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:

The final summarised results of the Models of Child Health Appraised (MOCHA) Project

Chapter Abstracts

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Issues and Opportunities in Primary Health Care for Children in Europe: The final summarised results of the Models of Child Health Appraised (MOCHA) Project

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Chapter Abstracts

This synopsis brings together the Abstracts of the nineteen chapters in the full document, which itself is available at http://www.childhealthservicemodels.eu/wp-content/uploads/MOCHA-Issues-and-Opportunities-in-Primary-Health-Care-for-Children-in-Europe.pdf. The full document will also be published in April 2019 as an Open Access on-line book (with full index) by Emerald Publishing (https://www.emeraldpublishing.com/), with a paperback version available too.

Separately, an overall Final Report to the European Commission Research Directorate on the overall project and key findings will be submitted in January 2019 and will also be available on www.childhealthservicemodels.eu, where details of scientific publication from the project will also be found..

Chapter 1

The MOCHA Project: Origins, Approach and Methods

Mitch Blair, Denise Alexander, Michael Rigby

Abstract

Primary care 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 primary care. However there is little research into how well primary care 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 primary care. This increase in multifactorial morbidities, such as obesity and learning disability, has led to the need for primary care 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 MOCHA project aimed to describe the primary care 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.

Chapter 2

Models of Primary Care and Appraisal Frameworks

Mitch Blair, Mariana Miranda Autran Sampaio, Michael Rigby, Denise Alexander

Abstract

The MOCHA project identified the different models of primary care that exist for children, examined the particular attributes that might be different from those directed at adults, and considered how these models might be appraised. The project took the multiple and interrelated dimensions of primary care and simplified them into a conceptual framework for appraisal. A general description of the models in existence in all 30 countries of the EU and EEA countries, focusing on lead practitioner, financial, and regulatory and service provision classifications was created. We then used the WHO 'building blocks' for high-performing health systems as a starting point for identifying a good system for children. The building blocks encompass safe and good quality services from an educated and empowered workforce, providing good data systems, access to all necessary medical products, prevention and treatments; and a service that is adequately financed and well led. An extensive search of the literature failed to identify a suitable appraisal framework for MOCHA, because none of the frameworks focused on child primary care in its own right. This led the research team to devise an alternative conceptualisation, at the heart of which is the core theme of child centricity and ecology, and the need to focus on delivery to the child through the life course. The MOCHA model also focuses on the primary care team and the societal and environmental context of the primary care system.

Chapter 3
Listening to young people

Kinga Zdunek, Manna Alma, Janine van Til, Karin Groothuis-Oudshoorn (2), Magda Boere-Boonekamp, Denise Alexander

Abstract

Children's voices are seldom heard directly. Most often, children, particularly young children, are represented by adults acting on their behalf who may or may not best represent the child's views or best interests. This can be beneficial or problematic, if the child's needs are not appreciated or recognised. This chapter looks at the changing attitudes to listening to young people, and the growing recognition of the value of children's needs, as well as the growing voices of the children themselves, who make their needs increasingly clear. The results of our MOCHA interviews with children and young people via the DIPEx International organisation give us clear direction as to the importance children using primary care services place on being taken seriously, being listened to and being able to make their own decisions. Other researchers asked input from primary care professionals on children's autonomy and how the current and future primary care systems can best address the needs of young people, as well as the placing of these issues in a wider cultural context, and how this influences and is influenced by children's choices. Finally, we look at how the MOCHA country agents have reported the assessment of the importance and function of listening to young people in our research.

