



Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

ISSUES AND OPPORTUNITIES IN PRIMARY HEALTH CARE FOR CHILDREN IN EUROPE

This page intentionally left blank

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



Certificate Number 1985
ISO 14001

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



INVESTOR IN PEOPLE

Contents

List of Figures	<i>ix</i>
List of Tables	<i>xiii</i>
List of Contributors	<i>xvii</i>
Foreword	<i>xix</i>
Chapter 1 The MOCHA Project: Origins, Approach and Methods <i>Mitch Blair, Denise Alexander and Michael Rigby</i>	<i>1</i>
Chapter 2 Models of Primary Care and Appraisal Frameworks <i>Mitch Blair, Mariana Miranda Autran Sampaio, Michael Rigby and Denise Alexander</i>	<i>13</i>
Chapter 3 Listening to Young People <i>Kinga Zdunek, Manna Alma, Janine van Til, Karin Groothuis-Oudshoorn, Magda Boere-Boonekamp and Denise Alexander</i>	<i>55</i>
Chapter 4 Child Centricity and Children's Rights <i>Kinga Zdunek, Michael Rigby, Shalmali Deshpande and Denise Alexander</i>	<i>77</i>
Chapter 5 Equity <i>Mitch Blair and Denise Alexander</i>	<i>99</i>
Chapter 6 The Limited Inclusion of Children in Health and Health-related Policy <i>Mitch Blair, Michael Rigby, Arjun Menon, Michael Mahgerefteh, Grit Kühne and Shalmali Deshpande</i>	<i>121</i>

Chapter 7 The Invisibility of Children in Data Systems	
<i>Michael Rigby, Shalmali Deshpande, Daniela Luzi, Fabrizio Pecoraro, Oscar Tamburis, Iliara Rocco, Barbara Corso, Nadia Minicuci, Harshana Liyanage, Uy Hoang, Filipa Ferreira, Simon de Lusignan, Ekelechi MacPepple and Heather Gage</i>	129
Chapter 8 The Conundrum of Measuring Children’s Primary Health Care	
<i>Iliara Rocco, Barbara Corso, Daniela Luzi, Fabrizio Pecoraro, Oscar Tamburis, Uy Hoang, Harshana Liyanage, Filipa Ferreira, Simon de Lusignan and Nadia Minicuci</i>	159
Chapter 9 Measurement Conundrums: Explaining Child Health Population Outcomes in MOCHA Countries	
<i>Heather Gage and Ekelechi MacPepple</i>	179
Chapter 10 Services and Boundary Negotiations for Children with Complex Care Needs in Europe	
<i>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</i>	199
Chapter 11 School Health Services	
<i>Danielle Jansen, Johanna P. M. Vervoort, Annemieke Visser, Sijmen A. Reijneveld, Paul Kocken, Gaby de Lijster and Pierre-André Michaud</i>	219
Chapter 12 Primary Care for Adolescents	
<i>Pierre-André Michaud, Johanna P.M. Vervoort and Danielle Jansen</i>	237
Chapter 13 Workforce and Professional Education	
<i>Mitch Blair, Heather Gage, Ekelechi MacPepple, Pierre-André Michaud, Carol Hilliard, Anne Clancy, Eleanor Hollywood, Maria Brenner, Amina Al-Yassin and Catharina Nitsche</i>	247
Chapter 14 e-Health as the Enabler of Primary Care for Children	
<i>Michael Rigby, Grit Kühne and Shalmali Deshpande</i>	283

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

This page intentionally left blank

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

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 (<i>n</i>) 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 children's primary health care	361
Figure 18.2.	Evidence usage in child health policy-making.	367
Figure 18.3.	Types of most effective format of recommendations.	369

This page intentionally left blank

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.. . . .	163
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).	166
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.	171
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).	185
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.	286
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.	317

Chapter 18

Table 18.1.	Overview of the quality aspects with a high potential for improvement, presented for each of the five countries.	365
-------------	--	-----

