

ISSUES AND OPPORTUNITIES IN PRIMARY HEALTH CARE FOR CHILDREN IN EUROPE

ISSUES AND OPPORTUNITIES IN PRIMARY HEALTH CARE FOR CHILDREN IN EUROPE

The Final Summarised Results of the Models of Child Health Appraised (MOCHA) Project

EDITED BY

MITCH BLAIR, MICHAEL RIGBY, DENISE ALEXANDER Imperial College London, UK



The project was funded by the European Commission through the Horizon 2020 Framework under the grant agreement number: 634201. The sole responsibility for the content of this work lies with the authors. It does not necessarily reflect the opinion of the European Union. The European Commission is not responsible for any use that may be made of the information contained therein



United Kingdom - North America - Japan - India - Malaysia - China

Emerald Publishing Limited Howard House, Wagon Lane, Bingley BD16 1WA, UK

First edition 2019

Copyright © 2019 European Commission.



Except where otherwise noted, this work is licensed under a Creative Commons Attribution 4.0 Licence (CC BY 4.0).

Anyone may reproduce, distribute, translate and create derivative works of this book (for both commercial and non-commercial purposes), subject to full attribution to the original publication and authors. The full terms of this licence may be seen at https:// creativecommons.org/licenses/by/4.0/

British Library Cataloguing in Publication Data

A catalogue record for this book is available from the British Library

ISBN: 978-1-78973-354-9 (Print) ISBN: 978-1-78973-351-8 (Online) ISBN: 978-1-78973-353-2 (Epub)



The ebook edition of this title is Open Access and is freely available to read online.

Open Access



ISOQAR certified Management System, awarded to Emerald for adherence to Environmental standard ISO 14001:2004.



Certificate Number 1985 ISO 14001

Contents

List of Figures	ix
List of Tables	xiii
List of Contributors	xvii
Foreword	xix

Chapter 1 The MOCHA Project: Origins, Approach and Methods Mitch Blair, Denise Alexander and Michael Rigby	1
Chapter 2 Models of Primary Care and Appraisal Frameworks	
Mitch Blair, Mariana Miranda Autran Sampaio,	
Michael Rigby and Denise Alexander	13
Chapter 3 Listening to Young People	
Kinga Zdunek, Manna Alma, Janine van Til,	
Karin Groothuis-Oudshoorn, Magda Boere-Boonekamp and	
Denise Alexander	55
Chapter 4 Child Centricity and Children's Rights	
Kinga Zdunek, Michael Rigby, Shalmali Deshpande and	
Denise Alexander	77
Chapter 5 Equity	
Mitch Blair and Denise Alexander	99
Chapter 6 The Limited Inclusion of Children in Health and	
Health-related Policy	
Mitch Blair, Michael Rigby, Arjun Menon,	
Michael Mahgerefteh, Grit Kühne and Shalmali Deshpande 12	21

Chapter 7 The Invisibility of Children in Data Systems

Michael Rigby, Shalmali Deshpande, Daniela Luzi, Fabrizio Pecoraro, Oscar Tamburis, Ilaria Rocco, Barbara Corso, Nadia Minicuci, Harshana Liyanage, Uy Hoang, Filipa Ferreira, Simon de Lusignan, Ekelechi MacPepple and Heather Gage 129

Chapter 8 The Conundrum of Measuring Children's Primary Health Care

Ilaria Rocco, Barbara Corso, Daniela Luzi, Fabrizio Pecoraro, Oscar Tamburis, Uy Hoang, Harshana Liyanage, Filipa Ferreira, Simon de Lusignan and Nadia Minicuci

Chapter 9 Measurement Conundrums: Explaining Child Health Population Outcomes in MOCHA Countries

Heather Gage and Ekelechi MacPepple

Chapter 10 Services and Boundary Negotiations for Children with Complex Care Needs in Europe