Chapter 4
Child Centricity and Children's Rights

Kinga Zdunek, Michael Rigby, Shalmali Deshpande, Denise Alexander

Abstract

The child is at the centre of all MOCHA research, and indeed all primary care delivery for children. Appraising models of primary care for children is incomplete without ensuring that experiences of primary care, design, treatment, management and outcomes are optimal for the child. However, the principle of child centricity is not implicit in many health care systems, and in many aspects of life, yet it is extremely important for optimal child health service design and child health. By exploring the changing concept of 'childhood', we understand better the emergence of the current attitude towards children and their role in today's Europe, and the evolution of child rights. Understanding child centricity, and the role of agents acting on behalf of the child, allows us to identify features of children's primary care systems that uphold the rights of a child to optimum health. This is placed against the legal commitments made by the countries of the EU and EEA to ensure that children's rights are respected.

Chapter 5
Equity

Mitch Blair, Denise Alexander

Abstract
Equity is an issue that pervades all aspects of primary care provision for children, and as such is a recurring theme in the MOCHA project. All EU member states agree to address inequalities in health outcomes, and include policies to address the gradient of health across society, and targeting particularly vulnerable population groups. The project sought to understand the contribution of primary care services to reducing inequity in health outcomes for children. We focused on some key features of inequity as they affect children, such as the importance of good health services in early childhood, and the effects of inequity on children, such as the higher health needs of underprivileged groups, but their generally lower access to health services. This indicates that health services have an important role in buffering the effects of social determinants of health by providing effective treatment that can improve the health and quality of life for children with chronic disorders. We identified common risk factors for inequity, such as gender, family situation, socioeconomic status, migrant or minority status and regional differences in health care provision, and attempted to measure inequity of service provision. We did this by analysing routine data of universal primary care procedures, such as vaccination, age at diagnosis of autism, or emergency hospital admission for conditions that can be generally treated in primary care; against variables of inequity, such as indicators of SES, migrant/ethnicity or urban/rural residency. In addition, we focused on the experiences of child population groups particularly at risk of inequity of primary care provision: migrant children and children in the state care system.

Chapter 6
The Limited Inclusion of Children in Health and Health-Related Policy

Mitch Blair, Michael Rigby, Arjun Menon, Michael Mahgerefteh, Grit Kühne, Shalmali Deshpande

Abstract
Whilst nations have overall responsibility for policies to protect and serve their populations, in many countries, health policy, and policies for children are delegated to regions or other local administrations, which makes it a challenging subject to explore on a national level. We sought to establish which countries had specific strategies for child and adolescent health care, and whether primary care, social care and school health care interface was described and planned for within any policies that exist. In addition we established the extent to which a child health strategy and meaningful reference to children's records and care delivery exist in an e-health context. Of concern in the MOCHA context is that 40% of EU and EEA countries had no health strategy for children, and more than a half had no reference to supporting delivery of children's health in their e-health strategy.

We investigated the differences in ownership and leadership of children's policy, which was a range of ministry input (health, education, labour, welfare or ministries of youth and family); as well as cross-ministerial involvement. In terms of national policy planning and provider planning,

we investigated the level of discussion, consultation and interaction between national health care bodies (including insurance bodies), providers and the public in policy implementation. The MOCHA project scrutinised the way countries aim to harness the latest technologies by means of e-health strategies, to support health services for children, and found that some had no explicit plans whereas a few were implementing significant innovation. Given that children are a key sector of the population, who by very nature have a need to rely on government and formally governed services for their wellbeing in the years when they cannot themselves seek or advocate for services, our findings are particularly worrying.

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, Heather Gage

Abstract
In order to assess the state of health of Europe's children, or to appraise the systems and models of healthcare delivery, data about children are essential, with as much precision and accuracy as possible by small group characteristic. Unfortunately, the experience of the MOCHA project and its scientists shows that this ideal is seldom met, and thus the accuracy of appraisal or planning work is compromised. In the project, we explored the data collected on children by a number of databases used in Europe and globally, to find that although the four quinquennial age bands are common, it is impossible to represent children aged 0-17 years as a legally defined group in statistical analysis. Adolescents, in particular, are the most invisible age group despite this being a time of life when they are rapidly changing and facing increasing challenges. In terms of measurement and monitoring, there is little progress from work of nearly two decades ago that recommended an information system, and no focus on the creation of a policy and ethical framework to allow collaborative analysis of the rich anonymised databases that hold real-world people-based data. In respect of data systems and surveillance, nearly all systems in European society pay lip-service to the importance of children, but do not accommodate them in a practical and statistical sense.