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

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

xviii List of Contributors

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

Chapter 1

The MOCHA Project: Origins, Approach and Methods

Mitch Blair, Denise Alexander and Michael Rigby

Abstract

Primary care (PC) is a strong determinant of overall health care. Children make up around a fifth of the population of the European Union and European Economic Area and have their own needs and uptake of PC. However, there is little research into how well PC services address their needs. There are large differences in childhood mortality and morbidity patterns in the EU and EEA countries, and there has been a major epidemiological shift in the past half century from predominantly communicable disease, to non-communicable diseases presenting and increasingly managed in PC. This increase in multifactorial morbidities, such as obesity and learning disability, has led to the need for PC systems to adapt to accommodate these changes. Europe presents a challenging picture of unexplained variation in health care delivery and style and of children's different health experiences and health-related behaviour. The Models of Child Health Appraised (MOCHA) project aimed to describe the PC systems in detail, analyse their components and appraise them from a number of different viewpoints, including professional, public, political and economic lenses. It did this through nine work packages supported by a core management team, and a network of national agents, individuals in each MOCHA country who had the expertise in research and knowledge of their national health care system to answer a wide range of questions posed by the MOCHA scientific teams.

Keywords: Child health; primary care; scientific appraisal; research; child morbidity; child



© European Commission. Published by Emerald Publishing Limited. This chapter is published under the Creative Commons Attribution (CC BY 4.0) licence. Anyone may reproduce, distribute, translate and create derivative works of this chapter (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 <http://creativecommons.org/licenses/by/4.0/legalcode>

Background and Origins

Primary care (PC) is the first point of contact with the health services for most people. Almost all health care, except for major trauma, starts in PC.¹ PC, therefore, strongly determines the overall pattern of health care, and also to a great extent, it influences the pattern of health of the population. Children are a fifth of the population and have their own needs for and patterns of uptake of PC. Despite this, there is little research into the use of PC by children and young people and into how well PC services address the needs of children and young people.

Children's health affects the future of Europe. Children are citizens, future workers, future parents and carers and the future elderly population. Ensuring an optimum healthy start to each child's life is the basis for later active and healthy ageing. Children may only make up to a fifth of the population of each country, but they are 100% of our future.

A child's health is determined by many factors over the life course, including the influence of the family, peers, culture, beliefs, education, physical environment and of course health services (World Health Organization, 2008). These elements can either protect and promote health, or restrict the family's choices about health. A child changes considerably at different ages and at developmental stages. At the beginning of life, he or she is entirely dependent on others and highly influenced by the family, social, educational and natural environment. In the teenage years, there is a shift to increasing independence and autonomy, requiring a different health service response.

PC health services are influenced by many determinants, such as the history, culture, politics and economics of a country (see Chapter 17; Blair, Stewart-Brown, Waterson, & Crowther, 2010). The child and family, also, exert a powerful influence in shaping health services through co-creation with health professionals (Ferrer, 2015). It is this dynamic interaction between the developing child and family and the health services that is a core aspect of the Models of Child Health Appraised (MOCHA) project, funded by the European Commission's Horizon 2020 research programme (European Commission, 2018).

Society has a duty to provide health care. Though much reliance is placed, rightly, on the family, it has to be recognised that for some children, this support is missing or compromised. In addition, a child's health is strongly affected by the immediate physical, economic and cultural environment; this can take the form of, among other factors, the relationship between pollution and respiratory health; the availability of toys or books in the house and cognitive and language development; or the impact of social media on self-image, peer relationships and well-being. The health services play an important role in safeguarding children from such threats to their health. Essentially, not only is a child's good health

¹According to the UK Royal College of General Practitioners in evidence to the UK Parliamentary Select Committee on Health, primary care accounts for 90% of patient contacts with the English NHS, but the source is not cited, and no equivalent figure is available from WHO, OECD or Eurostat.

desirable, but it is a fundamental right, as set out by the UN Convention on the Rights of the Child in Article 24 (United Nations, 1989; Chapter 4).

