



# Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

## Work Package 1: Final Report on Current Models of Primary Care for Children

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# **Final Report on Current Models of Primary Care for Children, including sections on context, Operation and Effects, and Related Business Models**

Editors: Mitch Blair, Michael Rigby, Denise Alexander

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# Executive Summary

## Background

The overall aim of the MOCHA project is to appraise the existing models of primary child health care in Europe, through a scientific and child-centric focus, with the ultimate objective of improving overall child health as a whole in Europe. We aim to do this through comparing the various systems and their component parts and how these relate to child health outcomes. To achieve this, we are using a mixed methods approach; a combination of literature review, national agents and patient/carer and informants, quantitative analysis including systematic review and meta-analysis and qualitative analysis of data gathered in the project. A number of tracer conditions (either specific clinical issues or experiences) have been used to illustrate how the systems work in each setting and to allow triangulation of results. More detailed methods are described within each subsequent chapter in this deliverable. An initial essential task, therefore, is to be able to describe the various existing systems in 30 countries and their constituent characteristics and functions. This in turn will set a framework to inform the other work packages and support the appraisal process.

Primary health care is defined broadly as the first point of call for any individual in need of preventive or curative health advice and action; it is an important determinant of health and takes many forms. Primary care for children is an important aspect of health care, but is at the same time an under-researched 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 (Wellbeing) and for future adults (Well-becoming). 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 an effective way of providing good European population health. This encompasses not only optimum physical health, but also mental health, and wellbeing of children who live in secure, healthy community settings.

Not only is a child's good health desirable, it is a fundamental right, as set out by the UN Convention on the Rights of the Child in Article 24 (<http://www.ohchr.org/en/professionalinterest/pages/crc.aspx>).

A child's health is determined by many factors over his or her lifecourse, including the influence of the family, peers, culture, beliefs, education, physical environment and of course health services. These elements can either protect and influence, or restrict choices about health. Similarly, the health services, set within these cultural contexts, are necessarily influenced by many determinants – and must also respond to the determinants of the societies in which they function. A child, as he or she grows up changes, considerably at different ages and at developmental stages. A child is, at the beginning of life, entirely dependent on others, and highly influenced by the family, social, educational and natural environment. As a child reaches the teenage years, he or she becomes increasingly autonomous, needing support but also desiring independence. Though much reliance is placed, rightly, on both the family and a caring society, it has to be recognised that for some children one or both of these supports is missing or at times negative, affecting health determinants and thus the role of primary care. The interaction of a child with the health service reflects these many dynamic changes.

Simultaneously, the child is at the centre of his or her health- and is able to make choices to a certain extent to influence and make decisions about what is available in terms of health in the

context of the family, who in turn influence the community, school and wider factors, which in turn affect health service provision and governance, media and wider social aspects.

A child, as he or she grows up changes considerably at different ages and at developmental stages. A child is, at the beginning of life, entirely dependent on others, and highly influenced by the family, social, educational and natural environment. As a child reaches the teenage years, he or she becomes increasingly autonomous, needing support but also desiring independence. The interaction of a child with the health service reflects these developmental changes.

## **Scope of Primary child health care in MOCHA**

There are many forms of primary care for children which are taken as being within the scope of the MOCHA project. These are:

- physician care (as above)
- nursing care (especially where the nurse acts autonomously or with only very broad supervision)
- school health (school and to some extent adolescent care is frequently considered as 'outside' the usual model of primary care services – but is often the primary access point for health care for this cohort of children)
- direct access services (particularly for adolescents)
- community pharmacy
- health promotion services (including dental)
- telephone hotlines, and web based services

We also recognise the contribution of dentists, allied health professionals and other forms of first contact care but these are outside scope of MOCHA

## **Scope and Status of this Report:**

### **Main findings about the current models of primary care for children**

As with many MOCHA deliverables, we have found that the available knowledge, analysis and evidence on the topic of children's primary care are significantly under-developed. While there are a number of descriptive texts they stop short of formulating models. Conversely there are many analyses of European health systems and aspects thereof, but they have little if any mention of children, despite the strategic importance and heavy health system dependence of this population group. Hence, as with several earlier Deliverables from MOCHA, this report is not a definitive summation of current knowledge in Europe, but instead a summary of work initiated but still ongoing at something short of the mid-point of our scientific work. Each section reports the current knowledge, but also indicates work in hand or remaining to be done. This is therefore a research situation analysis rather than a definitive and complete summation.

Description of models of health care can be approached from a number of dimensions and viewpoints, and with a variety of measures or values within each. This report reflects this approach with due reference to work currently in hand, and ahead of the synthesis into an integrated picture which is the aim of the final stage of the project in a further 18 months' time. The dimensions presented are:

- Current descriptions of models of primary care
- Systematic review and meta-analysis of the literature relating to key model characteristics using tracer conditions
- Patient experience

- Case studies as means of system testing
- Records and data
- Conceptual representation of business models using UML
- Contextual determinants of child health policy
- Incentives, penalties, and their effects
- Political and constitutional context of decision-making

## **Current models of primary care**

The core principles and functions of a quality primary care system were established by the MOCHA project as follows:

Primary care is generalist in nature; person centred in essence, and provides the first contact with health services. It is a referral gateway to other forms of care (there are different methods of referral, including self-referral). Care is coordinated by primary care – within its own multidisciplinary services, and with secondary or tertiary care. Primary care also provides continuity of care over the life course; and collaboration between different teams of health professionals. Primary care features preventive care throughout the life course, including during periods of children’s growth and development, prevention of disease or health problems, lifestyle advice, and physical and mental illness prevention. Primary care is centred on the home and family. Primary care for children fits within this generic picture, but has to accommodate the very different physiological and intellectual development of the individual compared with adults; the range of specific childhood conditions and illnesses; the high dependence at least in the early years on parents who are not the ‘patient’ but vital to the child’s wellbeing and their health access; and the complex interaction with society including in particular the education sector.

Initial analyses of models of primary care for children have focused on the type of lead practitioner. The models of lead practitioner have typically been categorised into three: those that are led by a primary care paediatrician; those that are led by a general practitioner; and those that have a mixed model, usually with additional health professionals available for consultation. However, there is little existing research or evidence as to which is likely to produce the best health outcomes for children. This implies that some countries may be providing sub-optimal services to their child populations. Several forms and models of primary care exist for children and young people in Europe and these include

- General practice/family practice (generalists seeing patients of all ages)
- Primary care paediatrics (seeing only child patients)
- Community nursing (often including home visiting)
- School health services
- Accident and emergency / trauma departments – as urgent first point of contact
- Community pharmacy services
- Telephone hotlines and Internet services
- Adolescent community access services e.g. reproductive health
- Dental practitioners
- Allied health professionals

We have focused our appraisal to date primarily on the first four categories although mindful of the need to include others where possible within the MOCHA project scope.

The literature on models of care has found that there is fragmentation and lack of coordination in many primary care systems. This can have serious consequences for children; particularly a

child with a complex or long-term condition, or whose condition deteriorates very quickly. Preventive care is extremely important for children, and yet does not appear to be understood or given priority in research into primary care services

## **Systematic Review and meta-analysis of the literature**

Data about children's experience of primary care was interrogated to establish differences in the types of primary care system that exist, and whether these differences had any impact on health outcomes.

- There is useful data on key processes in primary care around timely diagnosis of key conditions, acute emergency and chronic care management as well as measures of preventive care which is specific to practice in the EU
- Using lead practitioner (paediatrician-led, general practitioner-led or mixed) as the discriminatory factor has revealed the following key findings :
  - There was *no statistical difference* between type of model as defined by lead practitioner in terms of mean age of diagnosis of autistic spectrum disorder (ASD).
  - There was *no significant difference* in any of the three model classifications in terms of age of diagnosis of attention deficit hyperactivity disorder (ADHD).
  - Measles, mumps, rubella (MMR) immunisation coverage was statistically lower in GP-led systems compared to Mixed systems. There was no significant difference between Paediatrician-led systems and both Mixed and GP-led systems.
  - Measles vaccination coverage was significantly lower in Mixed system compared to both GP-led and Paediatrician-led systems.
  - Mumps vaccination coverage was significantly higher in Mixed system compared to Paediatrician-led system.
  - There was no significant difference between any of the three models of primary care in terms of children with asthma attending Accident and Emergency departments nor for hospitalization visits.
  - There was no research found for asthma-related unscheduled primary care visits in the Mixed system, while only one study was found for the Paediatrician-led system.
- Using lead practitioner as basis for distinguishing models has some utility but is *clearly an oversimplification of the necessary criteria for appraisal*.
- The methods of analysis used need to take into account multiple elements of the various models in a more complex regression model in the next phase of MOCHA

## **Patient experience**

Obtaining the views of children, young people and their parents is an essential factor in the appraisal of health systems. A system may well work efficiently, but if it has no relevance to its users, it cannot be considered a successful determinant of good health. Results of interviews commissioned by MOCHA in five countries will be available late in 2017.

- Qualitative inquiry of child's experience of primary health care will provide valuable triangulation and identification of areas of concern to children and young people, and their families
- The MOCHA researchers from the various Work Packages have helped develop the interview schedule to complement other data sources used.

- We have interviewed children and young people from five European countries: Czech Republic, Germany, Netherlands, Spain and the United Kingdom
- Initial themes emerging include themes emerging include quality of care, quality of primary health care professional communication and access to care – including opening hours

## Case study system testing

Case studies, using a range of clinical scenarios, were used to ask the MOCHA Country Agents to explain how systems worked *in real life* in each country in terms of particular tracer conditions that are common or indicative of a child's experience of health care at various life stages.

- For emergency and out of hours care, the first point of contact in 28 countries is the primary care physician - whether GP or paediatrician
- In a school setting, policy varies considerably in terms of who can provide assistance and access to medicines in an emergency.
- In only seven (28%) of these countries, is there access to the main primary care provider's record systems in an emergency.
- Although nearly four-fifths of countries have a formal hospital discharge summary, very few use digital transfer of information, and only eight countries use standard referral or discharge proformas.
- Protocols and guidelines for asthma are used in 21 (91%) of 23 countries, but only two of these are collaborative plans made with the family or child involvement

## Records and Data

Electronic record systems covering children's primary care, and consequent pooled data sets suitable for research analysis, are as yet little developed in Europe. Information surveillance of child health is identified as an area that is not optimum. Nevertheless, there is value in identifying the records and data available, as a means of telling us about primary care systems, and as a valuable tool for appraisal, and triangulation of results.

- We have identified a large number of potentially relevant databases, developing purposefully the MOCHA International Research Opportunity Instrument (MIROI) research tool.
- The inventory is hosted on line through agreement with a partner health database focussed European project.
- Of the 116 databases identified, only 14 were directly focused on children. In others, children were either part of a 'whole population' data collection, or grouped with other ages. In other words, many of the data items are not specific to children or to child primary care
- 28% of databases report requiring over 12 months lead time to obtain data
- Although gender was well recorded in the majority of databases, ethnicity and socioeconomic status was less well recorded, rendering analysis of inequalities difficult
- There is a real need for accessible, relevant, timely and comparable data about children in Europe.
- Europe is at an early stage of marshalling big data sets into a use environment in which they can be utilised to evaluate health provision, such as child health models.
- This MOCHA collation of potentially useful datasets is believed to be unique.

## **Conceptual representation of business models using UML**

Models of primary care for children differ considerably from country to country, due to cultural influences, and subtle changes over time. However, using techniques from software development allows MOCHA to identify the key activities and structures of every system; and provide a structure for future appraisal.

- The process of business modelling allows us to identify the main strengths of children primary care services and highlight potential gaps in the varying structures and processes of care that exist across the 30 EU and EEA countries. The use of this technique has been tested for feasibility in its application to the MOCHA project.
- A new methodology has been developed enriching the UML diagrams with a conceptual view represented by a rich picture focused on three maps of building blocks. They identify three main pathways in child care: well-being monitoring, disease management and social support.
- The conceptual model allows the identification of a set of homogeneous macro-activities (building blocks) that facilitate the comparison in the delivery of child primary care services across countries as well as the interface between primary, secondary and social care.
- The UML use case diagram makes it possible to provide a functional diagrammatic picture of primary health delivery models on the basis of clinical guidelines that represent a benchmark to compare health care business processes.
- The UML activity diagram gives a dynamic description of the interaction between actors derived from the responses to MOCHA Country Agent questions “in real-life context”.
- Access to a hospital emergency service is widely reported as a valid alternative in both scenarios, presumably when parents are particularly concerned with their child’s health status. This is particularly highlighted by country agent responses in the asthma scenario.

## **The contextual determinants of child health policy**

The identifying cultural factors that influence primary care child health policy yielded an extremely rich variety of concerns and protests about child health in Europe. What has been drawn from this is a map of the important actors, influences and determinants that affect or stimulate changes in child primary care policy. These consist of:

- The child as a central, causative actor, accompanied by executive actors – acting in both the proximal and distal environment of the child
- Contextual determinants of changes in policy in child primary care services – in terms of human and non-human factors
- Socio-cultural determinants of changes in policy in child primary care services
- Structural determinants
- International determinants
- Specific events
- Vehicles of public expression

The interaction of all these different elements is both complex and enlightening in terms of cultural influence on child health systems.

A number of specific policy themes emerged from the responses from the MOCHA country agents. The most reported are:

- Vaccination debates
- Disabled children's rights
- Child abuse
- Lifestyle changes
- Societal changes and effects on a child's mental health
- Child poverty and homelessness
- Provision and access to child health care and services
- Functioning of the health care system

## **Incentives, penalties and their effects**

There are numerous ways of encouraging, or even enforcing populations to use health services, and to act in certain socially acceptable ways. Similarly, actors within the health system can be the subject of positive or negative incentives. However, these policies often have effects that differ from that which was intended.

- Levers are ways in which providers and recipients of health services are persuaded to act in particular ways, which contribute to the notion of 'common good'.
- The most common form of leverage is financial – applying both to provider and recipient (parent as responsible for the child)
- Levers are used in almost all countries of the EU, yet there is very little evaluation of their effectiveness or perverse effects, and evaluations that exist are generally focused on economic measures of success and failure, not health and wellbeing outcomes.
- Incentives for vaccination and take up of preventive care in pregnancy and early years were amongst the commonest schemes
- Non-monetary incentives are rare and designed to increase engagement with health care services
- In some cases disincentives as penalties exist to support improved vaccination rates or eligibility for childcare
- The majority of Country Agent answers that reported levers were part of a mixed system of delivery. As such, it was not possible to identify a purely incentivised method of delivery, but to observe a range of incentives being available to increase the level of provision of certain key deliverables in each country context. This makes it difficult to identify confidently the effects of incentives (or indeed penalties) where outcomes driven by levers cannot be satisfactorily disaggregated from outcomes produced through other means.
- Levers are based on assumptions that are themselves uncertain in validity and strength – including that financial incentives will motivate behavioural change; that such behavioural change will deliver improvements in health; and that policy makers can distinguish between those aspects of clinical activity that would benefit from financial incentives, and those that would be affected adversely.
- There is little documented evidence of the "human" effects of manipulating behaviour in desired directions.
- There is little documented study of the perverse or unintended effects of such policies, or of who some groups may be inappropriately disadvantaged even when others benefit.

## **Political and constitutional context**

Health systems are necessarily placed within the political and constitutional concept of a nation. Consideration of this is essential for appraisal and for implementing any findings.

- A literature review revealed that no governance concepts exist specific to developing and implementing child health policy.
- To appraise models of primary care, the different sectors and levels of governance must be taken into account. These vary from country to country – and even from region to region.
- Multilevel and inter-sectoral governance offer a helpful two dimensional framework for research, policy analysis and policy development. These governance concepts help to understand what actors and institutions are of relevance for developing child-centric health care approaches within healthcare but also outside healthcare (such as in the education sector). A third dimension is added with the leading values for good governance.
- Non-state actors work alongside the standard health care actors, which are often public or semi-public. Lobbyists, civil society, NGOs and others play an important role in governance, and are fundamental elements of context in which models of child primary care are developed and implemented.
- Multi-level Governance as a concept is useful to understand the networks and interactions in which decisions and implementations take place; particularly in an inter-sectoral perspective for a model of primary child health care which is seeking to address current and future child health needs
- Recognising the **Good, Intersectoral, Multisectoral (GIM)**-governance framework including stressing the normative element of governance – what values contribute to the concept of “good governance” – is likely to facilitate the spread and implementation of good practices of child-centric health policy approaches across different governance models in the EU, as the variety of relevant stakeholders and institutions can better be mapped and taken into account.