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, Nadia Minicuci

Abstract
Evaluating primary care for children has not before been undertaken on a national level, and only infrequently on an international level, an adult-focused perspective is the norm. The MOCHA project explored the evaluation of quality of primary care for children in a nationally comparable way, which recognises the influence of all components of child well-being and well-becoming. Using adult-focused metrics fails to account for children's physical and psycho-social

development at different ages; differences in health and non-health determinants; patterns of disease and risk factors and the stages of the life course. To do this, we attempted to identify comparable measures of child health in the EU and EEA countries, we aimed to perform a structural equation modelling technique to identify causal effects of certain policies or procedures in children's primary care, and we aimed to identify and interrogate large data sets for key tracer conditions. We found that the creation of comparative data for children and child health services remains a low priority in Europe, and the largely unmet need for indicators covering all the health care dimensions hampers development of evidence-based policy. In terms of the MOCHA project objective of appraising models of child primary health care, the results of this specific work show that the means of appraisal of system and service quality are not yet agreed or mature, as well as having inadequate data to fuel them.

Chapter 9
Measurement conundrums: Explaining child health population outcomes in MOCHA countries

Heather Gage, Ekelechi MacPepple

Abstract

The MOCHA countries are diverse socially, culturally and economically, and differences exist in their health care systems and in the scope and role of primary care. An economic analysis was undertaken that sought to explain differences in child health outcomes between countries. The conceptual framework was that of a production function for health, whereby health outputs (or outcomes) are assumed affected by several 'inputs'. In the case of health, inputs include personal (genes, health behaviours) and socio-economic (income, living standards) factors, and the structure, organisation and workforce of the health care system. Random effects regression modelling was used, based on countries as the unit of analysis, with data from 2004 – 2016 from international sources and published categorisations of health care system. The chapter describes the data deficiencies and measurement conundrums faced, and how these were addressed. In the absence of consistent indicators of child health outcomes across countries, five mortality measures were used: neonatal, infant, under 5, diabetes (0-19 years), epilepsy (0-19 years). Factors found associated with reductions in mortality were: GDP per capita growth (neonatal, infant, under 5); higher density of paediatricians (neonatal, infant, under 5); less out-of-pocket expenditure (neonatal, diabetes 0-19); state based service provision (epilepsy 0-19); lower proportions of children in the population, a proxy for family size (all outcomes). Findings should be interpreted with caution due to the ecological nature of the analysis and the limitations presented by the data and measures employed.

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, Carol Hilliard

Abstract

Improvements in neonatal and paediatric care mean that many children with complex care needs (CCN) now survive into adulthood. This cohort of children place great challenges on health and social care delivery in the community: they require dynamic and responsive health and social care over a long period of time; they require organisational and delivery coordination functions; and health issues such as minor illnesses, normally presented to primary care, must be addressed in the context of the complex health issues. The clinical presentation of these in any individual may be difficult to recognise and therefore challenge local care management. Within this context is the desire to provide care close to home. The project explored the interface between primary care and specialised health services, and found that it is not easily navigated by children with CCNs and their families across EU and EEA countries. We described the referral-discharge interface, the management of a child with CCNs at the acute-community interface, social care, nursing preparedness for practice and the experiences of the child and family in all MOCHA countries. We investigated data integration, the presence of validated standards of care, including governance and co-creation of care. In addition, the needs of children with severe or long-lasting mental health disorders are distinct from children with physical health disorders and they often co-exist. A separate inquiry as to how the essential care is accessed, the level of parental involvement and the presence of multi-disciplinary teams was conducted. For all children with CCNs, we found wide variation in access to and governance of care. Effective communication between the child, family and health services remains challenging; particularly in the case of complex mental health conditions where there is fragmentation of care delivery across the health and social care sector; and limited service availability.