Children's Health in Europe

The variations in child and adolescent health status in Europe are well described in the latest Report from the World Health Organization (World Health Organization Regional Office for Europe, 2018b). In the past decade there have been considerable improvements in overall childhood mortality with major reductions being seen in all countries over time. Seventeen of the 30 MOCHA countries have adopted the WHO Child and Adolescent Health Regional Strategy 2015–2020 (Regional Committee for Europe, 2015) which was designed to help member states develop:

evidence-based frameworks for review and improvement of child and adolescent health and development policies, programmes and action plans from a life-course perspective; promote multisectoral action; and identify the health sectors role in developing and coordinating policy and delivering services that meet children's and adolescent's health needs.

(World Health Organization Regional Office for Europe, 2018b, p. 3)

Twelve of the 17 countries adopting the Strategy have reported that they specifically allocated budgets and have monitoring systems in place (World Health Organization Regional Office for Europe, 2018b).

Despite this, there are large differences between Member States in both mortality and morbidity patterns, risk-taking and exploratory behaviours, mental health and well-being, infectious diseases and environmental health, nutrition and physical activity levels and the degree to which rights and participation of children and young people are exercised. For example, the difference in recently reported hospitalisation rates of 0- to 14-year-olds varies fivefold between Spain and Bulgaria (52/1,000 and 256/1,000, respectively). About 90% of Lithuanian 15-year-old boys report "high life satisfaction levels" compared to 84% in the UK. Variations in PC family practitioner service provision indicate that Greece has almost nine times fewer general practitioners (GPs) per 100,000 population than Portugal (World Health Organization Regional Office for Europe, 2018b).

Thus, Europe presents a challenging picture of unexplained variation in health care delivery and style and of children's different health experiences and health-related behaviour. This also means that Europe provides a unique laboratory to examine different health systems in depth and, in particular, the PC system contribution to health and well-being and its contribution to the health of Europe's children. There is little knowledge relevant to twenty-first-century Europe of the effects on child health of publically funded health systems versus insurance based, and the relative access and provision of services (especially preventive services) to children within these, together with regulatory and governance issues; the benefits

or otherwise of some direct personal service provision (such as immunisation and screening) by dedicated public sector child health services; the role of and provision of different models of school health services; models of the availability and adequacy of direct access for adolescents to mental health and reproductive health services in particular, to avoid unnecessary morbidity and mortality; and models of care for children and their families at the acute–community interface and at health–social care interface for children at risk or in receipt of social care.

Changing Epidemiology

The last 50 years has seen a major shift in disease patterns in many countries from a predominance of communicable disease to one of the non-communicable morbidities, such as mental health, long-standing illness and injury (Haggerty, 1995; Wolfe, Thompson, et al., 2013). This epidemiological shift from single agent causes, such as infectious disease, to multifactorial morbidities such as obesity or learning disability requires a change in emphasis in PC practice. Specific professional skills are necessary to tackle these issues, while ensuring that the key attributes of PC – access, coordination, continuity and equitable service provision – are maintained (Starfield, Shi, & Macinko, 2005).

Defining Primary Care and Its Scope

The MOCHA project has worked to certain definitions of functions and features of PC:

- *Primary health care (PHC)* refers to the concept elaborated in the 1978 Declaration of Alma-Ata (World Health Organization, 1978), which is based on the principles of equity, participation, inter-sectoral action, appropriate technology and a central role played by the health system.
- *PC* is first-contact, accessible, continued, comprehensive and coordinated care. Ideally, first-contact care is accessible at the time of need, ongoing care focuses on the long-term health of a person rather than the short duration of a specific disease, comprehensive care is a range of services appropriate to the common problems in the respective members of the population, and coordination is the role by which PC acts to coordinate other specialists that the patient may need (World Health Organization, 2018a).
- *General practice* is a term now often used loosely to cover the general practitioner and other personnel and is therefore synonymous with PC and family medicine (FM). Originally, it was meant to describe the concept and model around the most significant single player in PC: the general practitioner or PC physician, while FM originally encompassed the notion of a team approach as well as recognition of the patient’s family own setting. The general practitioner is the only physician who operates at the nine levels of care: prevention, screening, early diagnosis, diagnosis of established disease, management of disease, management of disease complications, rehabilitation, palliative care and counselling (World Health Organization, 2018a).