Maria Brenner, Miriam O'Shea, Anne Clancy, Stine Lundstroem Kamionka, Philip Larkin, Sapfo Lignou, Daniela Luzi, Elena Montañana Olaso, Manna Alma, Fabrizio Pecoraro, Rose Satherley, Oscar Tamburis, Keishia Taylor, Austin Warters, Ingrid Wolfe, Jay Berry, Colman Noctor and Carol Hilliard 199

Chapter 11 School Health Services

Danielle Jansen, Johanna P. M. Vervoort, Annemieke Visser,Sijmen A. Reijneveld, Paul Kocken, Gaby de Lijster andPierre-André Michaud219

Chapter 12 Primary Care for Adolescents

Pierre-André Michaud, Johanna P.M. Vervoort and Danielle Jansen 237

Chapter 13 Workforce and Professional Education

Mitch Blair, Heather Gage, Ekelechi MacPepple,Pierre-André Michaud, Carol Hilliard, Anne Clancy,Eleanor Hollywood, Maria Brenner, Amina Al-Yassin andCatharina Nitsche247

Chapter 14	e-Health as the Enabler of Primary Care for Children	
Michael Rig	by, Grit Kühne and Shalmali Deshpande	283

179

159

Chapter 15 Affiliate Contributors to Primary Care for Children	
Denise Alexander, Uttara Kurup, Arjun Menon,	
Michael Mahgerefteh, Austin Warters, Michael Rigby and	
Mitch Blair	303
Chapter 16 The Transferability of Primary Child	
Healthcare Systems	
Paul Kocken, Eline Vlasblom, Gaby de Lijster, Helen Wells,	
Nicole van Kesteren, Renate van Zoonen, Kinga Zdunek,	
Sijmen A. Reijneveld, Mitch Blair and Denise Alexander	331
Chapter 17 National and Public Cultures as Determinants of	
Health Policy and Production	
Kinga Zdunek, Mitch Blair and Denise Alexander	345
Chapter 18 Bringing MOCHA Lessons to Your Service	
Magda Boere-Boonekamp, Karin Groothuis-Oudshoorn,	
Tamara Schloemer, Peter Schröder-Bäck, Janine van Til,	
Kinga Zdunek and Paul Kocken	359
Chapter 19 Evidence to Achieve an Optimal Model for	
Children's Health in Europe	
Mitch Blair, Michael Rigby and Denise Alexander	371
Appendix 1: List of MOCHA Scientists	385
Appendix 2: List of MOCHA Country Agents	391
Index	393

List of Figures

Chapter 1		
Figure 1.1.	The Country Agent process.	9
Figure 1.2.	Integration of MOCHA project activities over 42 months	11
Chapter 2		
Figure 2.1.	The MOCHA working model	40
Chapter 3		
Figure 3.1.	Respondents' opinions on the age at which a child should be able to do the activities mentioned in the 10 Questions, presented as cumulative percentages of respondents of the five countries together.	63
Figure 3.2.	Respondents' opinions on the age at which a child should be able to do the activities, averaged for the 10 questions, presented as cumulative percentages of respondents for each of the five countries.	64
Figure 3.3.	Percentage of agreement (summed percentage of respondents that agree and strongly agree) with the statements on autonomy-related attribute-items, indicated by the respondents of the five countries, based on their experiences.	67
Chapter 4		
Figure 4.1.	Child-centric health policy	84
Figure 4.2.	Child as the central actor in the process of shaping child health policy.	86
Chapter 6		
Figure 6.1.	Overview on consideration of children and adolescents in national e-health strategies in Europe.	126
Chapter 7		
Figure 7.1.	Overview of child health indicators available through the HBSC portal.	134
Figure 7.2.	Overview of health indicators available through the Eurostat database.	136
Figure 7.3.	Example of the four levels of hierarchy for causes of mortality.	138

