Luke, a 15 year old previously healthy adolescent, suffered a head injury in a skateboard accident. Initially he had no loss of consciousness but fifteen minutes later he was unresponsive with dilating and slow reacting pupils bilaterally. Following initial assessment in the ED he was transferred to the Paediatric Intensive Care Unit where he was ventilated and sedated. An MRI showed a left-sided extradural bleed with no midline shift and he had surgery for evacuation of the bleed on Day 2. He did not have any spinal injury. He was extubated after 6 days and was discharged to the neurological ward. After four weeks in hospital he was transferred to a rehabilitation centre where he spent five months. On his recent discharge to home he has ongoing right-sided weakness and has facial palsy, which is slowly improving. He is very anxious and is aggressive towards his parents and his twin sister. His care involves input from a large number of multidisciplinary healthcare professionals. In the coming months it is hoped that he will resume his education and in the coming years he will need to transfer to adult care services.
Screening, assessment and referral
Access to care
Care coordination
Community-based services
Family-professional partnerships
Transition to adulthood
Quality assurance and improvement
CA in each of the 30 countries - a local expert in child health services, who acts as the informant for obtaining data requested by the principal scientists in the project, from local indigenous sources (http://www.childhealthservicemodels.eu/partnerlisting/country-agents).

Stakeholders: clinical experts in acute and community settings; health care managers and discharge coordinators; European patient advocacy groups.
Key Facilitators and Barriers to Care Integration - LTV
24/7 access to Paediatric Intensive Care Unit

Access to unscheduled and urgent specialist care

24/7 access to Paediatric Emergency Department

Monthly specialist home visit

Coordinated pathway to specialist care

Pathway to non-urgent specialist care

Complex care centres

Psychological and psychiatric support

Hospice and respite care
Legal, policy and governance structure

- Transport
- Infrastructure
- Governance of care provided in the home
- Care coordination
- Standards for care delivery
- Data access and communication

Geographical variation

- Official disability
- Legal Status
- Advocacy
- Role of NGOs

- Right to long-term care
- Parent’s voice in initiatives

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Key Facilitators and Barriers to Care Integration - TBI

Transitioning to adult services

Environment of care

Adolescent units

Adolescent specific care

Voice of the adolescent

Adolescent and family engagement

Family support needs

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Key Facilitators and Barriers to Care Integration - IE

- Parental choice
- Need versus diagnosis
- Transitions in care
- Policy and Procedure
- Specialist referral
- Disability versus primary care services
- Migrant status
- Geographical isolation
Poor communication

Variable QA systems

National accreditation systems

Communication

Electronic records

Adult support services

Websites

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Proportion of Countries with Systems in Place to Identify all Healthcare Providers

![Bar chart showing the proportion of countries with systems in place to identify all healthcare providers for different conditions.](chart.png)

- **Long-term ventilation**: 70.0% Yes, 30.0% No
- **Intractable Epilepsy**: 45.0% Yes, 55.0% No
- **Traumatic Brain Injury**: 35.0% Yes, 65.0% No
Access to Psychological Support for Families

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Families Invited to Participate in Development of Policies

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Families Invited to Participate in National Quality Improvement Initiatives

![Bar chart showing participation rates for different conditions]

- LTV: 30.0% Yes, 65.0% No, 5.0% Missing response
- Intractable Epilepsy: 45.0% Yes, 50.0% No, 5.0% Missing response
- TBI: 25.0% Yes, 70.0% No, 5.0% Missing response

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Family involvement in Reviews of Culturally and Linguistically Appropriate Information

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Needs of children with complex conditions - cross cutting themes

Access to care / equity

Geographical variation / isolation
Pathways to health and social care

Inadequate
Shared documentation / electronic records

Challenges in participation in decisions / advocacy
Parent as catalyst

Care coordination / flexible support

Family/professional partnerships / participation
Optimal Models of Child Health Care

Work package distilling key elements for a range of condition types and situations reflective of primary care functions (Lead Paul Kocken TNO NL)

Early diagnosis

Chronic care quality

Preventive care coverage

School and adolescent health services

Vulnerable children – migrants
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Thank You

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