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

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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

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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-Boonekamp	University of Twente, Netherlands
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
Heather Gage	University of Surrey, UK
Karin Groothuis-Oudshoorn	University of Twente, Netherlands
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 Kamionka	University of Southern Denmark, Denmark
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
Simon de Lusignan	University of Surrey, UK

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

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

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

[1]According 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).

[2]A 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