- *FM or PC teams* can vary between countries and in size: the core team usually is the general practitioner and a nurse, but can comprise a multidisciplinary team of up to 30 professionals including community nurses, midwives, feldshers,² dentists, physiotherapists, social workers, psychiatrists, speech and language therapists, dietitians, pharmacists, administrative staff and managers. PC/FM teams should be patient-centred, so their composition and organisational model can change over time (World Health Organization, 2018a).
- *PC paediatricians* deal comprehensively with the health and well-being of infants, children and adolescents within the context of their families, communities and cultures. PC paediatrics sees infants, children and adolescents as its main subject of care, respecting their autonomy and involving parents, guardians and/or custodians as integral part of the ‘unit of care’. They may or may not work with multidisciplinary teams (ECPCP, 2018).
- *Nursing* encompasses autonomous and collaborative care of individuals of all ages, families, groups and communities, sick or well and in all settings. Nursing includes the promotion of health, prevention of illness and the care of ill, disabled and dying people. Advocacy, promotion of a safe environment, research, participation in shaping health policy and in patient and health systems management, and education are also key nursing roles. Nurses include professional nurses, enrolled nurses, auxiliary nurses and other nurses such as dental or PC nurses (International Council of Nurses, 2015).

Scope of Primary Child Health Care in MOCHA

The principles of PC can be described by their functioning; however, the pattern of provision of each can vary according to regulation and governance, funding mechanism, access rules and distribution within a community. Thus, there are many forms of PC for children across Europe which are taken as being within the scope of the MOCHA project. They are as follows:

- physician care for acute (in and out of office hours) and chronic illness;
- nursing care including home visiting (especially where the nurse acts autonomously or with only very broad supervision);
- school health (school is frequently considered as ‘outside’ the usual model of PC services – but is often the primary access point for health care for this cohort of children)
- direct access services, particularly for adolescents (also often considered outside PC, but a vital first contact point);
- community pharmacy;
- community dental services;
- health promotion services; and
- society-facing e-health (telephone hotlines, websites and apps).

²A health care professional who provides various medical services limited to emergency treatment and ambulance practice.

Despite PC being an important aspect of health care for children, it is at the same time a relatively under-addressed area of health systems research. This is despite the importance and potential for massive health gains that focusing on the child population of Europe can provide both for children and young people themselves (well-being) and for future adults (well becoming). On this background, a number of publications have described the previous provision of paediatric services in PC in Europe and have demonstrated a pattern of decreasing numbers of PC paediatric providers and an increase in GP led and mixed medical and nursing systems (Ehrich et al., 2015; van Esso et al., 2010; Katz, Rubino, Coller, Rosen, & Ehrich, 2002). However, evidence of differences in outcomes attributable to different systems is somewhat scant (Wolfe, Thompson, et al., 2013) and certainly there has to date been no systematic research of all 30 EU and EEA countries carried out prior to the MOCHA project.

The EC Horizon 2020 call in the area of public health care research in 2014 (*H2020-PHC-23-2014, Developing and comparing new models for safe and efficient, prevention oriented health and care systems*) gave an opportunity for us to bid successfully for a €6.8m grant to enable the Imperial College-led team to research the primary child health care provision in 28 EU and two EEA countries with the objective of describing and appraising this diversity of health care systems in relation to child health and with the advantage of a number of different and complementary scientific disciplines. We were keen to build on the knowledge and experience gained on previous European projects on which many of the scientists had worked together. These included CHILD (on indicators), PHASE (on public health actions for a safer Europe), EUGLOREH (on state of health), RICHE (on child health research gaps) and TRANSFoRm (on linking health databases), as well as the WHO European Region Child and Adolescent Health and Development Strategy 2005 and its monitoring subproject.

A strong feature of MOCHA, as was also the case in the aforementioned projects, has been the assembly of a very broad multidisciplinary research team of selected scientists from across Europe, together with focussed American and Australian input. The team consisted of 19 institutional partners in 11 countries with expert scientists in the fields of paediatric, adolescent and family practice medicine, child public health, nursing, psychology, policy and health management, political science, sociology, statistics, informatics, epidemiology and health economics. Like a kaleidoscope, we were able to shine many different lights on the issue and look at PC in its many forms. The following sections describe the overall aims and how the project was structured to meet these.