x List of Figures

Figure 7.4.	Overview of indicators available through World Bank Open Data database.	140
Figure 7.5.	Distribution (<i>n</i>) of measures available in international databases by disease – total number of countries providing data for at Least One measure related to the specific disease.	148
Figure 7.6.	Distribution (n) of measures provided by CAs by disease. Total number of CAs reporting at least one measure related to the specific disease.	150
Chapter 8		
Figure 8.1.	Path diagram of the relationships across the research questions.	169
Figure 8.2.	Path diagram of the hypothesised SEM model (structural and measurement models).	170
Figure 8.3.	Schematic diagram for the measures classification	174
Figure 8.4.	Flow of the compilation of metadata catalogue and semantic models to harmonise case definitions and facilitate comparison from different data sources.	176
Chapter 10		
Figure 10.1.	Model of key themes influencing the care of children with enduring mental health needs at the primary care interface.	212
Figure 10.2.	An Example of UML use of case diagram: provision of screening services for children with autism.	213
Chapter 12		
Figure 12.1.	Countries with extensive policy on AHS	240
Chapter 13		
Figure 13.1.	Skills and qualifications required to adequately treat and monitor vulnerable children.	261
Figure 13.2.	Nursing training requirements to look after children with CCN.	275
Figure 13.3.	Distribution of Child-related Content across the Different Modules in the Curriculum.	276
Chapter 14		
Figure 14.1.	Use of EHRs in delivery of primary care for children	285
Figure 14.2.	Use of child public health EHRs in Europe	286
Figure 14.3.	Overview of countries with URIs to link children's health records in the EU/EEA	287

Figure 14.4.	Overview on when the URI is issued	288
Figure 14.5.	Overview on national issuing process and URI function	288
Figure 14.6.	If there is not a linked record between primary care services and school health services, what type of information is it policy to pass <i>from</i> the SHS practitioner <i>to</i> the primary care practitioner?	295
Figure 14.7.	Looking at communication in the other direction, from primary care to school health service professionals, what is the policy of information sharing <i>from</i> primary care <i>to</i> the school health service?	296
Figure 14.8.	If a pupil sustains an injury in school that needs urgent medical treatment, is the school able to supply to the urgent treatment centre: the child's tetanus immunisation status?	297
Figure 14.9.	According to the policy for record keeping in your country, can a child request to have sight of their medical records?	297
Figure 14.10.	Countries where a child can specify that their parents <i>may not</i> see part of their medical records	298
Chapter 15		
Figure 15.1.	Training in the management and treatment of common illnesses in childhood.	307
Figure 15.2.	Conceptual framework behind the assessment framework	320
Figure 15.3.	Integration between primary health care/social care stipulated in legal/policy framework.	321
Chapter 16		
Figure 16.1.	The PIET-T model with systematised criteria to determine transferability.	333
Chapter 18		
Figure 18.1.	Adapted PIET-T model with systematised criteria to determine transferability with 'P' concretised for	2(1
Figure 10 2	children s primary health care	301
Figure 18.2.	Evidence usage in child health policy-making.	36/
Figure 18.5.	rypes of most effective format of recommendations	369

List of Tables

Chapter 2

Table 2.1.	Mapping of models of provision in MOCHA countries	17
Table 2.2.	Dimensions of the conceptual general health frameworks	32
Table 2.3.	Dimensions of the primary health care conceptual frameworks.	35
Table 2.4.	Structure of a model in terms of the MOCHA project	42
Table 2.5.	Primary care in a child centred ecological model and MOCHA.	45
Table 2.6.	Life stage of a child and the MOCHA project (Broadly illustrated by school ages, which may have different parameters in different countries).	48
Chapter 3		
Table 3.1.	Overview of number of children and number and type of interviews in each country.	59
Table 3.2.	Percentage of agreement (summed percentage of respondents that agree and strongly agree) with the statements on autonomy-related attribute items, indicated by the respondents of the five countries.	65
Chapter 4		
Table 4.1.	Timeline of increasing awareness and respect for the rights of a child in Europe.	81
Table 4.2.	Rights of children to primary health care	91
Chapter 5		
Table 5.1.	Levels of equality regarding entitlements to health care for three groups of migrant children compared to national children. (No data = no data were available)	111
Chapter 7		
Table 7.1.	Overview of child health indicators available on the WHO Health for All explorer.	133
Table 7.2.	Overview of child health indicators on the Eurostat database.	137
Table 7.3.	List of health indicators available through World Bank Open Data database.	141