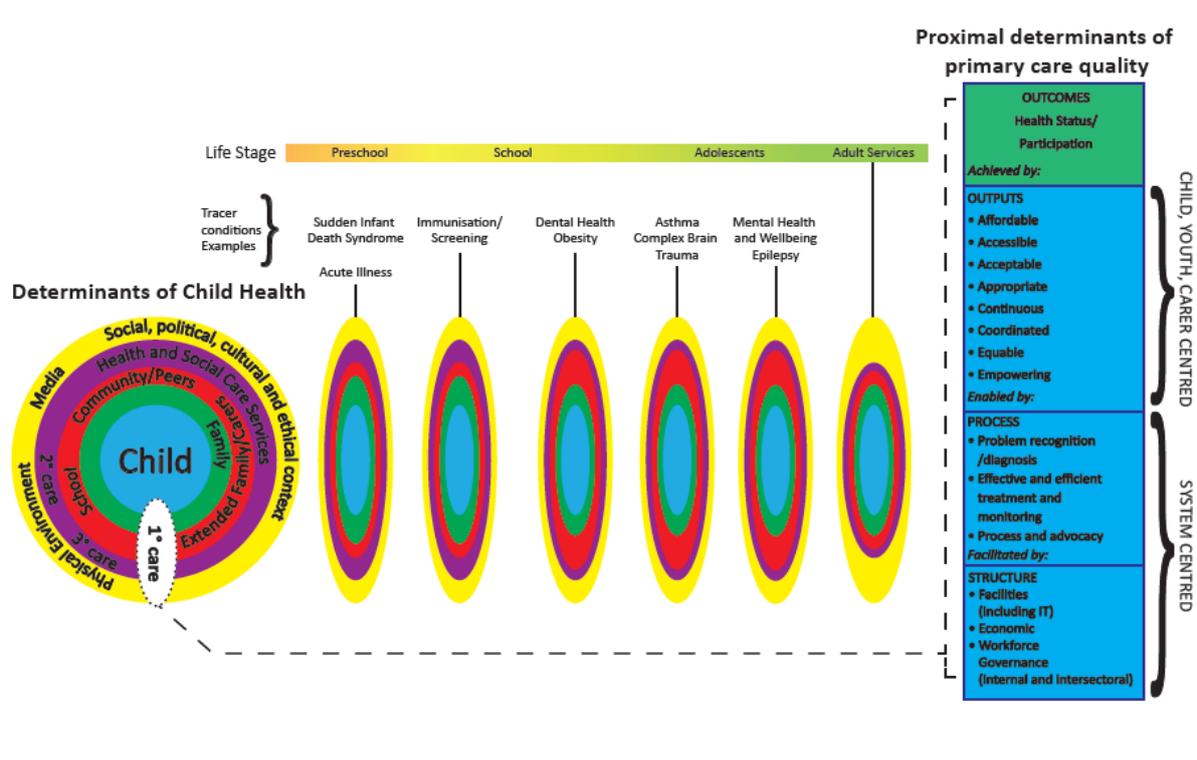
## **Conclusion**

Consideration of each different perspective of this complex structure of primary care for children in Europe, and the subsequent mappings, are essential to reflect the complexity of primary care and to identify the multitude of elements (and confounding factors) that interact between primary care systems and the health of each individual child. Approaching the investigation from different professional angles, using mixed methods allows for triangulation of results, which in turn ensures optimum robustness within the boundaries of the project.

### **Conceptual framework of a model**

Nevertheless, it is important to develop a model which successfully accommodates the diverse and profound influences on children’s health and the role of primary care services as a determinant of health. The model must accommodate the different needs of a child’s life course, the different stimuli, and the types of health condition encountered in that journey. This is summed up by the MOCHA conceptual framework, developed as a result of this initial in-project analysis and iteration.

## The MOCHA Conceptual Framework of a Model



This model and its emergence from analysis and synthesis within the project are described in Chapter 10.

It is anticipated that further refinement of this framework will be necessary to facilitate an effective child, adolescent and carer focused appraisal in relation to key structural characteristics and quality measures both from a system and patient carer perspective. However, this emergent model is an important reference framework for the ongoing analysis of results and ultimate appraisal of a children's primary health care in Europe by the MOCHA project.

# Introduction

Mitch Blair, Michael Rigby, Denise Alexander

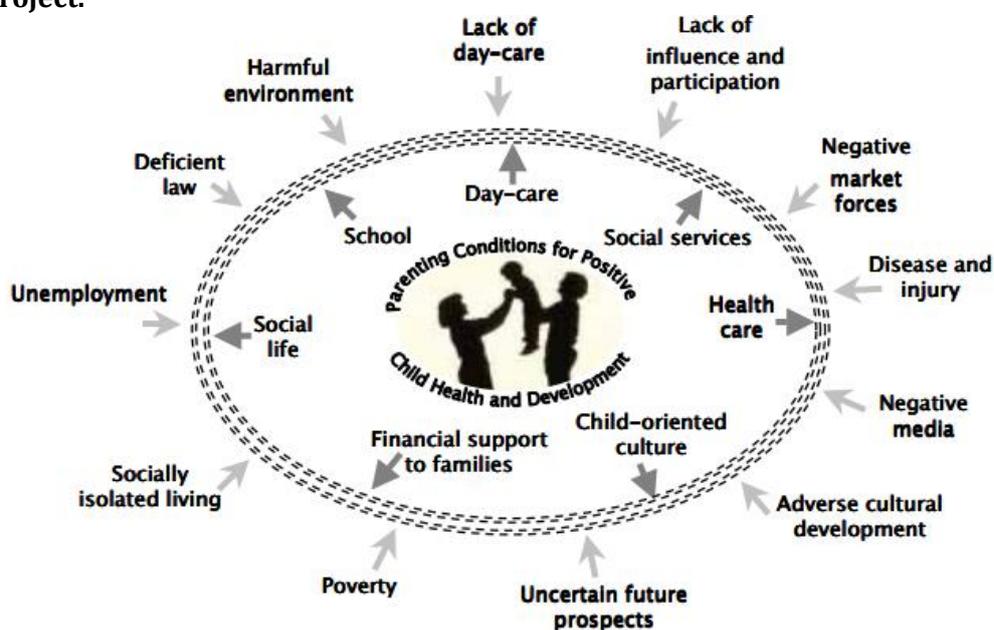
The overall aim of MOCHA is to appraise the existing models of primary child health care with the ultimate objective of improving overall child health as a whole in Europe. We aim to do this through comparing the various systems and their component parts and how these relate to child health outcomes. To achieve this, we are using a mixed methods approach; a combination of literature review, national agents and patient/carer and informants, quantitative analysis including systematic review and meta-analysis and qualitative analysis of data gathered in the project. A number of tracer conditions (either specific clinical issues or experiences) have been used to illustrate how the systems work in each setting and to allow triangulation of results. More detailed methods are described within each subsequent chapter in this deliverable. An initial essential task, therefore, is to be able to describe the various existing systems in 30 countries and their constituent characteristics and functions. This in turn will set a framework to inform the other work packages and support the appraisal process.

This report presents our knowledge about the current models of primary care for children in the EU and EEA countries. Primary health care is defined broadly as the first point of call for any individual in need of preventive or curative health advice and action and is an important determinant of health and takes many forms. The following paragraphs describe how such services are contextualised for the purpose of this deliverable

## Child health in the context of Primary Care

A child's health is determined by many factors over his or her lifecourse, including the influence of the family, peers, culture, beliefs, education, physical environment and of course health services. This is conceptualised in Figure 1, taken from the EU Child Health Indicators of Life and Development (CHILD) project (1).

Figure 1 Determinants of child health and development as visualised in the CHILD project.



Source: (1).

Viewed from the outside in, these can be seen as protecting and influencing or restricting choices about health. Influences range from media, social, political and cultural concepts which are important settings and influences for decisions about health, made on a policy level and an individual or family level. The health services, set within these cultural contexts, influence what is available to schools and to the community in which the health model operates. Within the community setting, a family makes choices and decisions about health based on what is available, knowledge and cultural influences, and finally – potentially influenced by all of these factors is the child. Alternatively, viewed from the inside outwards, it can be seen as the child in the centre, able to influence and make decisions about what is available to him or her in terms of health in the context of the family, who then can influence the needs of the community, school and wider social factors, which in turn affect health services and ultimately, the cultural, media and wider social settings. In practice, both situations occur, sometimes simultaneously, and depending on wider influences. It is a dynamic process that is constantly in flux and varies over time.

A child, as he or she grows up changes considerably at different ages and at developmental stages. A child is, at the beginning of life, entirely dependent on others, and highly influenced by the family, social, educational and natural environment. As a child reaches the teenage years, he or she becomes increasingly autonomous, needing support but also desiring independence. The interaction of a child with the health service reflects these developmental changes. This concept of child centricity, and the actors, such as parents, teachers or other adults that interact with the child and with the health service is explored further in Chapter 7.

### **Primary care in the context of child health**

Children and young people have unique needs of the primary care systems which require specific consideration. Primary care has an important role in supporting the optimisation of child health through effective health promotion, prevention of disease and protection from adverse health risks poverty, migrant status, education, housing levels etc. to ensure future lifecourse health in later adult years. Children are rapidly developing human organisms and have a lot of contact with primary care; contact which is especially important in the critical phases of early years (0-2 years of age ) and subsequently in early/mid adolescence (11- 15 years of age). Therefore, there are more opportunities for effective intervention within primary care for children compared to other population groups, such as adults.

The nature of acute childhood illness (rapid onset and resolution or deterioration) the way illness changes with age and the stage of development is such that primary care must be able to respond quickly and effectively to changes in health status. The epidemiology of children's health has changed in the past fifty years; they experience fewer communicable diseases since the introduction of vaccination; but experience many chronic conditions as a result of increased survival rates from congenital conditions, or the increased burden of non-communicable disease from environmental threats – such as mental health disorders, neurodevelopmental impairments, obesity and asthma.

Primary care for children is an important aspect of health care, but is at the same time an under-researched 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 (Wellbeing) and future adults (Well-becoming). 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 an effective way of providing good European population health. This encompasses

not only optimum physical health, but also mental health, and wellbeing of children who live in secure, healthy community settings.

Not only is a child's good health desirable, it is a fundamental right, as set out by the UN Convention on the Rights of the Child in Article 24 (2):  
(<http://www.ohchr.org/en/professionalinterest/pages/crc.aspx>)

*“States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.”*

*“States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures ... To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care; ... To combat disease and malnutrition, including within the framework of primary health care”*

Children are dependent on society to provide effective health services, and are not enfranchised to effect easily changes to make primary health care more applicable and accessible to them.

## **What we know already about primary child health care**

Initial analyses of models of primary care for children have focused on the type of lead practitioner – defined in the MOCHA project as the individual who takes clinical responsibility for the child. The models organised by lead practitioner have typically been organised into three broad categories, those that are led by a primary care paediatrician, those that are led by a general practitioner, and those that have a mixed model, with both (and additional) health professionals available for consultation. Not only is there very little research to establish how the practice pattern and organisational structure influence the health of children, but there is little evidence as to which is likely to produce the best health outcomes for children. This implies that some countries may be providing sub-optimal services to their child populations.

## **Scope of Primary child health care in MOCHA**

There are many forms of primary care for children which are within the scope of the MOCHA project. These are:

- physician care ( as above)
- nursing care
- school health (school and to some extent adolescent care is often ‘outside’ the usual model of primary care services – but may be the primary access point for health care for this cohort of children)
- direct access services (often adolescents)
- community pharmacy
- health promotion services (including dental)
- telephone hotlines, and web based services

We recognise the contribution of dentists, allied health professionals and other forms of first contact care but these are outside scope of MOCHA.

## **The MOCHA Country Agents**

Each of the 30 countries within the MOCHA is represented by a MOCHA Country Agent. These individuals are an extremely valuable resource to the MOCHA project, with the potential for our

research to gain a unique insight into how models of health care for children work, are structured and how they affect children and young people in every country in Europe. The Country Agent is able to contact experts within their country to answer a range of research questions and give each nation's unique perspective, and primary care function. Country agent questions are posed by the research teams in the MOCHA project, and then peer reviewed by the management team, and the MOCHA External Advisory Board before being sent to each Country Agent for answers. More information about the Country Agents can be found at [www.childhealthservicemodels.eu/partners](http://www.childhealthservicemodels.eu/partners).

## Structure of this report

**Chapter 1** is a Literature Review focusing on describing what is known about models of primary care and their respective characteristics both from an academic, practitioner and user perspectives

**Chapter 2:** is a Systematic Review and meta-analysis of the literature relevant to Europe focusing on 4 tracer conditions reflecting key functions of a primary care system: timely diagnosis (neurodevelopmental disorders of ADHD and Autism), responsive care (acute infectious disease) effective protection from disease (immunisation) and effective chronic care (asthma)

The following four chapters reflect important methodological developments designed to support analytical comparison and validation of findings between various systems both from patient and system perspectives.

**Chapter 3** describes how the MOCHA project is collecting patient experiences in terms of the key tracer conditions identified by the project.

**Chapter 4** uses case study methodology to describe the primary care systems in each country, and which are the most important elements of the system that interact with a child on a journey of ill health, management of a condition or needing ordinary care on top of managing a complex condition.

**Chapter 5** looks at what we can learn about the systems of primary care in terms of the records kept and the data available. Lack of data availability has been identified as a key feature in children's primary health care. Ascertaining what data exist in each country can tell us a great deal about

**Chapter 6** describes the Integration of a conceptual representation of business models with Unified modelling language (UML)

The final chapters describe the context in which the primary care systems operate. Each country has a unique context in which children live; and the primary care systems are naturally responsive to the local culture and practices that exist.

**Chapter 7** describes the cultural context that we have identified in each of the MOCHA countries in terms of identified health priorities in each country.

**Chapter 8** describes the complexities of incentives, penalties and societal effects which act as levers to influence the behaviour of the populations. Sometimes these penalties have unintended effects, which need to be identified in terms of how the model functions.

**Chapter 9** describes the political and governance context of primary care health systems.

**Chapter 10** sums up our knowledge about models of primary care systems for children, classifies the health systems, and the limitations of current systems.

## **References**

1. Rigby M, Kohler L. Child health indicators of life and development (CHILD): Report to the European Commission. European Commission Health Monitoring Programme; 2002.
2. United Nations Convention on the Rights of the Child in Article 24: Available online: <http://www.ohchr.org/en/professionalinterest/pages/crc.aspx>

# Chapter 1

## Current models of primary care

Mitch Blair, Denise Alexander

These findings were informed by the Internal MOCHA deliverable 1.3: Alexander, D; Blair, M; Rigby M. (2016) **Current models of child primary health care.**

### Main findings:

#### Core principles and functions of primary care

We identified a consensus on what are the core principles and functions of a quality primary care system. These are closely related, and often overlap. Primary care:

- is generalist in nature
- is person-centred
- provides the first contact with health services
- provides a referral point to other forms of care (there are different methods of referral, including self-referral)
- is where care is coordinated (within the disciplines of primary care, and with the other sectors of the health system)
- provides continuity of care over the life course and with chronic disease
- involves teamwork and collaboration
- features preventive care throughout the child's life course; for example: growth, development, prevention of health problems, lifestyle elements, physical and mental health
- home-centred care.

Several forms and models of primary care exist for children and young people in Europe and these include

- General practice/family practice (generalists seeing patients of all ages)
- Primary care paediatrics (seeing only child patients)
- Community nursing
- School health services
- Accident and emergency / trauma departments – as urgent first point of contact
- Community pharmacy services
- Telephone hotlines and Internet services
- Adolescent community access services e.g. sexual health
- Dental practitioners
- Allied health professionals

We have focused our appraisal primarily on the first four categories although mindful of the need to include others where possible within the MOCHA project scope.

Models of primary care comprise many different elements and combinations of elements, and there is considerable diversity of models in the EU / EEA countries. This literature review has illustrated common elements of a model within a general structure, process output and outcomes framework (see Chapter 10, Figure 41) and includes, for example, the type of lead practitioner, the funding and governance and record systems, workforce and training.

- There is **fragmentation and lack of coordination** in many primary care systems, this can have serious consequences for children – for example a child with a complex or long term condition, or a child whose condition deteriorates very quickly.
- **Preventive care** is extremely important for children, and yet does not appear to be understood or given priority in research into primary care services.

## Methods

This was an extensive literature review, looking at the main elements that the MOCHA project considers central in terms of appraising primary care for children. The literature review looked at:

- What is primary care and why is it important
- Children as a focus
- Identified characteristics of primary care
- What is a model of primary care
- Important elements of a model.

The literature studied on models of child health systems is from a diverse range of sources. As well as the scientific literature, grey literature, and reports from non-governmental organisations (NGOs) were scrutinised. In addition, a number of interests and viewpoints were accommodated in the literature review, as a purely medical viewpoint will not have given a holistic and child-centric view of the models of primary care for children in Europe. Balanced against this, however, was the discipline needed to keep the review focused on the needs of the MOCHA project.

Initial searches of relevant NGOs were carried out including publications from the European Observatory of Health Systems and Policy; The World Health Organisation (Regional Office for Europe and Global) publications about health systems and primary care, The European Paediatrics Association (EPA/UNESPA), The European Academy of Paediatrics (EAP), The International Society for Social Paediatrics and Child Health (ISSOP), The Strategic Paediatric Alliance for the future of child health in Europe (SPA) and the European Forum for Primary Care. In addition to this, a search of the Imperial College Library and of PubMed for peer reviewed literature was undertaken. Initial search terms were broad, using Primary AND healthcare OR care AND Systems AND Children OR Paediatric AND Europe. Literature was restricted to papers written in English, or with an English summary.