MOCHA Project Aims

A key objective for MOCHA was firstly to describe the PC systems in detail and their components and to appraise them from a number of different viewpoints,

professional, public (including parents, children and wider community), political and economic lenses.

More specifically, we wished:

- to describe the various models of PC that exist in the 28 EU countries and two EEA countries;
- to describe the full scope of PC that exists for young people including school and adolescent health services, helplines, community pharmacy and dental services;
- to research existing theoretical appraisal frameworks for PC systems and their use;
- to source measures of health systems outcomes and PC quality including national and regional databases;
- to describe the workforce structure in each country and economic aspects of health-care funding and spend and their relationship;
- to analyse equity of provision of the various models;
- to describe the types and use of health records systems as an integral part of a modern effective system;
- to explore child centred socio-political and cultural context and obtain patient and stakeholder views of the system;
- to identify optimal models of patient-centred, prevention-oriented, efficient, resilient, safe and sustainable child health system provision; and
- to raise awareness of the issues and assess transferability between settings.

MOCHA Project Structure and Operation

The project was designed around a number of discrete Scientific Work Packages (WPs) with their own leads and focusing on specific interrelated themes listed below:

- WP1: Identification of the various models of children's PHC;
- WP2: Safe and efficient interfaces of models of children's PHC;
- WP3: Effective models of school and adolescent health services;
- WP4: Identification and application of innovative measures of quality and outcomes of models;
- WP5: Identification and use of derivatives of large data sets and systems to measure quality;
- WP6: Economic and skill set evaluation and analysis of models;
- WP7: Ensuring equity for all children in all models;
- WP8: Use of electronic records to enable safe and efficient models; and
- WP9: Validated optimal models of children's prevention-oriented PHC.

The various scientific WPs were supported by a core project management team also responsible for dissemination strategy for the outputs. An external advisory board (EAB) was assembled to give further scientific and contextual

support to the core team and WP leads throughout the project period. This consisted of individuals drawn from international scientists, non-government organisations and European specialist associations, with its own chairperson.

A full list of the scientists in each WP and the leads and EAB members is given in Appendix 1.

Country Agents

Another principle feature has been the extensive use of country agents as informants with local knowledge of the national situation, who have responded to the survey questions set by the scientist teams.

Identifying the Country Agents

Each of the 11 EU/EEA Scientific Partner countries nominated one individual who could act as country agent for their country. In the remaining 19 countries where there was no research partner, the MOCHA country agents were identified through a combination of previous European Union research projects, word of mouth, contacts and requests. This group of individuals were required to undertake specific information gathering tasks to defined instructions and supply academically robust material (see Appendix 2 for a list of Country Agents). The MOCHA project used a mixed-methods approach, reflecting the many influences and components of PC. The agents were expected to have a good knowledge of children's health issues and the national health system and health determinant issues in their country. In addition, they needed to recognise the importance of complete and accurate data being obtained for research and to work with high integrity and have the ability to deal with vernacular material. High levels of trustworthiness and confidence were necessary prerequisites for the scientific team.

We knew that The MOCHA question topics were likely to be diverse, ranging from the care in the community of children with complex care needs, to national data surveillance of child PC tracer conditions, to qualitative research into cultural influences on child health policy-making. Thus, there was a clear expectation that they were also expected to have access to an adequate network to enable the collection of material on aspects on which they themselves were not necessarily always expert.

Developing the Country Agent Working Process and Project Timetable

The Country Agent process was based on 'rounds' of questioning; which began in October 2015 and ended in March 2018. Each round took approximately eight weeks to complete, and each stage within the process was timetabled so that everyone in the project knew when to expect questions and resulting data. In total, 15 rounds of questions were completed during the project.

Broadly, a round consisted of between two and four sets of questions from one or more of the MOCHA WPs. Within the overall scientific plan of the