Chapter 11

School Health Services

Danielle Jansen, Hanneke Vervoort, Annemieke Visser, Menno Reijneveld, Paul Kocken, Gaby de Lijster, Pierre Andre Michaud

Abstract

MOCHA defines school health services as those that exist due to a formal arrangement between educational institutions and primary health care. School health services are unique in that they are designed exclusively to address the needs of children and adolescents in this age group and setting.

We investigated school health services have been provided to schools, and how they contribute to primary health care services for school children. We did this by mapping the national school

health systems against the standards of the World Health Organization, and against a framework measuring the strength of primary care, adapting this from an existing, adult-focused framework.

We found that all but two countries in the EU and EEA have school health services. There, however, remains a need for much greater investment in the professional workforce to run the services, including training to ensure appropriateness and acceptability to young people. Greater collaboration between school health services and primary care services would lead to better coordination, and the potential for better health (and educational) outcomes. Involving young people and families in the design of school health services and as participants in its outputs would also improve school health.

Chapter 12

Primary care for adolescents

Pierre-Andre Michaud, Danielle Jansen

Abstract

Adolescence is a time when a young person develops his or her identity, acquires greater autonomy and independence, experiments and takes risks, and grows mentally and physically. To successfully navigate these changes, an accessible and health system when needed, is essential.

We assessed the structure and content of national primary care services against these standards in the field of adolescent health services. The main criteria identified by adolescents as important for primary care are: accessibility, staff attitude, communication in all its forms, staff competency and skills, confidential and continuous care, age appropriate environment, involvement in health care, equity and respect, and a strong link with the community.

We found that although half of the MOCHA countries have adopted adolescent-specific policies or guidelines, many countries do not meet the current standards of quality health care for adolescents. For example, the ability to provide emergency mental health care, or respond to life-threatening behaviour is limited. Many countries provide good access to contraception, but specialised care for a pregnant adolescent may be hard to find.

Access needs to be improved for vulnerable adolescents; greater advocacy should be given to adolescent health and the promotion of good health habits. Adolescent health services should be well publicised, and adolescents need to feel empowered to access them.

Chapter 13
Workforce and Professional Education

Mitch Blair, Heather Gage, Ekelechi MacPepple, Pierre-Andre Michaud, Carol Hilliard, Anne Clancy, Eleanor Hollywood, Maria Brenner, Amina Al-Yassin, Catharina Nitsche

Abstract

Given that the workforce constitutes a principal resource of primary care, appraisal of models of care requires thorough investigation of the health workforce in all MOCHA countries. This chapter explores this in terms of workforce composition, remuneration, qualifications, and training in relation to the needs of children and young people. We have focused on two principal disciplines of primary care – medicine and nursing, with a specific focus on training and skills to care for children in primary care, particularly those with complex care needs, adolescents and vulnerable groups. We found significant disparities in workforce provision and remuneration; in training curricula; and in resultant skills of physicians and nurses in EU and EEA Countries. A lack of overarching standards and recognition of the specific needs of children reflected in training of physicians and nurses may lead to sub-optimal care for children. There are, of course many other professions that also contribute to primary care services for children, some of which are discussed in Chapter 15, but we have not had resources to study these to the same detail.