In total 117 sources were retrieved and read. In addition to this, literature specifically pertaining to primary care systems for children in each Member State and Norway and Iceland was also sought.

Data was triangulated between sources and testing findings using the MOCHA Country Agents. The triangulation from Country Agents' data and research data allows a MOCHA consensus to be reached.

## Validation and Triangulation

We found a relative lack of literature specifically related to child and adolescent primary care. **Models of care** varied considerably across European countries primarily for historical, socio-

political and cultural reasons. Specifically evaluating how these are related to key child health outcomes is a significant research challenge.

Much of the research into health systems in Europe is based on all primary care, or on adult primary care, particularly the elderly (1, 2). At present, there is little evidence on which to base effective and responsive policy decisions for purposes of accountability, transparency and improvement on services for children.

There are many reasons why children should be considered as a group for more focussed attention, as described in the Introduction. Looking towards the future, children will grow up to be the future adults and eventually elderly citizens of Europe. Ensuring a healthy start will go a long way to improving overall population health and, ultimately, reducing some of the burden on primary care by all ages of population. Patient empowerment and patient-centred care seem important themes in current literature, but these need special consideration in terms of children. Children have a right to make choices around their health care, but also need particular support and advocacy to do so. Health literacy and health education are important elements that enter into the discussion with particular clarity in terms of children. Children's views are not often identified in research at present, which is almost entirely adult focused. Currently there is a huge gap in our knowledge. Without a supporting health information infrastructure on the performance of primary care for children, countries are unable to evaluate, improve and be accountable for their primary care services for children. This situation also highlights the need for primary care systems to work effectively with other systems that are also determinants of health for children – including education services, justice services, housing and so on.

A number of specific themes have emerged from the review which are described below

**Preventive care** is extremely important for children for the reasons stated above. This is delivered by primary care services in the form of clinical prevention and screening, such as vaccinations. But there is also an important health education function, reassurance about health worries and knowledge of how to use the health system itself. A young person worried about a mental health or sexual health issue needs to understand how to get help, and who to ask. Prevention seems to be a neglected aspect of research into health systems, as the focus is on adult 'curative' care. This is an important gap in our knowledge.

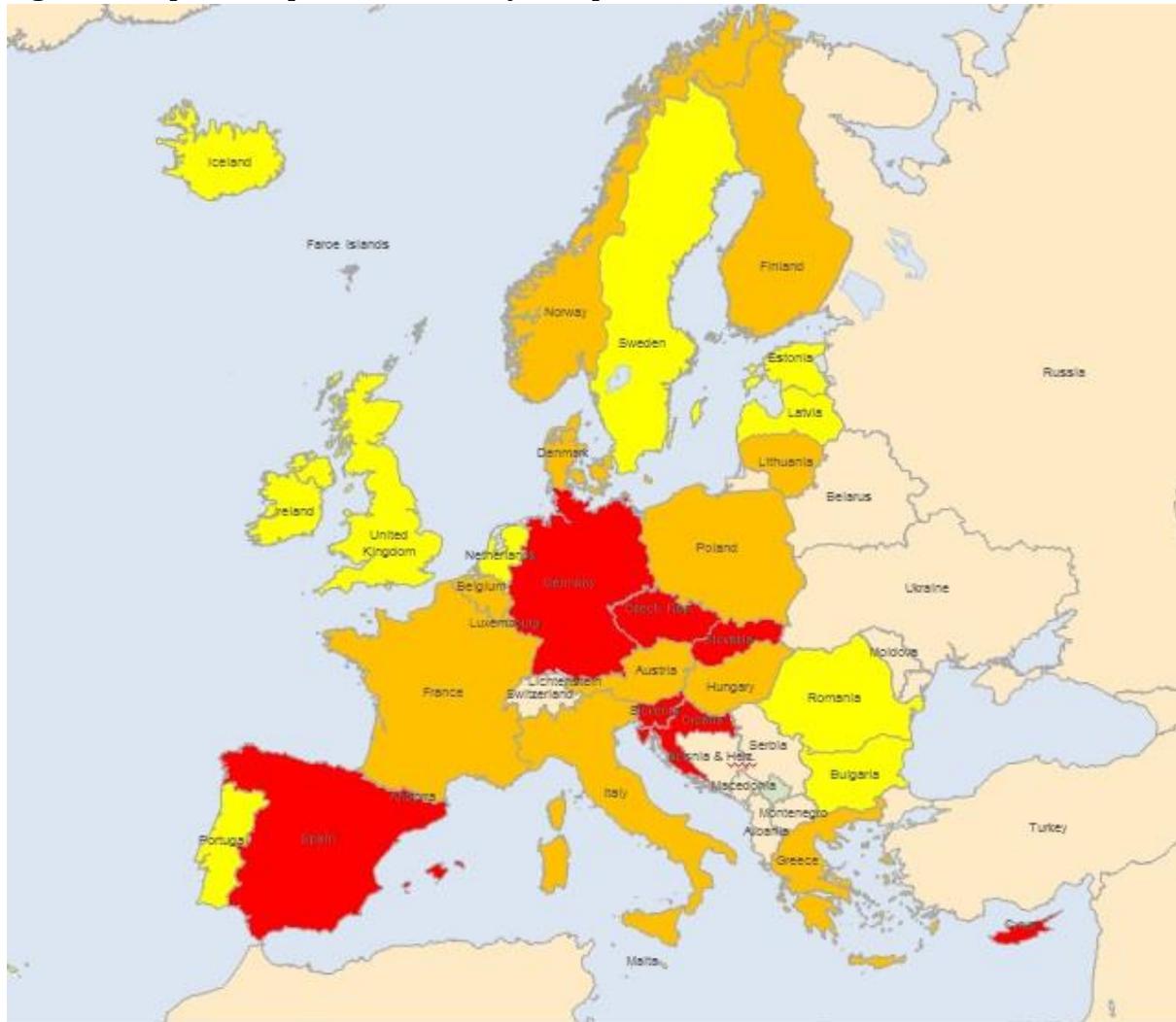
The World Health Organisation recognises that the existing structures of service delivery tend to reflect past disease burdens, and that **many models of primary care are outdated**. Old models focus on infectious disease prevention, but have struggled to adapt to modern issues such as non-communicable diseases, chronic illness and the development of good health habits to ensure an (increasingly) long life is a healthy one (3). A model that is specialist driven, and hospital focused is not only expensive – focusing on acute curative services and high tech diagnostics rather than health protection and promotion that is sympathetic to the population; it also risks missing important opportunities to help young people obtain optimum health that will last them into old age (3).

**Fragmentation and lack of coordination** of care for children is a feature noted by many parents and children themselves (See Chapter 3). This can affect a child who lives with a chronic condition and is cared for by several services at once; and a particularly important gap in our knowledge seems to be the transition of care from child services to adult services. At this point a child is potentially extremely vulnerable to missing out on proper health care.

### Map of the current models and brief commentary

Uniquely, the MOCHA project has attempted to map what we know about each country, in terms of children's primary care services. Using the traditional method of mapping by lead practitioner, the countries of the MOCHA project show a split between mixed, paediatrician-led and general practitioner-led services. This can be seen in Figure 2.

**Figure 2: Map of European countries by lead practitioner**



**Key:**

-  Paediatrician-led primary care systems
-  Mixed primary care system
-  General Practitioner-led primary care system

The issue, however, is far more complex, and this is shown in more detail in Table 1. The table collates what is known from the literature and from other sources about the health services in each country in the MOCHA project, in terms of the model parameters devised. The nations of Europe are heterogeneous in terms of many of their health services, but each country's system is inextricably linked to their cultural, economic and social history. In addition, the child

population, number of doctors and other factors influence decisions made in terms of health system and the importance placed on primary care (4).

The huge diversity in models of care in Europe provides us with a potential great richness of knowledge, but at the same time, it makes appraisal of the models challenging.

Imposing a model that works well in one country is unlikely to work as well in a different country and culture because of these national differences. In addition, the needs of children as primary care users are changing, and will continue to do so in the future. It is of great importance to be able to anticipate change, and adapt the health system accordingly so that it addresses the needs of the community in terms of changing needs both from a medical and epidemiological sense but also changing cultural and political factors influencing how and in what ways these systems can adapt (5).

Many of the sources of data are adult focused, or have a general focus, and it is difficult to identify the type of care that is afforded to children in the national population. Indeed, in some cases, the definitions of type of care seem contradictory, or their conclusions have been disputed by other experts. For example: the Czech Republic is defined as having a Paediatrician-led service, however – the definition of paediatrician may differ from that in other countries, making it hard to categorise. The Czech Republic has a “specialty” called PLDD “*praktický lékař pro děti a dorost*” “General Practitioner for Children and Adolescents” who, when selected by parents becomes the “Registering paediatrician” for the child. This complexity of definition demonstrates some of the challenges of defining and categorising a primary care health system and its relevance to children.

This table will act as the foundation blocks for further appraisal of the health systems in each country in relation children and young people. How precisely these model elements can be combined together with possible further categorisation in relation to forms of governance , sociocultural factors and the presence or absence of incentive and penalty schemes will need to be considered in the analytical phase of the project. The table has been created using available literature sources, and confirmed and corrected as necessary by the MOCHA Country Agents.

#### **Key to table:**

This table includes certain MOCHA definitions:

- **Practitioner at first point of contact:** This is the first person a child or family will speak to about the medical issue that is of concern. It does not refer to persons such as the medical receptionists, but to the individual to whom symptoms and worries are first described. In some countries this is a doctor, in other countries nurses or other health professionals take on this role.
- **Lead practitioner:** this is the person who assumes clinical responsibility for the child patient. In some countries, although the child may first see a nurse or other health professional in primary care – the responsibility of care is held by the physician.
- CA – MOCHA Country Agent ([www.childhealthservicemodels.eu/partners](http://www.childhealthservicemodels.eu/partners))
- HIT – European Observatory on Health Systems and policies: Health In Transition (HIT) series [www.euro.who.int/en/about-us/partners/observatory/publications/health-system-reviews-hits](http://www.euro.who.int/en/about-us/partners/observatory/publications/health-system-reviews-hits)
- OECD Classification definitions – (adapted from 6)

- **National Health Service:** a dominant role of the state.
- **National Health Insurance:** services are contracted out to for-profit providers.
- **Social Health Insurance system:** societal actors have competencies to regulate and finance the health system but where most service providers perform for profit.
- **Etatist Social Health System:** the state holds the regulatory power but grants privileges for the financing and provision of health services to societal actors (e.g. sickness funds with their own health facilities).

**Table 1: Mapping of Models of Provision in MOCHA countries**

	Practitioner at first point of contact*	Lead practitioner – clinical responsibility				Financial organisation		Referral / Access system to secondary care
	From CA questions and (7)	From: WP1 CA questions R1	From (8)	From (9)	MOCHA AGREED Primary care Lead practitioner –	From relevant HIT documents	OECD Classification From: (6).	From relevant HIT documents / Country Agent comments
Austria	GP or paediatrician	GP and paediatrician	Combined - Both	“Pediatric primary health care in Austria involves the services of general pediatricians and general practitioners” <a href="http://www.jpeds.com/article/S0022-3476(16)30142-1/fulltext">http://www.jpeds.com/article/S0022-3476(16)30142-1/fulltext</a>	Both(GP / Paediatrician)	Compulsory health insurance, children up to age 18, or 21 if unemployed, 26 if in full-time education are insured with close relatives (eg. Parent)	Social health insurance	Open access
Belgium	Family doctor or 1 <sup>st</sup> line paediatrician	Family doctor or 1 <sup>st</sup> line paediatrician	Combined		Combined (GP / Paediatrician)	Mixture of state social security and private health insurance. Fee for service	Etatist social health insurance	Open access
Bulgaria	GP or paediatrician	GP for those with health insurance. Pre 2000 was mandatory for community paed for children up to 18; Younger GPs only have 9 weeks paed training.	GP Led		GP	State health insurance and voluntary health insurance.	<i>Please select the most appropriate classification from the Böhm diagram below</i>	Primary care is gatekeeper to other health services  GP has a limited number of referrals per year. 70% use Primary care as entry point to system

Croatia	GP or paediatrician	Primary care paediatrician or GP		“Pediatricians and school medicine specialists provide comprehensive preventive health care for both preschool and school-aged children” <a href="http://www.jpeds.com/article/S0022-3476(16)30143-3/fulltext">http://www.jpeds.com/article/S0022-3476(16)30143-3/fulltext</a>	Primary care paediatrician	Mandatory health insurance fund and private insurance for additional services. Children are free.	Etatist Social Health System	Primary care is mainly gatekeeper to other health services
Cyprus	Paediatrician	Private paediatrician, or public hospital Paed	Paediatrician led		Primary care paediatrician	Two parallel systems, the state and private sector. Since the economic crisis more uptake of public sector. 5-10 % have private health insurance	<i>Government and Private health system</i>	Open access
Czech Republic	Paediatrician	“registering paediatrician” accessed via triage nurse	Paediatrician led However, this may be misleading. The Czech Republic has a “specialty” called PLDD “praktický lékař pro děti a dorost” “General Practitioner for Children and Adolescents” who, when selected by parents becomes the “Registering paediatrician” for the child	“does not involve general practitioners (GPs) in primary child health care. Indeed, all parents in the Czech Republic can choose their own paediatrician at the level of primary care.” <a href="http://www.jpeds.com/article/S0022-3476(16)30144-5/fulltext">www.jpeds.com/article/S0022-3476(16)30144-5/fulltext</a>	Primary care paediatrician	90% have health insurance via public health insurance companies “so called sickness funds” : For people who are not employed (including children, pensioned, job-less the fund receives monthly payments from the state.	Etatist social health insurance	Access to secondary care is open but at the same time a referral system is functional
Denmark			GP	“child primary care is taken care of by general practitioners who have 6 months	Combined GP / Health nurse	State funded, but voluntary health insurance as well	National health service	Primary care is gatekeeper to other health services. For school children the

				of pediatric training as part of their specialty training and, therefore, are qualified to work as gatekeepers for the secondary health care at the hospitals” <a href="http://www.jpeds.com/article/S0022-3476(16)30145-7/fulltext">http://www.jpeds.com/article/S0022-3476(16)30145-7/fulltext</a>		Overall tax financed-voluntary health insurance exist but is very seldom relevant in this situation because the access to health nurse/GP is not a problem		health nurse attached to the school or the school dentist service (which is more constant present) may be the primary contact and may in many cases solve the minor problems
Estonia	GP	GP	GP	“For the last 20 years, family doctors have been responsible for the primary care of children. Pediatric subspecialists work mainly in 2 children's hospitals” <a href="http://www.jpeds.com/article/S0022-3476(16)30146-9/fulltext">http://www.jpeds.com/article/S0022-3476(16)30146-9/fulltext</a>	GP	Estonian health insurance fund (mandatory) covers 95% of population	Etatist social health insurance	Primary care is <b>partial</b> gatekeeper to other health services  Some can be contacted directly
Finland	Nurse in health centres (public health nurses, nurses and midwives have a limited right to prescribe, for children less than 12 years only)	GP	GP		Combined other (nurse / GP / Paed)	Municipality financed	National health service	Primary care is gatekeeper to other health services  Nurse acts as gatekeeper to GP
France	GP or Paediatrici	Family physician	Combined		Combined other (nurse /	Social insurance, but strong state	Etatist social health insurance	PC has a <b>Semi gatekeeping</b>

	an	who is either a Paediatrician or a GP The direct access to a specialist usually involves an extra cost for the patients, except for paediatricians (along with gynaecologist, ophthalmologist, psychiatrist)			GP / Paed) Nurses are generally supervised by doctors, except in a few institutions (PMI-Maternal and Infant Protection, "crèches", school) where they can have a role of screening and orientation	influence on health		functioning.  There are incentives to use primary care as gatekeeper But the scarcity of liberal doctors, especially in large cities, makes direct use of hospital emergencies specifically paediatric very frequent, and without financial consequences.
Germany	Paediatrician	Paediatrician	Combined		Primary care paediatrician	Mandatory health insurance	Social health insurance	Open access
Greece	Paediatrician or GP	GP or Paediatrician chosen from insurance co. list. Usually paediatrician up to 18 years old.	Paediatrician led		Primary care paediatrician	Economic crisis severe in Greece. NHS and Social insurance systems co-exist	<i>Please select the most appropriate classification from the Böhm diagram below</i>	Primary care is gatekeeper to other health services
Hungary			Combined		Combined (GP / Paediatrician)	Health insurance fund	Etatist social health insurance	Primary care is partial (but more or less acts as the) gatekeeper to other health services  Partial gatekeeping
Iceland	GP or Paediatrician	One family doctor from a health care centre, or private paediatrician	Combined		GP	Health insurance covers all who have lived in Iceland for six months or more.	National health service	Open access so far, no user charges for children in PHC but minor costs with private consultations. After 1 February 2017,