xiv List of Tables

Table 7.4.	Distribution of measures by age ranges in international databases.	146
Table 7.5.	Distribution of measures by age ranges according to Country Agent responses.	147
Table 7.6.	National data on health expenditure and financing and for the MOCHA countries.	153
Chapter 8		
Table 8.1.	Measures identified by WP-leader related to coordination and assumed values.	162
Table 8.2.	Measures identified by WP-leader related to coordination and attributed scores	
Table 8.3.	Scores assumed in the coordination measures by the MOCHA countries.	164
Table 8.4.	Kendall's correlation matrix (* $p < 0.05$)	165
Table 8.5.	Countries distribution by e-coordination strength	165
Table 8.6.	National expenditure on 'Governance and health system administration' by e-coordination strength (Euro Per Inhabitant, 2015).	
Table 8.7.	Current health care expenditure by e-coordination strength (Euro Per Inhabitant, 2015)	166
Table 8.8.	Decomposition of the effects estimated by the hypothesised SEM model.	17
Chapter 9		
Table 9.1.	Financing and service delivery classifications	183
Table 9.2.	PHAMEU scoring system for the strength of the countries' primary care system (Kringos et al., 2013).	18:
Table 9.3.	Description of dependent and independent variables used in the analysis.	187
Table 9.4.	Summary descriptive statistics of quantitative variables included in the analysis for the 30 MOCHA countries, $2004-2016$ ($N = 390$ is complete data for all countries and all years).	189
Table 9.5.	Values of quantitative variables by country – last year for which data were available.	190
Table 9.6.	Results of regression modelling.	192

Chapter 10		
Table 10.1.	Access to care for children with complex care needs	203
Table 10.2.	Co-creation of care for children with complex care needs	206
Table 10.3.	Effective integrated governance for children with complex care needs.	208
Chapter 11		
Table 11.1.	Essential indicators of access of SHS	224
Table 11.2.	Essential indicators of workforce in school health services	229
Chapter 12		
Table 12.1.	Indicators of quality management for mental health services and sexual and reproductive health care for adolescents	242
Chapter 13		
Table 13.1.	Healthcare expenditure and workforce data for the MOCHA countries.	249
Table 13.2.	Density of paediatricians by MOCHA typology of primary care for children.	251
Table 13.3.	Questions on workforce sent to Country Agents	252
Table 13.4.	Primary care (PC) workforce configuration, summary of Country Agent responses.	254
Table 13.5.	Country Agent responses to questions on training of workforce for children in primary care	256
Table 13.6.	A whole population approach: patient segments in child health.	260
Table 13.7.	Three representative countries	262
Table 13.8.	Characteristics of the European medical schools' curricula analysed by MOCHA.	262
Table 13.9.	Mandatory courses related to health care of subgroups of vulnerable children in Bulgaria, Germany and Iceland	264
Table 13.10.	Skills and qualifications to overcome challenges in adequate treatment of vulnerable children	265
Table 13.11.	A child health provider's required qualifications	266
Table 13.12.	Training in adolescent health delivered within various disciplines and important topics in primary care, across all participating countries.	268