Chapter 14
E-Health as the Enabler of Primary Care for Children

Michael Rigby, Grit Kühne, Shalmali Deshpande

Abstract

Information communication technologies (ICT) can transform how services can be and are delivered; as has already happened in other arenas, such as civil aviation, financial services, and retailing. Most modern healthcare is heavily dependent on e-health, including record keeping, targeted information sharing, and digital diagnostic and imaging techniques. However, there remains little scientific knowledge base for optimal system content and function in primary health care, particularly for children. MOCHA aimed to establish the current e-health situation in children's primary care services. Electronic health records (EHRs) are in regular use in much of northern and western Europe and in some new EU Member States; but other countries lag behind. MOCHA investigated the use of unique identifiers, the use of case-based public health EHRs and the capability of record linkage; linkage of information with school health data; and monitoring of social media influences, such as health websites and health apps. A widespread lack of standards underlined a lack of research inquiry into this issue in terms of children's health data and health knowledge. Health websites and apps are a growing area of health care delivery, but there is a worrying lack of safeguards in place. The challenge for policy makers and practitioners is to be aware and lead on the innovative harnessing of new technologies, while protecting child users against new harms.

Chapter 15
Affiliate contributors to primary care for children

Denise Alexander, Uttara Kurup, Arjun Menon, Michael Mahgerefteh, Austin Warters, Michael Rigby, Mitch Blair

Abstract

There is more to primary care than solely medical and nursing services. MOCHA explored the role of the professions of pharmacy, dental health and social care as examples of affiliate contributors to primary care in providing health advice and treatment to children and young people. Pharmacies are much used, but their value as a resource for children seems to be insufficiently recognised in most EU and EEA countries. Advice from a pharmacist is invaluable, particularly because many medicines for children are only available off-label, or not available in the correct dose; access to a pharmacist for simple queries around certain health issues is often easier and quicker than access to a primary care physician or nursing service. Preventive dentistry is available throughout the EU and EEA, but there are few targeted incentives to ensure all children receive the service, and accessibility to dental treatment is variable, particularly for disabled children or those with specific health needs. Social care services are an essential part of health care for many extremely vulnerable children, for example those with complex care needs. Mapping social care services and the interaction with health services is challenging due to their fragmented provision and the variability of access across the EU and EEA. A lack of coherent structure of the health and social care interface requires parents or other family members to navigate complex systems with little assistance. The needs of pharmacy, dentistry and social care are varied and interwoven with needs from each other and from the health care system. Yet, because this inter-connectivity is not sufficiently recognised in the EU and EEA countries, there is a need for improvement of coordination, and with the need for these services to focus more fully on children and young people.

Chapter 16

The transferability of primary child health care systems

Paul Kocken, Eline Vlasblom, Gaby de Lijster, Helen Wells, Nicole van Kesteren, Renate van Zoonen, Kinga Zdunek, Mitch Blair, Denise Alexander

Abstract

There is considerable heterogeneity between primary care systems that have evolved in individual national cultural environments. MOCHA studied how the transfer of models or their individual components can be achieved across nations, using examples of combinations of settings, functions, target groups and tracer conditions. There are many factors that determine the feasibility of successful transfer of these from one setting to another, which must be recognised and taken into account. These include the environment of the care system, national policy making and contextual means of directing population behaviour – in the form of penalties and incentives, which cannot be assessed or expected to work by means of rational actions alone. MOCHA developed a list of criteria to assess transferability, summarised in a PIET-T process; that identifies key **P**opulation characteristics, **I**ntervention content, **E**nvironment and **T**ransfer. To explore the process and means of transferability, we obtained consensus statements from the researchers on optimum model scenarios, and conducted a survey of stakeholders, professionals and users of children's primary care services that involved three specific health topics:

vaccination coverage in infants, monitoring of a chronic or complex condition and early recognition of mental health problems. The results give insight into features of transferability – such as the availability and use of guidelines and formal procedures; the barriers and facilitators of implementation and similarities and differences between model practices and the existing model of child primary care in the country. We found that successful transfer of an optimal model is impossible without tailoring the model to a specific country setting. It is vital to be aware of the sensitivity of the population and environmental characteristics of a country before starting to change the system of primary care.