								it is to become a referral system with the GP as lead practitioner and continued low cost for specialist consultation; if not GP referral to specialist, increased costs for families.
Ireland	GP	GP	GP	GP "There is free access to acute hospital care, but not for primary care, for all children. About 40% of the population have free access to primary care. Universal preventive public health services, including vaccination and immunization, newborn blood spot screening, and universal neonatal hearing screening are free." <a href="http://www.jpeds.com/article/S0022-3476(16)30149-4/fulltext">http://www.jpeds.com/article/S0022-3476(16)30149-4/fulltext</a>	GP	Tax funded state health system with extra health insurance funding.  Policy is currently changing, with phased introduction of free GP care for children based on government reimbursement of general practitioners. From 2015, all children under 6 receive free primary health care if their parents register with a GP participating in the national scheme. Also free GP care for children whose families do not meet an income threshold or children with certain long term conditions.	National health insurance	Primary care is gatekeeper to other health services
Italy	Paediatrician or GP	< 6 have paediatrician (or GP, only if no paed locally	Combined	"Italian pediatricians related to the Public Health Care System work in their own private offices,	Combined (GP / Paediatrician)	National health service, funded by taxation	National health insurance	Primary care is gatekeeper to other health services

		available); 6-14 have paediatrician OR GP. Max 800 children per paediatrician (in several areas, 1000- 1200)		providing primary care of patients from birth to 14 years of age (to 16 for some cases of chronic diseases) ... parents can choose between a pediatrician and a GP for their children who are between 6 and 14 years of age. <a href="http://www.jpeds.com/article/S0022-3476(16)30151-2/fulltext">http://www.jpeds.com/article/S0022-3476(16)30151-2/fulltext</a>				
Latvia	GP	GP / family doctor or a paediatrician	GP		<b>GP</b>	The financial system the same in 2016. Resources mainly come through general taxation, but out of pocket payment (OOP) are as well , like private voluntary insurance or for services with a long waiting time or services not covered by state budget and provided by private doctors . National Health service (HHS) under the Ministry of Health acts a pooler of health funds and the purchaser of service. Service providers may be public or private. In primary care predominantly all GP are private, but secondary care	Between National Health service and National Health Insurance system  The Latvian HC system is between – in inpatient care for children -state gives money and majority of providers are state hospitals, but in outpatient care (primary care) – money comes from state, but providers (GP) are private	Primary care is gatekeeper to other health services  But once referred can choose specialist

						providers predominantly are public.		
Lithuania	GP or paediatrician	Family doctor/GP or paediatrician	Combined		Combined (GP / Paed)	National Health insurance fund	<i>National Health Service</i>	Primary care is gatekeeper to other health services (developing)
Luxembourg	Paediatrician or GP	Family doctor. Paediatrician up to the age of 2 years.	Combined		Combined (GP / Paed)	Three company insurance schemes	Social health insurance	Open access
Malta	GP	Family doctor (private) or walk in community health centre			GP	Public – free; private care accounts for 2/3 of primary care workload	<i>Please select the most appropriate classification from the Böhm diagram below</i>	Open access
Netherlands	GP	GP (Triaged by nurse)	GP	GP “The GPs treat almost all uncomplicated health problems; as a consequence, Dutch paediatricians see few common child health problems.” <a href="http://www.jpeds.com/article/S0022-3476(16)30153-6/fulltext">http://www.jpeds.com/article/S0022-3476(16)30153-6/fulltext</a>	GP  Footnote: preventive care in children has a separate lead; the preventive child physician		Etatist social health insurance	Primary care is gatekeeper to other health services
Norway	GP	GP	GP		Combined (GP / Paed)  Paediatrician at the municipal health care centres/clinics see children at	Taxes and grants  Primary care is financed from municipal taxes, block grants from the central government and earmarked grants for specific	National Health Service	Primary care is gatekeeper to other health services

					regular periods, have an important public health role (and screening vaccination) but GP are most important with acute illness or concerns.	purposes. A major source of financing of primary care is also the NIS (through fee-for-service payments and reimbursement of user fees). Reference: Health in Transition: Norway 2013		
Poland	GP  In Poland, the GP is called the family doctor and in accordance with the Notice of the Minister of Health of 17 December 2015 on the uniform text of the Regulation of the Minister of Health on the guaranteed benefits in the field of primary health care the services	GP in Poland is called the Family doctor (the doctor of primary health care) or Paediatrician <del>chosen from insurance company list</del> This is in accordance with the currently binding legislation the primary health care might be provided by both 1) the medical doctor specialized in family medicine or general medicine and	GP		Combined (GP / Paed)  This is in accordance with the currently binding legislation the primary health care might be provided by both 1) the medical doctor specialized in family medicine or general medicine and 2) medical doctor specialized in paediatrics	70% from public universal health insurance; Voluntary health insurance limited role	Etatist social health insurance	Primary care is gatekeeper to other health services

	within primary health care might be provided by: the medical doctor specialized (or during the specialization course) in family medicine or the medical doctor specialized in general medicine, as well as the medical doctor specialize in paediatrics	2) medical doctor specialized in paediatrics						
Portugal	GP	GP (80%) or private paediatrician	GP	Mixed (GP and Paediatrician) mostly offered by general practitioners (GPs) (approximately 70% of patients) or by pediatricians (caring for approximately 30% of children). There are an estimated number of children that are followed by both GPs and pediatricians.	Combined (GP / Paediatrician)		National health service	Primary care is gatekeeper to other health services

				<a href="http://www.jpeds.com/article/S0022-3476(16)30154-8/fulltext">http://www.jpeds.com/article/S0022-3476(16)30154-8/fulltext</a>				
Romania	Family doctor (the function is called family doctor, and the training is General Practitioner)	Family doctor			GP	State health insurance system, based on individual contribution of insured adults. Primary care is a mix of funded and fee-for-service care. All children have free health care at all levels.	<i>Please select the most appropriate classification from the Böhm diagram below</i>  Etatist Social Health Insurance  (the state holds the regulatory power, grants privileges for the financing and provision of health services and allows private health services at all levels).	Mixed access. As there are many private health services for adults and children where anybody has access if they pay, we can call it Open access, on the other hand, the primary health care (family doctors) act as gate keepers for all free health care services and even some of the specialized treatments.
Slovakia	Paediatrician	Primary paediatrician	Paediatrician		Primary care paediatrician  Combined (GP / Paediatrician) – only for those older than 18 yrs – until 28 yrs of age so called adolescenthood care but only possible to be done by paediatrician who has specialization in adolescent's care, if not only GP can treat adolescents	Comprehensive health insurance – For adults there is a State (mandatory) health insurance system (3 insurance companies – 1 state and 2 private – family or patient himself are allowed to choose insurance either state or private one – but its mandatory to choose one), universal coverage, for children its free level of care	Etatist social health insurance	Open access

					and young adults older than 18 and younger than 28 as all adult patients			
Slovenia			Paediatrician	<p>“Physicians working with children and adolescents in primary level have a 5-year specialization in pediatrics.”</p> <p>General practitioners (GPs) and family doctors provide care for 1.5% of children 0-6 years of age and 7.7% of children 7 - 18 years of age.  <a href="http://www.jpeds.com/article/S0022-3476(16)30160-3/fulltext">http://www.jpeds.com/article/S0022-3476(16)30160-3/fulltext</a></p>	Primary care paediatrician	<p>Mandatory health insurance, private insurance becoming more common.</p> <p>Children under 18 years of age, students under 26 years of age are entitled to the health benefits covered under compulsory insurance scheme.</p> <p>Children under 18 years of age, students under 26 years of age are exempt from co-payments and therefore do not need to pay voluntary health insurance.</p>	<p>Etatist Social Health System</p> <p>However:Slovenia stands out as a special case. Slovenia is characterized by universal coverage, financing through earmarked taxes, a purchaser-provider split, public hospitals, and private or mixed delivery in the outpatient sector.</p> <p>The state still provides most of the healthcare services with own facilities while funding is delegated to a social health insurance scheme.</p> <p>Social-based mixed-type. Slovenia challenges theoretical assumptions about the specifications of dimensions in healthcare through the combination of state-led provision with societal financing and</p>	<p>Primary care is gatekeeper to other health services.</p> <p>Primary paediatricians are holders of lists of patients as patients (parents for their children) are entitled to select their own/their child’s personal physician. Primary paediatricians have the role of gatekeepers to secondary and tertiary health care level.</p> <p>But patient can choose specialist once referred.</p>

							regulation. <a href="http://edoc.vifapol.de/opus/volltexte/2012/4221/pdf/AP_165_2012.pdf">http://edoc.vifapol.de/opus/volltexte/2012/4221/pdf/AP_165_2012.pdf</a>	
Spain	Paediatrician	Primary care Paediatrician	Paediatrics-based system	Primary care Paediatrician  Primary paediatric care is provided by employed paediatricians in the primary care centres public network	Primary care paediatrician	National health service/ Primary care services funded through general taxation	National health service (NHS)	Primary health care is gatekeeper to other NHS services/health care levels
Sweden	Nurse or doctor in health centres (nurses can prescribe)	Primary care for children in Sweden is divided in two parts; preventive and curative. The preventive health services are built around nurses, in preventive child health centres before school age and school health services. The nurses have a team of consultants who are also directly involved in the preventive	GP	Within the primary care sector, most children receive care from family physicians.  Irrespective of registration, however, primary care rarely has a formal gate-keeping role and, thus, patients are free to contact specialists directly. <a href="http://www.jpeds.com/article/S0022-3476(16)30161-5/fulltext">http://www.jpeds.com/article/S0022-3476(16)30161-5/fulltext</a>	GP	Health services in Sweden are run by 21 county councils who take up taxes to fund the system. There are national	National health service	Open access (PC has guiding role)  The positioning of the paediatricians vary somewhat between counties. In Stockholm county (about 30% of the Swedish population) a referral is not needed to see a paediatrician in outpatient clinics, but in most counties a referral from a GP is needed to see a paediatrician and they only work in hospitals. GP referral is necessary for most secondary care, but child psychiatric services is quite often, but not always open access.

		<p>care; physicians (GP:s or paediatrician s), psychologists (and more often in schools) social workers.</p> <p>The curative primary care is built around GP:s in primary care health centres, but there are also district nurses in these centres who may be involved in giving injections etc. ordered by the GP responsible for the child.</p>						
United Kingdom	Nurse or doctor in PC group practice (nurses can prescribe)	GP as a named accountable professional	GP	GPs are the usual first port of call if a child is unwell, acting as gatekeepers for further referrals to other specialists. Children are immunized either in primary care or in school.	GP	Tax-based national health system. Some differences in funding arrangements in the four devolved countries of England / Wales / Scotland and Northern Ireland	National health service	Primary care is gatekeeper to other health services

				<a href="http://www.jpeds.com/article/S0022-3476(16)30164-0/fulltext">http://www.jpeds.com/article/S0022-3476(16)30164-0/fulltext</a>				
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## Chapter 2

### Systematic review and meta-analysis of the literature

Nadia Minicuci, Barbara Corso, Ilaria Rocco

This chapter is informed by the MOCHA Commission Deliverable D2 (Parts I and II). Minicuci N, Corso B, Rocco I. **Report on systematic review and meta-analysis of the literature on models** for WP1.

#### Main findings

- There is useful data on key processes in primary care around timely diagnosis of key conditions, acute emergency and chronic care management as well as measures of preventive care which is specific to practice in the EU
- Using lead practitioner (paediatrician-led, general practitioner-led or mixed) as the discriminatory factor has revealed the following key findings :
  - There was no statistical difference between type of model as defined by lead practitioner in terms of mean age of diagnosis of ASD.
  - There was no significant difference in any of the three model classifications in terms of age of diagnosis of ADHD.
  - MMR immunisation coverage was statistically lower in GP-led systems compared to Mixed systems. There was no significant difference between Paediatrician-led systems and both Mixed and GP-led systems.
  - Measles vaccination coverage was significantly lower in Mixed system compared to both GP-led and Paediatrician-led systems.
  - Mumps vaccination coverage was significantly higher in Mixed system compared to Paediatrician-led system.
  - There was no significant difference between any of the three models of primary care in terms of children with asthma attending Accident and Emergency departments nor for hospitalization visits.
  - There was no research found for asthma-related unscheduled primary care visits in the Mixed system, while only one study was found for the Paediatrician-led system.
- Using lead practitioner as basis for distinguishing models has some utility but is clearly an oversimplification of the necessary criteria for appraisal.
- The methods of analysis used need to take into account multiple elements of the various models in a more complex regression model in the next phase of MOCHA

#### Methods

This systematic review was conducted to collate the published scientific evidence of European models of primary care delivery to inform the development of a framework describing model type and key characteristics. It was a first test of the commonly-used classification of models of primary care services in the EU and EEA – namely classified by lead practitioner who has clinical responsibility for the child as patient.

This edition formed a sound building block for other MOCHA activities.

In order to describe the different models of care provided in Member States, Norway and Iceland, a systematic review of the literature and meta-analysis of the evidence for different models was conducted, by selecting three different aspects of children's primary care, each of which reflects a different perspective of the primary care health system:

1. making an early diagnosis
2. prevention
3. how to deal with a chronic condition

The four '**tracer**' **conditions** chosen reflect, as far as is possible, a generic experience of interaction with a primary care system. Although the individual experience will not be identical for different diseases, these cases have been identified as they reflect the needs of a modern and responsive primary child health care system where neurodevelopmental conditions, chronic long standing illness and maintaining protection from communicable diseases are priorities (1). The tracer conditions are:

- Age of first diagnosis of **Autistic Spectrum Disorder (ASD)** (in particular: Autism/ autistic disorder; Asperger's syndrome; Pervasive developmental disorder not otherwise specified; Childhood disintegrative disorder)
- Age of first diagnosis of **Attention Deficit Hyperactivity Disorder (ADHD)**
- Coverage of **immunisation** of children (in particular: measles, mumps and rubella)
- Coverage
- The control of **asthma** in children aged over 5, with a particular focus on hospital admissions, unscheduled primary care visits and the availability of spirometry at a primary care level- a key quality indicator.

## Methods

A comprehensive electronic search was performed using PubMed.

For **ASD** the following key words have been set for the search in the title or in the abstract: (autism spectrum disorder OR autistic disorder OR Asperger OR Asperger's syndrome OR Asperger's disorder OR pdd-nos OR pervasive developmental disorder OR childhood disintegrative disorder OR cdd); moreover ((age) AND (diagnosis OR onset)) was set for the search in the full-text. The filter child: birth <18 was set.

For **ADHD** the following key words have been set for the search in the title or in the abstract: (ADHD OR "Attention deficit" OR "Hyperactivity disorder" OR "Attention disorder"); moreover ((age) AND (diagnosis OR onset)) was set for the search in the full-text.

The filters "Text availability: Full text" and "Languages: English" were set. Authors' affiliations: only European affiliated authors were included.

For **immunisation** the following key words have been set for the search in the title or in the abstract: (vaccine\* OR immuniz\*) AND (meas\* OR mump\* OR rubell\* OR mmr) AND (coverage), using the filters child: birth <18 and humans.

For **asthma**, the word "asthma" was searched in the title or in the abstract, in combination with the following key words searched in the text: (emergency OR emergency department OR unschedul\*) AND (admission\* OR care OR visit\*), using the filters humans. Authors' affiliations: only European affiliated authors were included.

A second search was undertaken using the word “spirometer” and “availability” in the text.

All potentially eligible articles were screened at title, abstract, and full-text stages in order to sequentially identify the study country and the availability of the investigated outcomes.

The PubMed search was supplemented with hand-searching of reference lists of all potentially eligible full-text articles.

### **Eligibility criteria**

*Types of study design:* Any type of study design has been included in the search; however the search identified mainly observational studies, either cross-sectional or longitudinal.

*Reference year:* all papers published in the range of years 2000-2016.

*Language restriction:* only papers published in English were considered

*Outcomes investigated:*

- a) ASD focused on the age at onset of the following conditions:
  - a1) Autism/ autistic disorder;
  - a2) Asperger’s syndrome;
  - a3) Pervasive developmental disorder not otherwise specified;
  - a4) Childhood disintegrative disorder;
- b) ADHD age at onset.
- c) Immunisation investigated the coverage of the following conditions:
  - c1) Measles;
  - c2) Mumps;
  - c3) Rubella.
- d) In asthmatic children the % or alternatively the absolute number of:
  - d1) Accident & Emergency Department/Room visits for asthma;
  - d2) Hospital admissions for asthma;
  - d3) Unscheduled primary care visits for asthma;
  - d4) the availability of the spirometry at a primary care level.

### **Data extraction**

The following data were extracted from all included papers: the first author’s last name, publication year, country where the study was conducted, the study design, the outcome measures investigated, the sample size, the age of reference, and gender.