Chapter 14

Table 14.1.	Functionality and data exchange of child public health systems.	280
Table 14.2.	Overview on organisational linkages electronic record data sharing.	290
Table 14.3.	Overview on types of electronic health data exchanged	291
Table 14.4.	What is the policy in your country for health professionals of the school health service (SHS) in keeping their own health records?	293
Table 14.5.	MOCHA countries with website accreditation process in place.	299
Table 14.6.	MOCHA countries with apps accreditation process reported.	299
Chapter 15		
Table 15.1.	Policy for provision of consulting rooms in pharmacies	305
Table 15.2.	Is there a policy that all children have access to a dentist free of charge?	310
Table 15.3.	Access for children with a disability or with a specific clinical risk.	312
Table 15.4.	Legal entitlement to social care for children with complex care needs in European countries.	31′
Chapter 18		
Table 18.1.	Overview of the quality aspects with a high potential for improvement, presented for each of the five countries	36:
Chapter 19		
Table 19.1.	Total non-accidental deaths and Rate of Change in 20–24-year-olds (2006–2016) (GBD Study)	374

List of Contributors

Denise Alexander Imperial College London, UK Manna Alma University Medical Center Groningen, Netherlands Amina Al-Yassin Imperial College London, UK Jay Berry Boston Children's Hospital, USA Mitch Blair Imperial College London, UK Magda Boere-University of Twente, Netherlands Boonekamp Maria Brenner Trinity College Dublin, Ireland Anne Clancy University of Tromsø, Norway Barbara Corso CNR Neuroscience Institute (IN), Padova, Italy Shalmali Deshpande Imperial College London, UK Filipa Ferreira University of Surrey, UK University of Surrey, UK Heather Gage Karin Groothuis-University of Twente, Netherlands Oudshoorn Carol Hilliard Our Lady's Children's Hospital, Crumlin, Dublin Eleanor Hollywood Trinity College Dublin, Ireland Uy Hoang University of Surrey, UK Danielle Jansen University Medical Center Groningen, Netherlands Stine Lundstroem University of Southern Denmark, Denmark Kamionka Nicole van Kesteren TNO (Netherlands Organisation for Applied Scientific Research), Netherlands Paul Kocken TNO (Netherlands Organisation for Applied Scientific Research), Netherlands Grit Kühne Imperial College London, UK Uttara Kurup Imperial College London, UK Philip Larkin Université de Lausanne, Switzerland, previously Sapfo Lignou King's College London, UK Gaby de Lijster TNO (Netherlands Organisation for Applied Scientific Research), Netherlands Harshana Liyanage University of Surrey, UK University of Surrey, UK Simon de Lusignan

Daniela Luzi

Daniela Luzi	CNR Institute for Research on Population and Social Policies (IRPPS), Rome, Italy
Ekelechi MacPepple	University of Surrey, UK
Michael Mahgerefteh	Imperial College London, UK
Arjun Menon	Imperial College London, UK
Pierre-André Michaud	University Hospital of Lausanne, Switzerland
Nadia Minicuci	CNR Neuroscience Institute (IN), Padova, Italy
Elena Montañana Olaso	Trinity College Dublin, Ireland
Miriam O'Shea	Trinity College Dublin, Ireland
Catharina Nitsche	Imperial College London, UK
Colman Noctor	Trinity College Dublin, Ireland
Fabrizio Pecoraro	CNR Institute for Research on Population and Social Policies (IRPPS), Rome, Italy
Sijmen A. Reijneveld	University Medical Center Groningen, Netherlands
Michael Rigby	Imperial College London, UK
Ilaria Rocco	CNR Neuroscience Institute (IN), Padova, Italy
Mariana Miranda Autran Sampaio	Imperial College London, UK
Rose Satherley	King's College London, UK
Tamara Schloemer	Maastricht University, Netherlands
Peter Schröder-Bäck	Maastricht University, Netherlands
Oscar Tamburis	CNR Institute for Research on Population and Social Policies (IRPPS), Rome, Italy
Keishia Taylor	Trinity College Dublin, Ireland
Janine van Til	University of Twente, Netherlands
Johanna P. M. Vervoort	University Medical Center Groningen, Netherlands
Annemieke Visser	University Medical Center Groningen, Netherlands
Eline Vlasblom	TNO (Netherlands Organisation for Applied Scientific Research), Netherlands
Austin Warters	Trinity College Dublin, Ireland
Helen Wells	Keele University, UK
Ingrid Wolfe	King's College London, UK
Kinga Zdunek	Medical University of Lublin, Poland
Renate van Zoonen	TNO (Netherlands Organisation for Applied Scientific Research), Netherlands