Chapter 17

National and Public Cultures as Determinants of Health Policy and Production

Kinga Zdunek, Mitch Blair, Denise Alexander

Abstract

The MOCHA project recognises that child health policy is determined to a great extent by national culture, thus, exploring and understanding the cultural influences on national policies is essential to fully appraise the models of primary care. Cultures are created by the population who adopt national rituals, beliefs and code systems; and are unique to each country. To understand the effects of culture on public policy, and the resulting primary care services, we explored the socio-cultural background of four components of policy making: content, actors, contexts and processes. Responses from the MOCHA Country Agents about recent key national concerns and debates about child health and policy were analysed to identify key factors as determinants of policy. These included awareness, contextual change, freedom, history, lifestyle, religion, societal activation, and tolerance. To understand the influence of these factors of policy, we identified important internal and external structural determinants, which we grouped into those identified within the structure of health care policy (internal), and those which are only indirectly correlated with the policy environment (external). An important child-focus aspect of cultural determinants of policy is the national attitudes to child abuse. We focused on the role of primary care in preventing and identifying abuse of children and young people, and treating its consequences, which can last a lifetime.

Chapter 18

Bringing MOCHA Lessons to your Service

Magda Boere-Boonekamp, Karin Groothuis-Oudshoorn, Tamara Schloemer, Peter Schröder-Bäck, Janine van Til, Kinga Zdunek, Paul Kocken

Abstract

Identifying the qualities of primary care that have the potential to produce optimal health outcomes is only half the story. The MOCHA project has explored how to transfer these to other national contexts, but also which successful components should be transferred. It is important to

assess the population criteria of the identified sociodemographic, cultural and social characteristics, and the population perspectives on a care system's components. The project analysed public experiences and perceptions of the quality of primary care for children from a representative sample of the general public in five EU Member States. The public perception of children's primary care services, in particular the perceived quality of care and expectations of children and their care is important to understand before MOCHA lessons can be effectively adopted in a country. We found that the socio-cultural characteristics of a country inform the population perceptions and preferences with regard to the care system. In the five countries surveyed there was agreement about aspects of quality of care – such as accessible opening hours, confidential consultations for children and timeliness of consultation for an illness; but there was a difference in opinion about giving priority to items such as making an appointment without a referral, or a child's right to a confidential consultation. The cultural context of transferability and the means of addressing this such as defining the target audience and the different means of disseminating important messages to the wider community to address contextual factors can act as barriers or facilitators to the introduction of new components of primary care models.

Chapter 19
Evidence to Achieve an Optimal Model for Children's Health in Europe

Mitch Blair, Michael Rigby, Denise Alexander

Abstract

MOCHA was a wide-ranging, multidisciplinary and multi-method study that aimed to identify the best models of provision of primary care for the children of the European Union. The research has identified two main conclusions: 1. The depth of interdependency of health, economy and society. Primary care needs to be an active partner in public debate about current child health concerns. It should orientate more effectively in addressing wider societal influences on child health through advocacy and collaborative inter-sectoral public health approaches with those agencies responsible for public and community health if it is to address effectively issues such as childhood obesity, mental health and vaccine hesitancy. As part of this it needs to address its workforce composition and skills, not least in two-way communication. 2. The European Community has many visions and commitments to children and child health policies, but their effectiveness is largely unfulfilled. The Commission can strengthen its impact on children's health and healthcare services within current remits and resources by focusing on a number of key fields: planned and structured research; providing insight into optimal human resources and skills in child primary care; developing and using ethical means of listening to children's views; remedying the invisibility of children in data; measuring the quality of primary care from a child-centric perspective; understanding the economics of investing in children's health; developing e-health standards and evaluation; collaborative and harmonised use of downloaded research databases; understanding and respecting children's rights and equity; and appreciating and allowing for children's evolving autonomy as they grow up. An optimal model of primary care for children is proactive, inclusive, corporately linked, based on and providing robust evidence, and respects the wider determinants of health and children's involvement in their health trajectory.