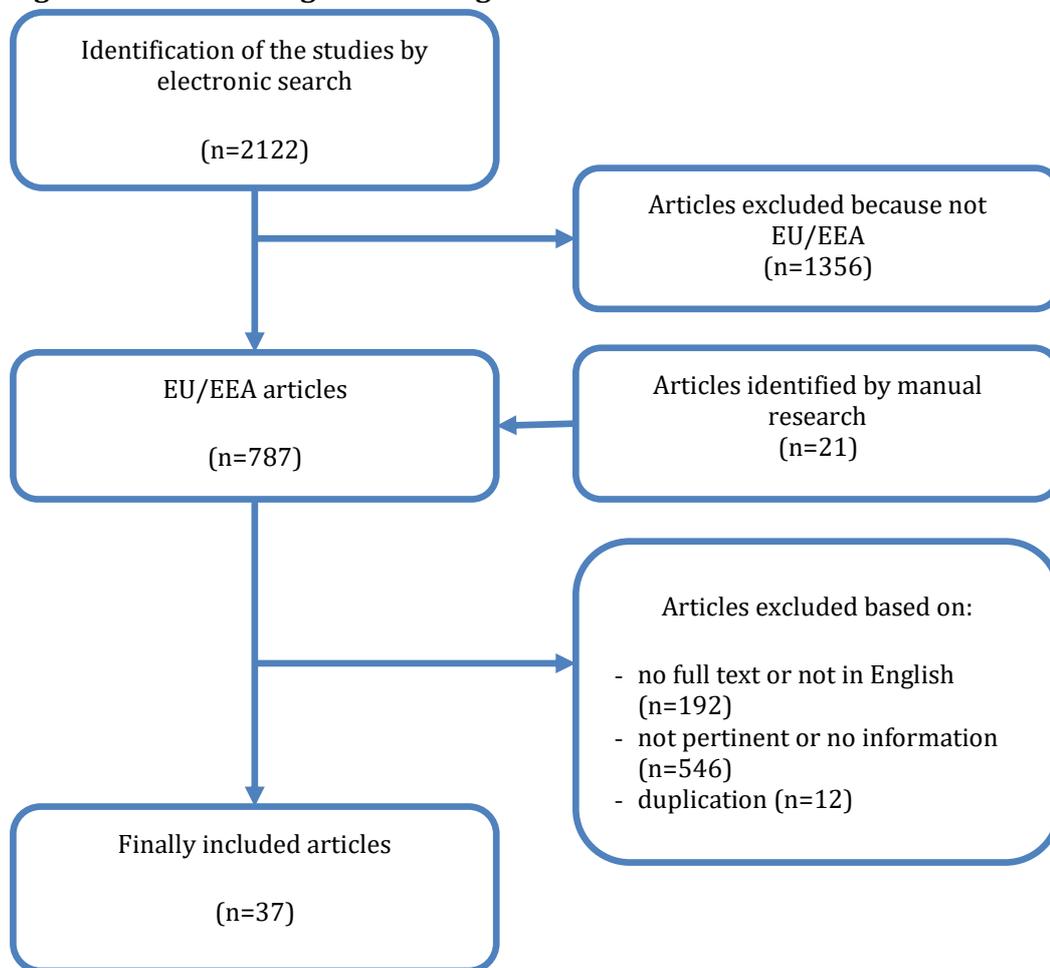
### **Summary of the study selection process**

The following figures show the different steps of the selection process for ASD, ADHD Immunisation and asthma, respectively.

### ASD

The PubMed search retrieved 2122 articles on ASD from year 2000 to 2016. Sixty-nine percent of these papers (1356/2122) have been excluded since the research was not carried out in a European Country. Selecting the EU countries articles was particularly time-consuming as it often required reading the full-text. Twenty-one articles were retrieved manually, leading to 787 articles read as a full text. Out of these, only 37 have been included in our systematic review (4.7%).

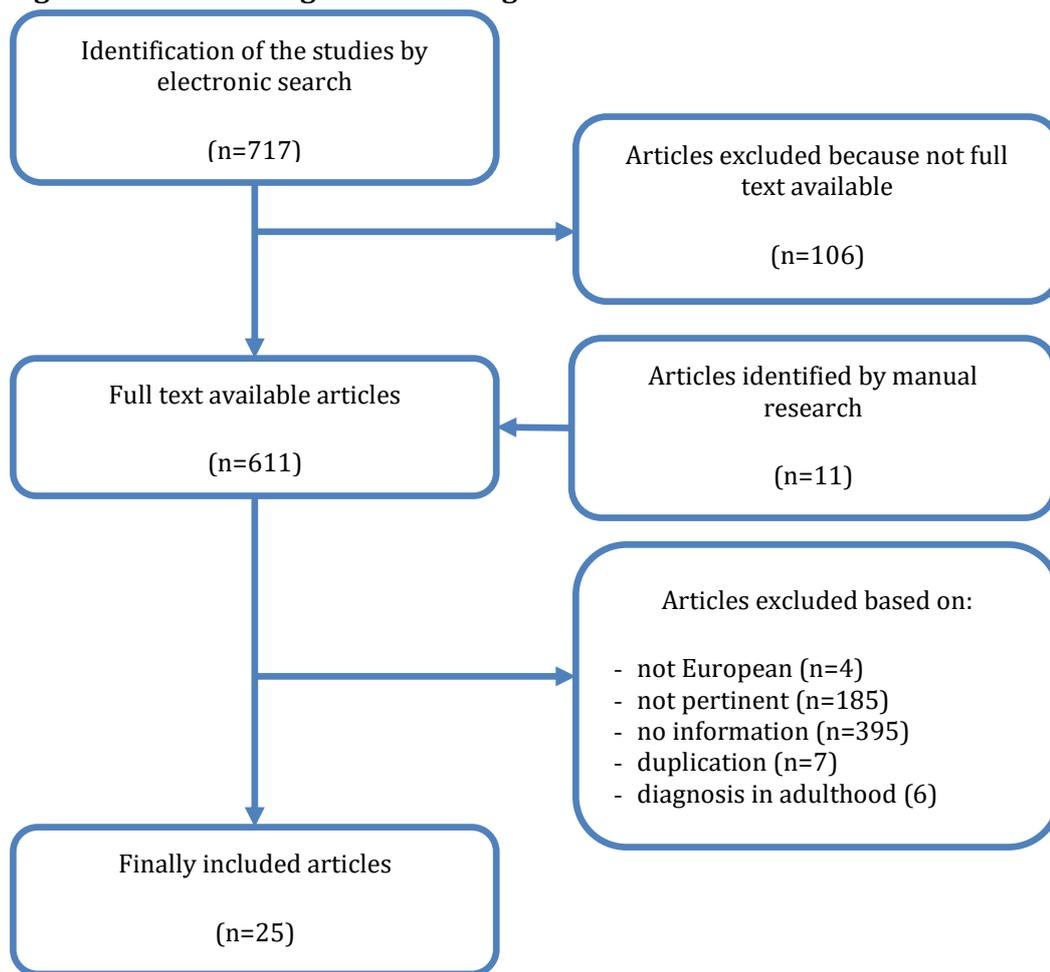
**Figure 3: Flow chart age at ASD diagnosis**



### ADHD

The PubMed search retrieved 717 articles on ADHD from year 2000 to 2016. Fifteen percent of these papers (106/717) have been excluded since the full text of the articles was not available. Eleven articles have been retrieved manually, leading to 622 articles read as a full text. Out of these, only 25 have been included in our systematic review (3.5%).

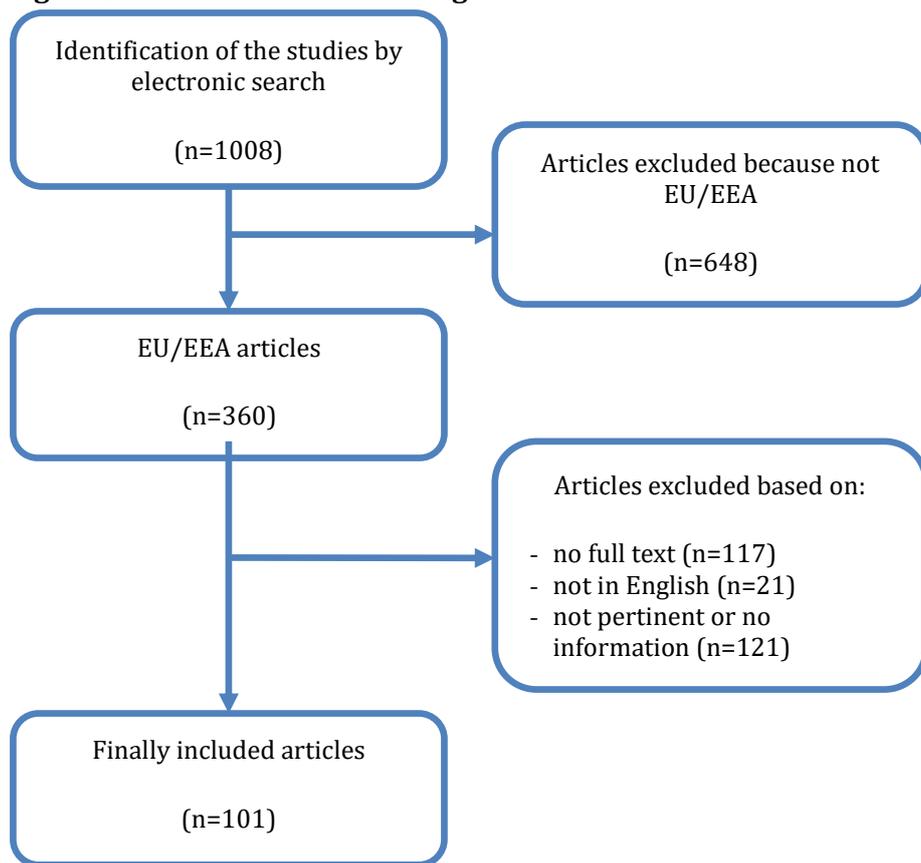
**Figure 4: Flow chart age at ADHD diagnosis**



### ***Immunisation***

The PubMed search retrieved 1008 articles on Immunisation from year 2000 to 2016. Sixty-four percent of these papers (648/1008) have been excluded since the research was not carried out in a European Country. The mere selection of the EU and EEA countries' articles was particularly time-consuming since, often, it had required the reading of the full-text. Sixty-four percent of these papers (648/1008) have been excluded since the research was not carried out in a European Country. The full-text reading of the 360 articles lead to 101 articles to be included in our systematic review.

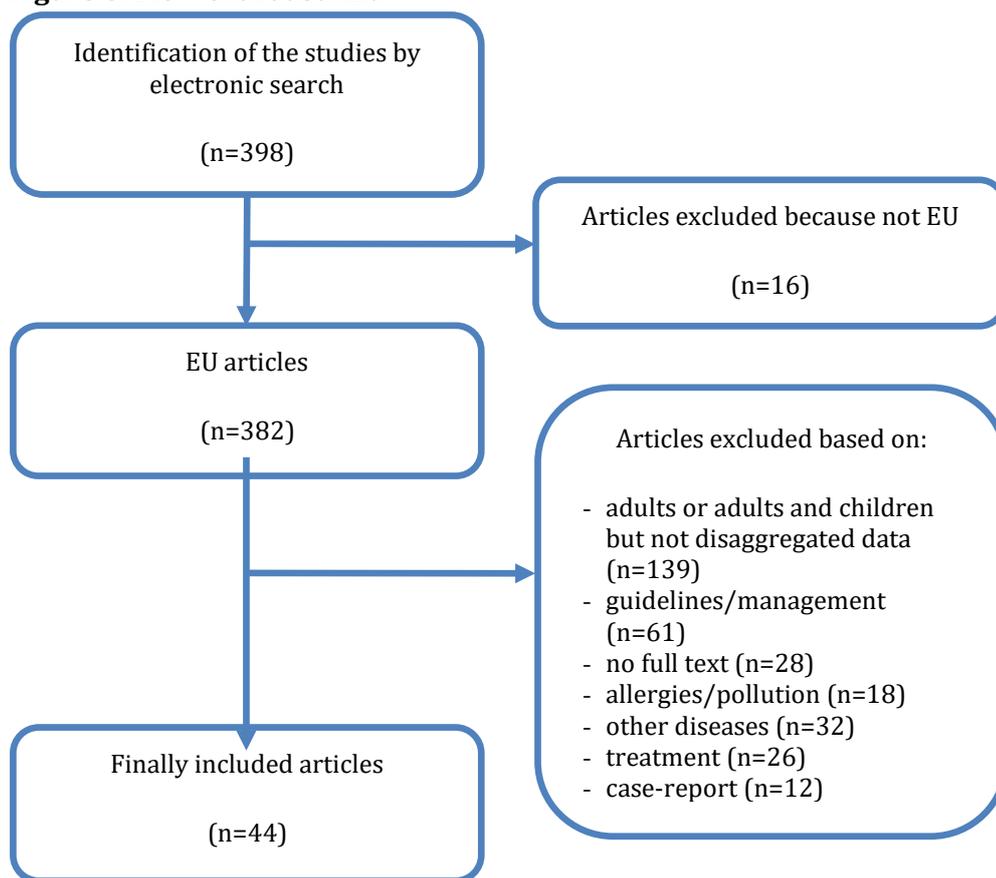
**Figure 5: Flow chart MMR coverage**



***Asthma***

The PubMed search retrieved 398 articles on asthma for the ED/hospital/unscheduled primary care visits, from year 2000 to 2016. Although the restriction on authors' affiliation, 16 of these papers have been excluded since the research was not carried out in a European Country. The full-text reading of the 382 articles lead to 44 articles to be included in our systematic review.

**Figure 6: Flow chart asthma**



The PubMed search retrieved 15 articles on spirometry instrument, but only 4 of them reported the %/absolute number of available spirometers at a primary care level.

### **Meta-analysis**

In our search the primary interest lies in the descriptive estimates, as opposed to comparative estimates that arise naturally for Randomized Controlled Trial studies or cohort studies (where exposed are compared with the unexposed) or case-control studies (where people with the condition are compared with people without the condition).

Investigated outcomes have been combined in a pooled estimate, using the method of the inverse of the variance, that is the weighting assigned to the different studies is related with the inverse of the standard error and therefore indirectly to the sample size. This implies that studies with smaller standard error and larger sample size are given more weight in the calculation of the pooled estimates. Fixed effects or random effects models have been used, according to the presence of heterogeneity which was tested by means of the Cochrane's Q test and the Higgins I<sup>2</sup> statistic which was interpreted as follows: I<sup>2</sup> of 25 % = low heterogeneity. I<sup>2</sup> of 50 % = medium heterogeneity. I<sup>2</sup> = 75 % = high heterogeneity. The results of the different studies and the overall estimate with its 95% Confidence Interval (95%CI) are illustrated in a "forest plot" graph.

### **Type of care: country classification**

The EU and EEA countries have been classified according to their primary care system defined as: Paediatrician mainly oriented (Paed); General Practitioner mainly oriented (GP); Mixed. This

classification is the outcome of the MOCHA classification task group based on the Country Agent investigations upon a specific request from the WP leaders on a case study (See Introduction).

Table 2 reports the description of the health system given by the Country Agents, the findings from van Esso et al. (2) (who have used the term “combined” when referring to GP and Paediatrician systems) and the MOCHA classification working group. The term mixed incorporates other professionals’ involvement as first line contacts e.g. nursing staff.

**Table 2: Type of primary care for each EU country**

Country	Description of type of primary care	Source: (2)	MOCHA AGREED Primary care Lead practitioner -
Austria	GP and paediatrician	Combined	Both(GP / Paediatrician)
Belgium	Family doctor or 1 <sup>st</sup> line paediatrician	Combined	Combined GP/Paediatrician
Bulgaria	GP for those with health insurance. Pre 2000 was mandatory to have a community paediatrician for children up to 18; this generation now retiring and GPs only have 9 weeks paediatrics training.	GP	GP
Croatia	Primary care doctor / paediatrician	-	Primary care paediatrician
Cyprus	Private paediatrician or public funded GP who will refer to hospital Paediatrician if necessary	Paed	Primary care paediatrician
Czech Republic	“registering paediatrician” accessed via triage nurse	Paed	Primary care paediatrician
Denmark	-	GP	GP / Nurse combined
Estonia	GP	GP	GP
Finland	GP	GP	Combined other (nurse / GP / Paed)
France	Family physician or GP who is either a Paediatrician or a GP	GP	Combined other (nurse / GP / Paed)  Nurses are generally supervised by doctors, except in a few institutions (PMI-Maternal and Infant Protection, “crèches”, school) where they can have a role of screening and orientation
Germany	Paediatrician	GP	Primary care paediatrician

Greece	GP or Paediatrician chosen from insurance co list Usually paediatrician up to 18 years old.	Paed	Paed
Hungary	-	Combined	Combined (GP / Paediatrician)
Iceland	One family doctor from a health care centre or private paediatrician	Combined	GP
Ireland	GP	GP	GP
Italy	0-14 have paediatrician or GP if none locally. Max 800 children per paediatrician	Mixed	Combined (GP / Paediatrician)
Latvia	GP / family doctor or a paediatrician	GP	GP
Lithuania	Family doctor or paediatrician	Combined	Combined (GP / Paed)
Luxembourg	Family doctor. Paediatrician up to the age of 2 years.	Combined	Combined (GP / Paediatrician)
Malta	Family doctor (private) or walk in community health centre	-	GP
Netherlands	GP (Triaged by nurse)	GP	GP Footnote: preventive care in children has a separate lead; the preventive child physician
Norway	GP	GP	Combined (GP / Paed) Paediatrician at the municipal health care centres/clinics see children at regular periods, have an important public health role (and screening vaccination) but GP are most important with acute illness or concerns.
Poland	GP or Paediatrician chosen from insurance company list	GP	Combined (GP / Paed) This is in accordance with the currently binding legislation the primary health care might be provided by both 1) the

			medical doctor specialized in family medicine or general medicine and 2) medical doctor specialized in paediatrics
Portugal	GP (80%) or private paediatrician	GP	Combined (GP / Paediatrician)
Romania	Family doctor	-	GP
Slovakia	-	Paed	Paed
Slovenia	-	Paed	Paed
Spain	Family doctor in health care centre or a paediatrician	Paed	Primary care paediatrician
Sweden	Child health care nurse up to age 6; school health nurse afterwards. GP/Paediatricians in hospital contacted by nurse	GP	GP
United Kingdom	GP as a named accountable professional	GP	GP

The Paed/GP/Mixed MOCHA classification was used to perform the meta-analysis for each type of primary care and allow some speculations on possible difference across types of primary care systems.