Foreword

When I reflect back on the last 35 years of clinical practice as a paediatrician, I am very aware of the considerable changes to children's health which have occurred in my country and in Europe. Many diseases I saw as a student and young trainee have all but disappeared through the development and administration of new vaccines or the introduction of novel technological discoveries such as artificial surfactant, home ventilation and new drugs for cancer treatment. These have resulted in improved survival of so many children and young people who would have otherwise suffered premature death from the myriad of different congenital or acquired conditions. At the same time, I am all too cognisant of the effects of the degree of social change both in terms of the changing nature of family structure and stability, of unacceptable levels of poverty and inequity, environmental challenges such as nutrition, housing and pollution, the effects of national and international conflict leading to unprecedented movement of families between continents and of the huge changes in the speed and breadth of communication and social media. In parallel, there are increased levels of mental health disorder, obesity, neurodevelopmental issues such as specific learning difficulties, ADHD and autism and the sheer complexity of multimorbidity of twenty-first-century children and young people.

How do we ensure that we keep up to date and that clinical care remains relevant and effective in such circumstances? Clearly, clinical practice not only depends on the capacity and competence of well-trained practitioners but also depends on the context of a country or region's health care system and this, in turn, has its own historical, cultural, political and economic origins. And in any country, primary care is the first port of call, where the great majority of prevention, diagnosis and treatment are carried out.

It is the attention to both the clinical and the wider aspects of primary child health care which was the focus and purpose of the Models of Child Health Appraised (MOCHA) project, funded by the European Union's Horizon 2020 programme from 2015 to 2018. MOCHA set out to describe the organisation of primary care for children and young people in all 28 EU and two EEA countries in Europe. We originally set out to answer which systems work best and how might we use such knowledge to improve the delivery of primary care for this population; it also allowed us a unique view of the current situation in Europe and how we might shape the next era. As a multidisciplinary international research team of over 80 individuals, we wanted to explore this from multiple perspectives and this is reflected in the fact that we drew expertise from many different professional and scientific disciplines: paediatrics, school and adolescent specialists, public health and family practice, nursing, social science and care, political science, economics, health management, informatics, epidemiology, statistics and even criminology. Michael, Denise and I have worked with each other for at least two decades on a number of European projects and for MOCHA – this itself is a story, to be told elsewhere, of the slow evolution of European child public health projects. In MOCHA, we were most ably supported by our project manager, Christine Chow. My respect for and gratitude to them all is immeasurable. This core team, along with the committed group of co-worker scientists slowly growing in number and influence over this period, very much bonded as a 'family' over the last four years, and together we have been on a fascinating voyage of discovery, challenge and mutual learning. In another aspect of development, eight babies were born to members of the MOCHA family over that time!

It has been an extraordinarily rich experience for me personally and I am sure this is the same for many of those involved. We have had many challenges. It was frustrating and disappointing that we were unable to find robust and readily available routine data to inform so many of our appraisal processes, an important discovery in itself. However, we gained enormously from the insights of children in a number of countries who told us what they thought about the services offered, and especially and uniquely, from the detailed answers from the country agents in each country and from the extensive literature and other reviews carried out by the MOCHA scientists. This book is the culmination of that joint learning which I know will help us all to take the next steps in further improving the outcomes for millions of children and young people in Europe.

Professor Mitch Blair – Principle Investigator, MOCHA. Imperial College, London, UK