### Triangulation and validation

This systematic review is the first to appraise all models of primary care for children using these tracer conditions. It broke new ground in this respect. The results are informative, as it shows that there must be factors, other than the lead practitioner, that influence the differences in outcome for children in the different primary care systems. This is reflected in the development of the MOCHA concept of a model (See Chapter 10, Figure 41), which outlines the many influences on primary care services, and the many influences on a child's health and access to that service. The tracer conditions were chosen in accordance with what is known to be important to children, as discussed in Chapter 1 and elsewhere in the MOCHA project ([www.childhealthservicemodels.eu/publications/deliverables/](http://www.childhealthservicemodels.eu/publications/deliverables/)).

### Summary of results

Table 3 summarises the statistical analysis to date (a more detailed set of plots and summary statistics is available from the Deliverable 2 D1.1. on the MOCHA website although this is likely to be updated as the project develops. [www.childhealthservicemodels.eu/deliverables](http://www.childhealthservicemodels.eu/deliverables))

**Table 3: Summary of the Meta-Analysis Findings**

	<b>Paed</b>	<b>GP</b>	<b>Mixed</b>	<b>Note</b>
<b>Mean age at onset/diagnosis and 95% CI</b>				
<b>ASD (months)</b>	42.7 (37.8-47.6)	59.2 (42.3-76.2)	48.7 (43.0-54.4)	No difference
Autistic disorder (months)	only two estimates for mean age	56.2 (41.3-71.0)	only two estimates for mean age	-
Asperger's syndrome (months)	only two estimates for mean age	97.4 (70.9-124.0)	only one estimate for mean age	-
PDD-NOS (months)	No article found	67.9 (42.9-93.0)	only one estimate for mean age	-
<b>ADHD (years)</b>	8.4 (7.0-9.8)	10.5 (8.8-12.3)	8.3 (7.7-9.0)	No difference
<b>Immunisation Coverage (%) and 95% CI</b>				
MMR	81.9 (42.2-100.0)	79.5 (73.5-84.9)	89.7 (86.3-92.7)	Difference between GP and Mixed (favoured)
Measles	90.4 (85.8-94.1)	92.1 (88.9-94.8)	66.9 (59.9-73.5)	Difference between Mixed and GP (favoured); Difference between Mixed and Paediatrician (favoured)
Mumps	70.5 (49.4-87.7)*	No article found	90.9 (89.9-91.8)	Difference between Paediatrician and Mixed (favoured)
Rubella	87.3 (72.8-96.8)*	no article found	only two estimates for coverage %	-
<b>Asthma (%) and 95% CI</b>				
Accident & Emergency Department/room visits	45.0 (12.3-80.4)	23.1 (7.5-43.9)	37.7 (8.1-73.8)	No difference
Hospitalizations visits	11.4 (4.1-21.8)	6.3 (3.8-9.3)	31.1 (1.8-93.6)	No difference
Unscheduled primary care visits	less than 3 countries	25.8 (3.3-59.9)	no article found	-

## Strengths and limitations

A meta-analysis is the statistical part of the systematic review process and has some advantages. Meta-analysis includes more participants than a single constituent study, which implies a reduction of random errors and an increase of the power. Moreover, a meta-analysis is capable of exploring variations between studies. However, there are some limitations of both the primary studies and the systematic review.

For ASD, depending the age-range of the analysed sample, the age at diagnosis of ASD could be subject to bias. For example, some studies considered adolescents as the reference population while other studies included children under the age of 4 years. It is plausible that the latter case would underestimate the mean age at diagnosis.

The systematic review for PDD-NOS was unable to retrieve studies for countries using the Paediatrician-led (no studies) and Mixed models (only one study), which made a true meta-analysis impossible. In terms of autistic disorder, only two studies were found that referred to the Paediatrician-led and Mixed models. Also for Asperger's syndrome, the meta-analysis was carried out only for the GP-led model.

For ADHD, depending on the age-range of the analysed sample, the age at diagnosis of ADHD could be susceptible of bias. For example, a study considered children up to 16 years of age, while another study involved subjects between 15 and 55 years. In the meta-analysis of the Paediatric system, out of 10 studies included 7 were from Germany.

Regarding vaccination, different countries administer the first dose of MMR at different ages: within 12 months of age in 10 countries, within 16 months of age in 15 countries and within the second year of age in 6 countries. Almost all countries have introduced the second dose of MMR vaccination within the second year of life, while in other countries it is administered between 3 and 9 years old.

Usually immunisation coverage is assessed, and reported, at 24, 36 months of age. However, some of the retrieved studies take into account different age setting and retrospectively assess the immunisation coverage through child's personal vaccination card, so the coverage for these studies could be overestimated if compared to other studies that took into consideration younger ages.

No comparison was performed for Rubella, since no studies were found for the countries within the GP model (as for Mumps) and only two studies (conducted in France) were found for the Mixed model.

For asthma, the majority of the papers (17/44) found with the systematic review were "case-only", meaning that the study investigated some characteristics of children with asthma admitted to hospital or who had an ED visit asthma-related. Therefore these studies provided only the absolute number of children and did not allow the computation of the prevalence. In some papers the access to ED/hospital in the previous/following 12 months was reported, but again this information could not have been used in the meta-analysis, since it represented a "second hospitalised/admission".

For the Mixed system model regarding unscheduled primary care visits for asthma, the systematic review search did not identify any studies eligible for the meta-analysis. Whereas for the Paediatrician-led model only one study (conducted in Spain) was found.

Due to the lack of studies, the meta-analysis on the availability of spirometry at primary care level could not be performed.

Finally, the MOCHA country classification of type of primary care is based on the actual health system running in the country, whereas the retrieved articles for the systematic review refer to precedent years during which the health system may have had a different legislation and regulation. As the project progresses and different parameters of models of care are considered, it is possible to carry out further re- analyses according to typologies of care provision other than the predominant medical professional type.

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## Chapter 3

### Patient experience

Manna Alma

#### Main findings

- Qualitative inquiry of child's experience of primary health care will provide valuable triangulation and identification of areas of concern to children and young people, and their families.
- The MOCHA researchers from the various Work Packages have helped develop the interview schedule to complement other data sources used.
- We have interviewed children and young people from five European countries: Czech Republic, Germany, Netherlands, Spain and the United Kingdom.
- Initial themes emerging include themes emerging include quality of care, quality of primary health care professional and access to care – including opening hours.

The use of this technique is particularly important when thinking about a child's experience of primary health care, because of the lack of autonomy of children, and the lack of power they have to effect change or influence how care is delivered to them. This triangulation is essential, as without the input of young people it is difficult to ensure the suitability of primary care systems to meet the needs of children and young people.

#### Methods

We have conducted interviews with and obtained experiences from both parents and children from five European countries - Czech Republic, Germany, Netherlands, Spain and the United Kingdom. A maximum variation sampling strategy was used to produce a sample with a broad range of experiences. We achieved variety in demographic details (for example age, gender, socio-economic status and so on) as well as for variety in health status of the child (including healthy children, children with chronic conditions, and children with mental health conditions). Parents and children were recruited through a number of different routes including GPs, primary health care centres, youth care, rehabilitation centres, schools, youth clubs, advertising on websites, in social media and by word of mouth. A purposive (or maximum variation sampling strategy is used for each project to produce a sample with a broad range of experiences in terms of the particular issue or health condition being studied, and the demographic details of the participants (1). Recruiting participants and collecting interviews is continued until the researchers are convinced that all the main experiences and views of people are represented and 'saturation' of information is achieved.

Before data collection can start, all DIPEX members acquired ethical approval for the MOCHA study from local ethical committees.

#### Data collection

The interviews took place in various venues in the participating countries. Often, children were interviewed in their own homes, but occasionally elsewhere if they prefer. Older children were interviewed alone, and younger children had a parent present. All the interviews were audio tape recorded for analysis. If the respondent is happy to consent, interviews are also video recorded.

In the first part of the interview people were asked to tell their story of what has happened to them, perhaps from when they first began to suspect there was ‘a problem’. The researcher does not interrupt the person while they are telling their story. This part of the interview can take more than one hour and contains mostly unstructured narrative data. In the second part of the interview, which is semi-structured, the researcher asks additional questions. These may have been prompted by issues raised by the interviewee, identified in earlier interviews or from the literature review.

It is usual for qualitative interview studies to have an overlap between collecting and analysing the interviews. Two researchers (the main researcher and a ‘buddy’) discuss the emerging themes after a few interviews have been completed and new ideas may be suggested. This may lead to changes in the interview guide for subsequent interviews to enable issues that are important in peoples’ stories to be explored more fully.

The financial and time constraints of the MOCHA project meant that it was not possible to conduct 40-50 interviews, which is normally needed to reach data saturation; but we conducted additional focus group interviews and secondary analysis of interviews conducted in earlier studies done by the DIPEX members to take account for this potential limitation.

The specific topic list and interview guides was developed in conjunction with other researchers on the MOCHA project, to ensure that triangulation through patient views was concurrent with the Country Agent questions and the research interests of the MOCHA project as a whole (See Introduction for more about the Country Agents).

Due to the different populations that were included in the study, several interview guides were developed: – for example for parents and children, for (parents of) healthy children, for (parents of) children with chronic conditions and so on. Figure 7 gives the broad outline of the interview guide. These are flexible and change throughout the interview process, this is not a final document.

**Figure 7: Interview guide for parents and children combined**

**Narrative**

Where the parent or child talks about a recent visit to primary care

**Semi structured interview; comprising elements such as:**

- Impact of chronic conditions
- Access / thoughts and feelings before the consultation
- The primary care practice and feelings about the consultation
- Feelings of responsibility for child’s health
- Coordination of care and transition to further care
- Out of hours and roles of nurses
- Other primary care professionals
- Incentives and penalties
- How can primary care be improved for children

**Parents’ views:** To obtain parents’ views on primary care in-depth interviews were conducted throughout the five countries. In the first part of the interview parents are asked to tell their story of what happened the last time their child was ill or what happened the last time they visited a primary health care professional (for example a GP) with their child. If applicable, parents of children will be asked to tell their story what happened when they heard that their child was discharged from hospital or rehabilitation centre. In the second part of the interview, which is semi- structured, questions were asked about issues raised by the interviewee in the earlier interviews, from the literature review or

raised by other MOCHA researchers. In addition to the in-depth interviews, additional focus group interviews were conducted to validate the data.

**Children's views:** Children's' experiences with primary care were obtained by in-depth interviews as well as by focus groups interviews. Depending on the child or the group, several methods are used to collect data during these interviews:

- “normal” in-depth interview, in which children are asked to tell their story of what happened the last time they were ill, or visited a GP. In the semi-structured part of the interview, additional questions will be asked about issues raised by the interviewee, identified in earlier interviews, from the literature review, or raised by other MOCHA researchers.
- Pictures will be used as a starting point of a (group) discussion.
- Children are asked to make a drawing of the last time they were ill. This drawing will act as a starting point for the interview / group discussion.
- A group of children is asked to do a role play about the last time they visited their GP. This role play will then act as a starting point for the group discussion.
- Children are asked to write a letter to their GP about what they like and dislike about their GP.

Researchers are flexible in using these methods depending on the child or the group.

## Validation and Triangulation

In terms of triangulation within the project, each interview is taped, and fully transcribed verbatim and the transcript is returned to the interviewee for review.

Before analysis takes place, a list of topic categories for analysis was drawn up, which were initially identified from the literature and from the first interviews. As the analysis progressed, additional categories were added to this list. The data was then entered into a specialist software package, which helps organize and analyse emergent (i.e., unexpected) themes, as well as those that were anticipated, using the method of constant comparison (2). Analysis begins soon after the first interviews (3).

During the analysis, the researchers group and link all of the sections of the interviews that cover a similar topic through a process of coding. When this coding is finished, the researchers can then scrutinise all the responses about a particular topic, gathered together in one or more reports. These reports are the basis for the analysis and for writing the topic summaries. The researcher and the buddy researcher look at the reports to ensure the important points, and every respondent's perspective, have been included in the topic summaries. The role of the buddy researcher is to be a 'critical friend' who takes an independent view of the data collected. At this stage there may be some discussion about meaning and interpretation of points made during the interviews. For a more detailed description of the analysis process see Ziebland and McPherson (4).

## Secondary analysis

In addition to in-depth interviews and focus group interviews, secondary analysis has been conducted of interviews undertaken in earlier or currently running DIPEX projects. For example:

- **Germany:** DIPEX Germany is running a project on experiences of people with ADHD. They include younger persons (16-18) in their study too. These interviews will be used for secondary analyses.
- **Netherlands:** DIPEX Netherlands is working on a project on rare diseases. In this project, parents will be interviewed about the time between the first signals and the final diagnosis of a rare disease in their child. These interviews will be used for secondary analysis of what these parents say about primary health care.

- **Spain:** Several years ago, DIPEX Spain participated in a study on children with asthma. They will see whether these interviews might be valuable for secondary analysis with respect to the MOCHA topic.
- **UK:** As founder of DIPEX, DIPEX UK has at its disposal an enormous collection of in- depth interviews with patients, including younger persons (aged 12 and above). DIPEX UK will do a secondary analysis of what young people (and a few parents) say about primary care and the primary / secondary care interface. This collection will include interviews from a study on young people's experiences of primary care, and interviews with (parents of) children with arthritis, depression, diabetes type 1, epilepsy and long term health conditions.

To date, most of the interviews have been conducted; and will be analysed in the late spring of 2017. This work is an extremely important element of triangulation for the MOCHA project.

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## Chapter 4

### Current model infrastructure and responsivity

Ingrid Wolfe, Sapfo Lignou, Carol Hilliard, Denise Alexander

This chapter is taken from the internal deliverable D1.6: Current Model Infrastructure and Responsivity, and the Primary/Secondary Healthcare Interface: evidence from case studies.

#### Main findings

- For emergency and out of hours care, the first point of contact in 28 countries is the primary care physician -whether GP or paediatrician
- In a school setting, policy varies considerably in terms of who can provide assistance and access to medicines in an emergency.
- In 28% (n=7) of countries, there is access to the main primary care provider's record systems in an emergency.
- Although nearly four-fifths of countries have a formal hospital discharge summary, very few use digital transfer of information, and only eight countries use standard referral or discharge proformas
- Protocols and guidelines for asthma are use in 91% (n=21 of the 23 responding Country Agents) of countries, but only two of these are collaborative plans made with the family or child involvement

#### Methods

The purpose of the narrative reviews was to explore key issues of children's primary care focusing specifically on the primary-secondary care interface and its impact on the quality, safety and timeliness of care. A search of the following academic literature databases was conducted for English language research published from 2006-2017: Medline, CINAHL, the Cochrane Library, and ProQuest (includes PsychInfo, Worldwide Political Science Abstracts and Web of Science). In order to avoid overlooking relevant papers, the search was initially broadly framed by using the Medical Subject Heading (MeSH) terms 'Primary Health Care' and 'Secondary Care'. Additional search terms and Boolean operators (AND/OR/NOT) were used to refine the search, including: *referral, discharge, interface/handover/transfer/transition, quality, safety, child\** (truncation used to widen the search). Papers were excluded if they did not include an element of the primary-secondary interface. Where possible, paediatric research only was used, but where this was not available or it was sufficient, evidence from studies conducted in adult healthcare was used.

An additional electronic search was conducted to retrieve relevant grey literature from Europe and internationally, including reports and policy documents. Finally, a snowballing technique (1) was used to source literature by reviewing the reference lists of the retrieved literature and using citation tracking to identify literature which has cited papers retrieved in the electronic literature search. Due to the language competencies of the writers, the literature search was limited to English language publication, which we concede is a limitation as it omits potentially valuable research written in other European languages.

This ensured that the case study methodology used by the MOCHA project was as rigorous as possible. We could also build upon any previously unidentified, relevant, high-quality research.

As is common throughout the project, the use of case studies is interdependent with other facets of the MOCHA project – as case studies are used by a number of other work packages: including potentially Work Package 2 Interfaces of Models of Primary care with Secondary, Social and Complex care; Work Package 3: School and adolescent health services; and Work Package 7: Equity in health services. For more information see [www.childhealthservicemodels.eu/topics](http://www.childhealthservicemodels.eu/topics).

### **Study design:**

There are three main types of clinical case study (2). Intrinsic case studies give insight to a unique phenomenon; instrumental case studies use a particular case to gain a broader appreciation of an issue or phenomenon; and collective case studies involve studying multiple cases simultaneously, in order to develop a broad appreciation of a particular issue (2).

For the MOCHA investigation, we used a multiple case study design in order to obtain collective instrumental data on primary care models for children and young people in all 30 European countries. We selected a ‘typical’ clinical scenario, to allow the researcher to investigate the primary care health system at particular points of need of the child (3, 4)

### **The cases**

Research questions using case studies must be carefully formulated using knowledge from existing literature (2, 5) and are thus based on an in depth knowledge of theoretical and empirical literature. The case study should have a pre-defined boundary clarifying its scope, beginning and end, the relevant social group or geographical area, and the priorities of data collection and analysis (3). In the case of the MOCHA case studies, the boundaries included the age of the child, setting (primary care or educational setting) and geographical boundaries (national boundaries).

We constructed clinical scenarios designed to describe ways that children and young people use primary care in the real world. They allowed the illustration of pathways that start from and end with the child at home; and include interfaces between primary care, secondary care and school. Multiple clinical scenarios were used to operationalise case studies in order to build a multi-dimensional picture of primary care (4). Clinical scenarios and case studies have been used in European child health services research (6). The clinical scenarios used in this report to illustrate the structures, processes, and outcomes of primary care for children and young people are designed to examine universal aspects of both unscheduled and scheduled care.

Four questionnaires were developed based on two potential high risk clinical scenarios:

- acute mild illness
- simple chronic illness (asthma)

Brief hypothetical but universally relevant clinical scenarios were used to enhance the extent to which the typical situation in a country could be described using clinical concepts that are consistent between countries. Table 4 presents the scenarios, along with the rationale for their selection.

**Table 4: Clinical scenarios used in Country Agent questionnaires**

<p><b>Round 1: Acute Mild Illness</b></p> <p><i>Please consider the situation of a 2 year old child. The child quickly develops a mild fever, and rash, and is clearly uncomfortable. It is Wednesday late afternoon (during usual business hours) and the family are at home.</i></p> <p><i>The parents want their child to be seen by a health professional within 24 hours. The question from MOCHA is to inform us what happens typically in your country.</i></p>
<p><b>Rationale for selection:</b> This scenario identifies the first contact point for the child with the health service. It also represents the start point for exploring the primary-secondary interface since a variety of factors may determine the setting of the first contact with the health service for this particular scenario.</p>
<p><b>Round 4: Common or single Chronic Illness</b></p> <p><i>In the event of a moderately severe asthma attack, which sort of health professional is likely to see the child (e.g. GP, paediatrician, family doctor, specialised doctor)?</i></p> <p><i>If the child is referred and/or admitted to hospital with an asthma attack, how is communication, in both directions, between primary and secondary care usually achieved? (e.g. a written letter, an email, a phone call?)</i></p>
<p><b>Rationale for selection:</b> Asthma is the most common chronic disease of childhood, and therefore this scenario presents a typical situation in which a child may navigate between primary and secondary care. National asthma programmes and international guidelines exist in relation to the diagnosis and treatment of asthma, and the criteria for referral to and from specialist care (for example Global Initiative for Asthma (GINA) 2016). This scenario allows us to examine issues related to the governance, coordination and continuity of care.</p>
<p><b>Round 5: Common or single Chronic Illness and the school setting</b></p> <p><i>Jakob is a 10 year old boy who has a 2 year history of asthma and takes regular medications (by using an inhaler) for this. Most of the time he is well, but occasionally he has an acute wheezy attack usually, in response to a cold or flu or when exposed to furry animals or grass pollen. Additionally, on occasions he will need to use an inhaler when he does physical exercise in the gym or playground.</i></p>
<p><b>Rationale for selection:</b> This scenario allows us to examine if, and how, health systems interact with school systems in relation to the care needs of a child with asthma. The prevalence of asthma in Europe allows this scenario to represent what typically happens in each country. The scenario also allows for the exploration of the individualisation of care.</p>

Questions were sent to the MOCHA Country Agents (See Introduction) in each European country on specific aspects of the clinical scenarios.

### **Data Analysis**

Data from the Country Agent questionnaire was transferred onto a spreadsheet to facilitate management of the large volumes of information. This spreadsheet, together with files of raw data comprises a case study database to facilitate both any subsequent analyses and review. Data analysis was by narrative themes and descriptive statistics including frequency and frequency percent using

Country Agent responses, triangulating information using the results of literature searches where possible.

### **Validation and Triangulation**

Case studies can be used to identify and describe primary care models, and their characteristics and qualities. This is an important approach for the MOCHA project, as extant research specifically on primary care models for children is sparse. The use of case studies allows the project to highlight and identify elements of a model from a child's perspective.

Country Agent response rates to the questionnaires ranged from 77% (n=23) completed Round 4 and Round 5 questionnaires, to 93% (n=28) completed Round 1 questionnaires. The responses are discussed in terms of: Policy and Guidelines Framework, Access to Care, Coordination and Continuity of Care.

### **Policy and Guidelines Framework**

The MOCHA Country Agents were asked about the national policy framework in their countries, specifically whether the country has a National Asthma Programme, and a national policy about the holding of/access to asthma medication in the school setting. Country Agents were also asked to identify if explicit asthma guidelines were in use in their countries. Table 5 describes the response for each country.

**Table 5: Policy and guideline frameworks underpinning asthma care in MOCHA countries**

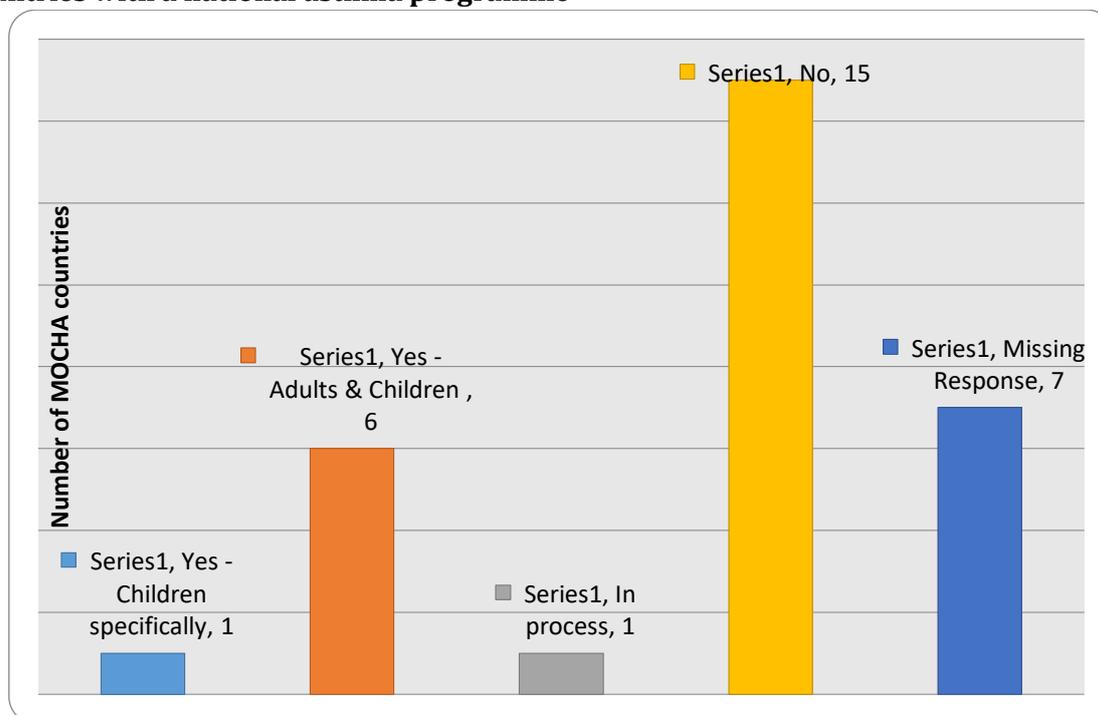
		Round 4 (n=23)		Round 4 (n=23)		Round 5 (n=23)	
		Is there a national asthma programme in your country	What is the focus of the programme - adults, children or both	Are there explicit asthma guidelines in your country	If yes, is there a formal reporting procedure for reporting adherence to the guidelines	Is there a national policy regarding children/their teachers, holding and having access to emergency asthma treatment for children in school setting	Is it the responsibility of individual schools to set their own policy?
1	Austria	No data		No data		No	No
2	Belgium	No data		No data		No data	No data
3	Bulgaria	No		Yes - based on GINA	No	No data	No data
4	Croatia	No		Yes	No	No	Yes - part of general school policy for children with chronic illnesses
5	Cyprus	No		No		No	No
6	Czech Rep	No		Yes	No	Yes	No
7	Denmark	No data		No data		No data	No data
8	Estonia	No		Yes	No	No data	No
9	Finland	Yes	Adults and Children	Yes	No	No data	No
10	France	No data		No data		No data	No data
11	Germany	No data		No data		No data	No data
12	Greece	No		Yes	No	No data	No
13	Hungary	No		In progress		No	No
14	Iceland	Yes	Specifically for children	Yes	No data	No	Yes
15	Ireland	Yes	Adults and Children	Yes - based on GINA	Under development	No	Yes
16	Italy	No		Yes - based on GINA	Yes - measurement of some indicators	Yes - not specifically for asthma	Yes

17	Latvia	No		Yes	No data	No	No
18	Lithuania	No		Yes	No	No	No
19	Luxembourg	No data		No data		Yes	No
20	Malta	No		Yes – based on GINA	No	No	No – coordinated by Dept of Education
21	Netherlands	Yes	Adults and Children	Yes	Yes	Yes	Yes
22	Norway	In process		Yes	No data	Yes – not specifically for asthma	Yes
23	Poland	Yes	Adults and Children	Yes – based on GINA	No	No data	No data
24	Portugal	Yes (part of wider programme for respiratory disease)	Adults and Children	Yes	No	Yes	Yes
25	Romania	No		Yes	No	No	No
26	Slovakia	Yes	Adults and Children	Yes	No	No	Yes
27	Slovenia	No data		No data		No data	No data
28	Spain	No		Yes	No	No	No
29	Sweden	No		Yes	No	No	No – coordinated at municipality level
30	United Kingdom	No		Yes	No - May be part of national audit in 2017/8	Yes (except in Scotland)	Yes (except in Scotland)

### **National Asthma Programme**

In Round 4, Country Agents were asked if their countries have a national asthma programme for children. Of the 23 countries who responded to the questionnaire, seven (26%) have a national programme for asthma, one of which one is directed specifically at children (Iceland), and six are directed at both adults and children (Finland, Ireland, Netherlands, Poland, Portugal, Slovakia). A programme is currently under development in one country (Norway), and half of the MOCHA countries (n=15) indicated that they did not have a national programme. This is illustrated by Figure 8.

**Figure 8: National Asthma Programme for Children in MOCHA countries: number of countries with a national asthma programme**



Where national asthma programmes are in operation, certain commonalities were identified amongst the programmes' stated aims:

- Improvement in early diagnosis of asthma
- Improvement in pharmacological control
- Maximise the number of patients with controlled asthma
- Reduction in asthma-related hospitalisation and mortality
- Reduction in asthma-related health expenditure.

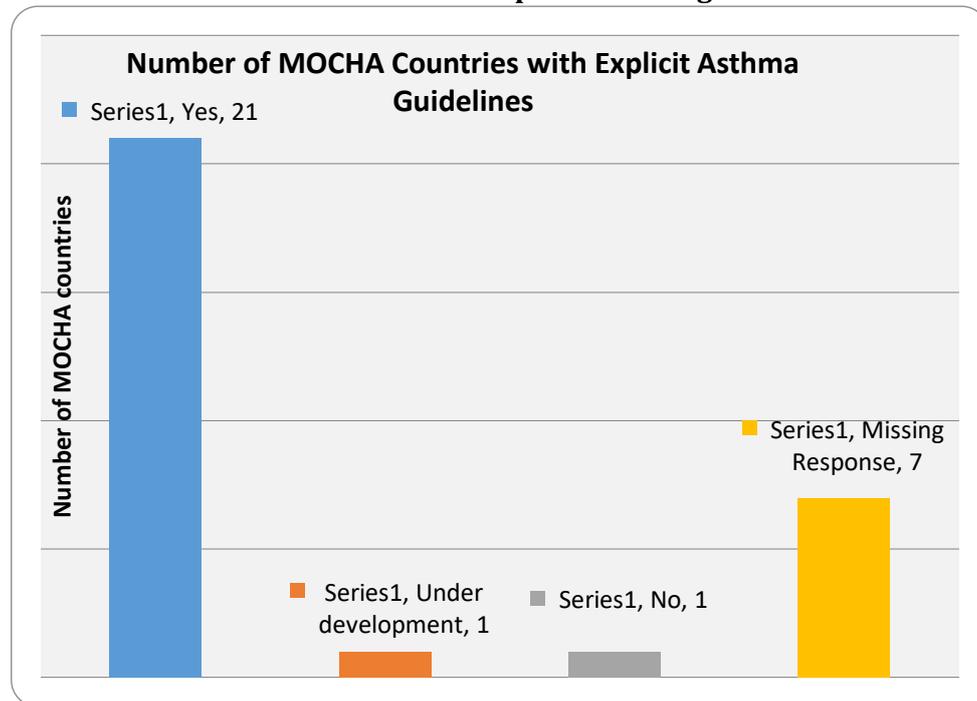
Of those countries with a National Asthma Programme, there is little evidence of evaluation of outcomes specifically associated with the programmes. However, several Country Agents indicated that the programmes are in the process of being delivered, and consequently outcomes data is limited at this point.

### **National Asthma Guidelines**

In response to the question of whether each country had explicit asthma guidelines which describe the optimum management and treatment of asthma, 21 (91%) of the 23 responding Country Agents indicated that such guidelines were available, with one other country indicating that guidelines were currently under development (Hungary). Only one country (Cyprus) stated

that they did not have guidelines in place. Five countries with guidelines in place specifically indicated that these were based on the Global Initiative for Asthma (GINA) guidelines ([www.ginasthma.org](http://www.ginasthma.org)) (Bulgaria, Ireland, Italy, Malta, and Poland). This is illustrated by Figure 9.

**Figure 9: Number of MOCHA countries with explicit asthma guidelines**



Formal processes to determine adherence to these guidelines are limited. Two countries (Italy and Netherlands) reported that they had mechanisms to measure adherence to the guidelines. For example, in Italy, some of the indicators in the guidelines are monitored as a means of measuring adherence. Of the 23 countries that responded to the Round 4 questionnaire which sought information on the use of guidelines, six (26%) indicated that there had not been any difficulties experienced with implementing the guidelines in practice. Some Country Agents from these countries offered additional information about factors which may contribute to the successful assimilation of the guidelines into practice, for example, education and training for healthcare professionals caring for children with asthma, and subsidised asthma medications.

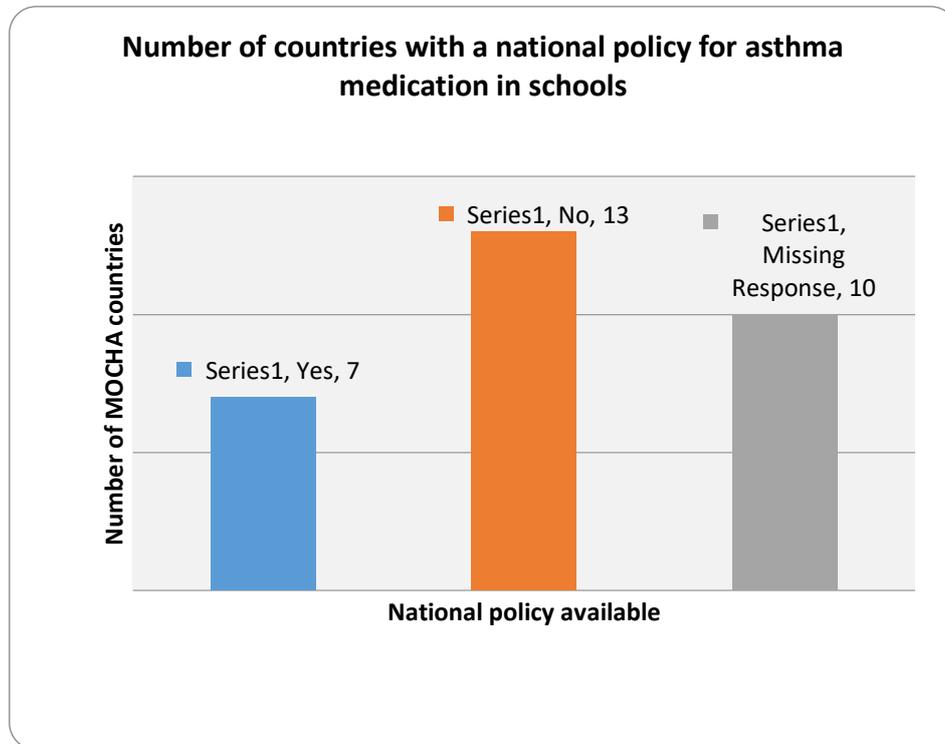
Some Country Agents acknowledged that it is unknown at this point if there are difficulties with the implementation of the guidelines, as monitoring and evaluation has yet to be undertaken. However, almost half of the responding countries (11, 48%) indicated that there were difficulties in the implementation of recommended treatment practices. Several reasons were given for these difficulties, including:

- No formal implementation or evaluation programme
- Absence of interoperable healthcare records between sectors which hinders seamless communication and limits the ability to be aware of or evaluate treatments undertaken elsewhere
- Variation in implementation of the guidelines at practitioner level
- Workload of healthcare professionals creates time constraints which limit the:
- opportunity of healthcare professionals to attend education and training
- time available to educate children and parents on effective asthma management
- A lack of general knowledge and awareness of asthma amongst the general population

### ***Asthma Management in Schools***

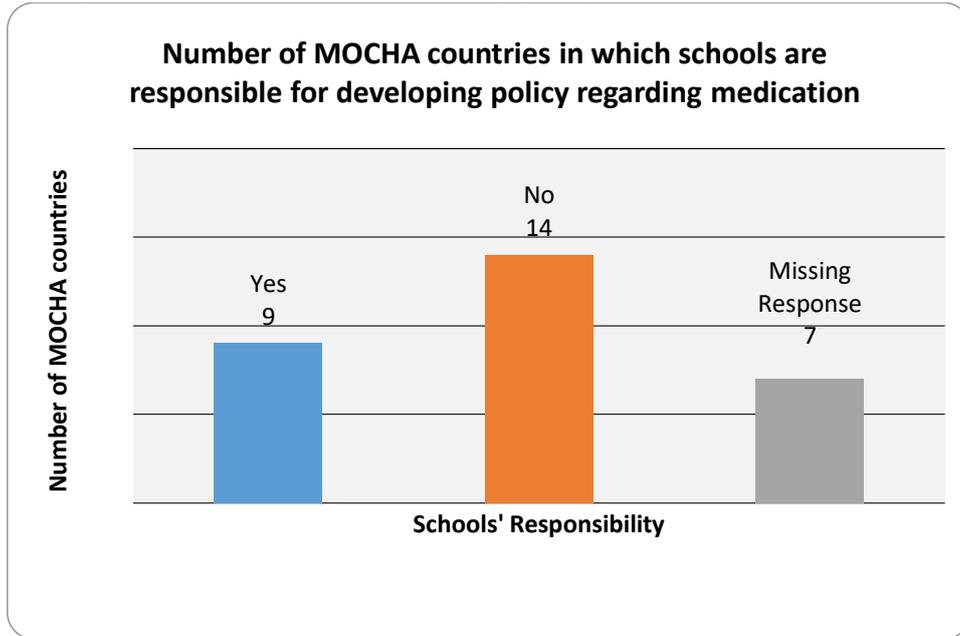
Of the thirty MOCHA countries, twenty responded (66%) to the question about whether there is a national policy in relation to children or their teachers holding or having access to emergency asthma treatment in the school setting. The Country Agents of seven countries (35%) from which responses were received (total 66%, n= 20) indicated that such a policy existed. In two of these countries (Italy and Norway), the policies apply to the wider context of all medication in the school setting, rather than being directed specifically at asthma medication. There is no policy in almost half (13) of the MOCHA countries. This is shown in Figure 10.

**Figure 10: Number of MOCHA countries with a national policy for asthma medication in schools**



A further question explored whether it is the responsibility of schools to develop their own policy in relation to the use of asthma medication in schools. The answers are illustrated in Figure 11. Of the seven countries which have a national policy about asthma medication in schools, three require schools to also develop their own policies (Italy, Netherlands and Norway). Six other countries also require schools to develop their own policies (Croatia, Iceland, Ireland, Portugal, Slovakia and United Kingdom). Fourteen countries indicated that it was not the schools' responsibility to develop a policy.

**Figure 11: Responsibility of schools to develop policy for medication in schools**



**Access to Care**

Country Agents were asked to identify the first contact professional for the child with an acute illness, and the child presenting with a moderate/severe asthma attack. Additional questions explored the access to asthma treatment in the school setting. Table 6 presents the summary responses to these questions.

**Table 6: First contact healthcare professional and emergency management in MOCHA countries**

		Round 1 (n=28)			Round 4 (n=23)	Round 5 (n=23)
		Will parents already have a doctor (or other) for child's primary care	Type of doctor / healthcare professional	On this occasion, what healthcare professional is most likely to see the child	On this occasion, what healthcare professional is most likely to see the child	Who within the school (if anyone) would be able to support the child in the event of a medical (asthma) emergency?
				<i>Child 2 years, with fever and rash</i>	<i>Child has a moderately severe asthma attack in school</i>	
1	Austria	Yes	Paediatrician or GP	Child's own doctor <i>After hours:</i> OOH# GP service or ED\$	<i>No data</i>	Trained teacher
2	Belgium	Yes usually	Paediatrician or GP	Child's own doctor <i>After hours:</i> OOH# GP service or ED\$	<i>No data</i>	<i>No data</i>
3	Bulgaria	Yes	GP or GP who is a Specialist in Paediatrics	Child's own doctor <i>After hours:</i> OOH# GP service or ED\$	Child's own doctor, Specialist or ED	<i>No data</i>
4	Croatia	Yes	Paediatrician or GP	Child's own doctor <i>After hours:</i> no data	Child's own doctor	Trained teacher
5	Cyprus	Yes	Paediatrician	Child's own doctor <i>After hours:</i> ED\$	Child's own doctor	No-one
6	Czech Rep	Yes	Paediatrician	Child's own doctor <i>After hours:</i> ED\$	Child's own doctor and referral to specialist if needed <i>e.g. allergist</i>	Trained teacher
7	Denmark	<i>No data</i>	GP*	<i>No data</i>	<i>No data</i>	<i>No data</i>
8	Estonia	Yes	GP	Child's own doctor <i>After hours:</i> OOH# Phone Consultation or ED\$	Child's own doctor or ED Referral to specialist if needed <i>e.g. allergist</i>	School nurse In an emergency - teacher
9	Finland	Yes	GP	Child's own doctor <i>After hours:</i> no data	ED Likely to be the GP in rural areas	School nurse or Trained teacher
10	France	Yes usually	Paediatrician or GP	Child's own doctor <i>After hours:</i> ED\$	<i>No data</i>	<i>No data</i>
11	Germany	Yes	Paediatrician or GP	Child's own doctor <i>After hours:</i> no data	<i>No data</i>	<i>No data</i>
12	Greece	Yes	Paediatrician (rural areas likely to be a GP)	Child's own doctor <i>After hours:</i> OOH# GP service or ED\$	Child's own doctor or ED	Teacher
13	Hungary	Yes	Paediatrician or GP	Child's own doctor <i>After hours:</i> no data	Child's own doctor	School nurse or Trained teacher
14	Iceland	Yes	Paediatrician or GP	Child's own doctor <i>After hours:</i> OOH# GP service	Child's own doctor, Specialist or ED	School nurse

15	Ireland	Yes	GP	Child's own doctor <i>After hours:</i> OOH# GP service or ED\$	Child's own doctor with referral to ED if needed	Trained teacher
16	Italy	Yes	Paediatrician	Child's own doctor <i>After hours:</i> no data	Child's own doctor or ED/OOH service	Trained teacher
17	Latvia	Yes	Paediatrician or GP	Child's own doctor <i>After hours:</i> no data	Child's own doctor and referral to specialist if needed <i>e.g. pulmonologist or allergist</i>	School nurse
18	Lithuania	Yes	Paediatrician or GP	Child's own doctor or Private Paediatrician <i>After hours:</i> ED\$	Child's own doctor or ED	School nurse
19	Luxembourg	Yes	Paediatrician or GP	Child's own doctor <i>After hours:</i> ED\$	<i>No data</i>	Trained teacher
20	Malta	Public system: Not named GP, but access to GP	Public: GP (May attend Paediatrician privately)	Child's own doctor or Private Paediatrician <i>After hours:</i> ED\$	Child's own doctor or ED	No one unless school nurse is available
21	Netherlands	Yes	GP	Child's own doctor <i>After hours:</i> OOH# GP service	Child's own doctor or ED, and referral to specialist if needed	Teacher
22	Norway	Yes	GP	Child's own doctor <i>After hours:</i> OOH# GP service	Child's own doctor	Designated school staff member
23	Poland	Yes	Paediatrician or GP	Child's own doctor <i>After hours:</i> OOH# GP service	Child's own doctor or ED	Nurse, first aider, trained teacher.
24	Portugal	Yes	GP (or Paediatrician privately)	Child's own doctor <i>After hours:</i> OOH# GP service or ED\$	Child's own doctor	School nurse or Trained teacher
25	Romania	Yes	GP	Child's own doctor <i>After hours:</i> no data	Child's own doctor or ED	School nurse or doctor
26	Slovakia	Yes	Paediatrician	Child's own doctor <i>After hours:</i> OOH# Home visit service (private, so not state funded) or ED\$	Child's own doctor or Specialist, <i>e.g. Pneumonologist or Allergist</i>	Teacher
27	Slovenia	<i>No data</i>	Paediatrician*	<i>No data</i>	<i>No data</i>	<i>No data</i>
28	Spain	Yes	Paediatrician	Child's own doctor <i>After hours:</i> no data	Child's own doctor	Teacher
29	Sweden	Yes	Child Health Nurse and GP	Telephone advice from Child Health Nurse first. Then, Child's own doctor <i>After hours:</i> no data	Child's own doctor or ED	School nurse or Teacher
30	United Kingdom	Yes	GP	Child's own doctor <i>After hours:</i> OOH# GP service or ED\$	Child's own doctor or ED	Designated school staff members
#OOH: Out of Hours    \$ED: Emergency Department    ^EHR: Electronic Healthcare Record    *Data taken from van Esso et al. 2010						

### ***First contact healthcare professional***

Of the 28 countries which responded to the Round 1 questionnaire, all indicated that the child would have a usual doctor or healthcare professional for their primary care needs.

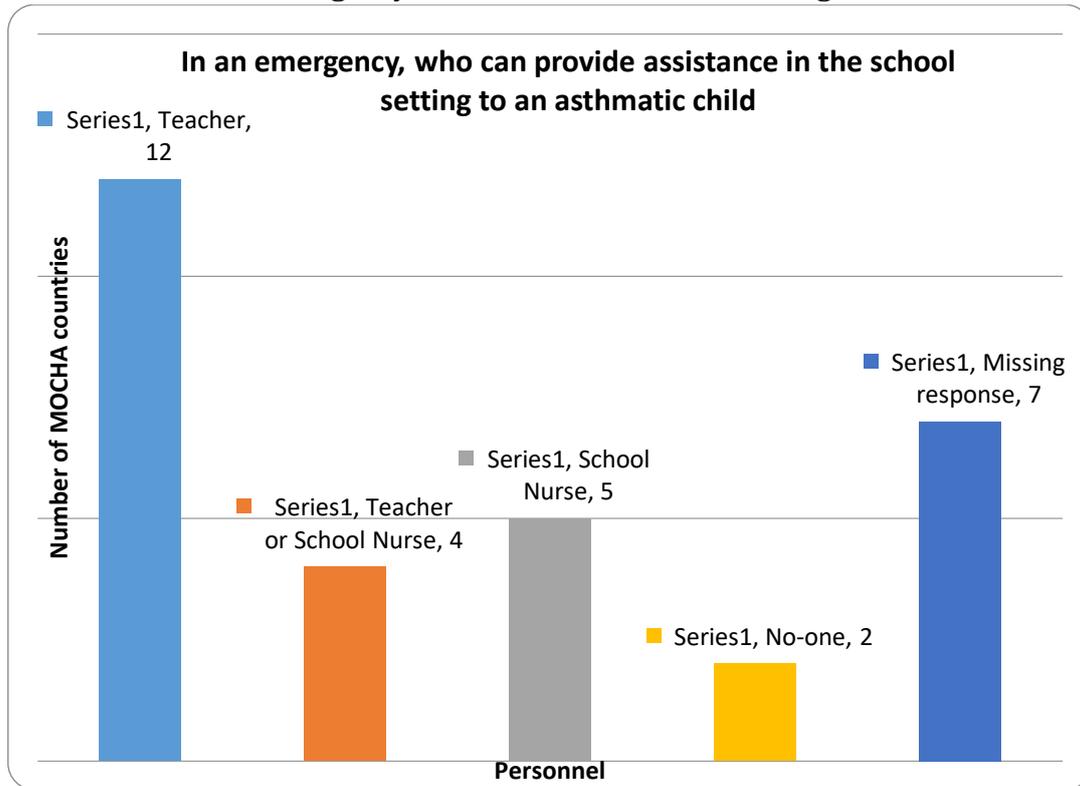
In the two scenarios presented to Country Agents which explored who would be the most likely first contact (A 2 year old child with a rash and fever and a child with a moderately severe asthmatic attack), respondents indicated that the child would be most likely to attend their own doctor. In the event that an appointment was not available, or that it was after the practice hours and the parents were concerned about the child, Country Agents indicated that the child would attend an Out-of-Hours (OOH) GP service or the Emergency Department (ED). The parents' decision to access OOH or ED is influenced by the availability of an OOH service and its geographical proximity to the family. For example in some countries, families living in urban areas are likely to attend the ED, especially if there is a difficulty or time delay in getting an appointment with a primary care physician. Country agents in seven countries indicated that the child with asthma may also see a specialist, or be referred by their GP to a specialist, for example, an allergist or pulmonologist. Country Agents were not asked if there are referral criteria for the children in these scenarios in their countries, or if referral processes are underpinned by guidelines.

Some measures were identified to disincentivise families from attending the ED as a first contact. For example, in Portugal, a 24 hour phone consultation service exists which allows the child to be triaged by a nurse. If the child requires emergency care, the referral is fast-tracked or prioritised, which limits the waiting time in the ED. In Ireland, if a child attends their GP and is subsequently referred to the ED, only the GP costs are paid by the family and the ED attendance is free of charge. If however, the family attend the ED without a GP referral, they are liable for a €100 charge (See Chapter 8 for further discussion about incentives and penalties).

### ***Emergency assistance in the school setting***

One of the questions required respondents to identify who, if anyone, was available in the school setting to support a child in an asthma-related medical emergency. The majority (12, 52%) of the 23 countries which responded to this round indicated that a trained teacher or designated school staff member would provide the emergency assistance. Five countries reported that a school nurse would provide assistance, while a further four countries indicated that it would be provided by the nurse *or* a teacher. In Malta, there is a state-funded programme in which nurses will visit school to administer planned medication, for example, insulin, but there is no provision for the administration of emergency medication. Similarly in Cyprus, there is no-one identified as being responsible for providing assistance in this scenario. This is illustrated by Figure 12.

**Figure 12: Provision of emergency assistance in the school setting**



Some Country Agents offered additional information about current debates and structures in their countries about the administration of medication or the handling of emergency situations such as an asthmatic attack in the school setting. In Italy, following a legal ruling, there is a legislative requirement for the school principal to comply with a parent’s written request for the administration of medication to the child in school, and to put in place a strategy to meet the medication needs of the child. In Malta, discussions have been held between the Department of Education and teachers’ unions in relation to the need for a legal framework to support teachers who administer medication to children in school. In the United Kingdom, since October 2014, primary and secondary schools have had permission to purchase a salbutamol inhaler without a prescription for use in emergencies when a child with asthma cannot access their own inhaler. It is not a requirement for schools to keep an emergency inhaler, but is up to the discretion of each school. Schools that choose to keep emergency inhalers are advised to establish supporting policies and protocols, and at least two staff members must be designated with responsibility to implement the protocol.

### **Coordination and Continuity of Care**

Questions related to the coordination and continuity of care were threaded through the three questionnaires, and focused on such items as access to healthcare records, the referral and discharge processes, and communication between sectors. The answers are outlined in Table 7.

**Table 7: Access to healthcare records and referral / discharge processes in MOCHA countries**

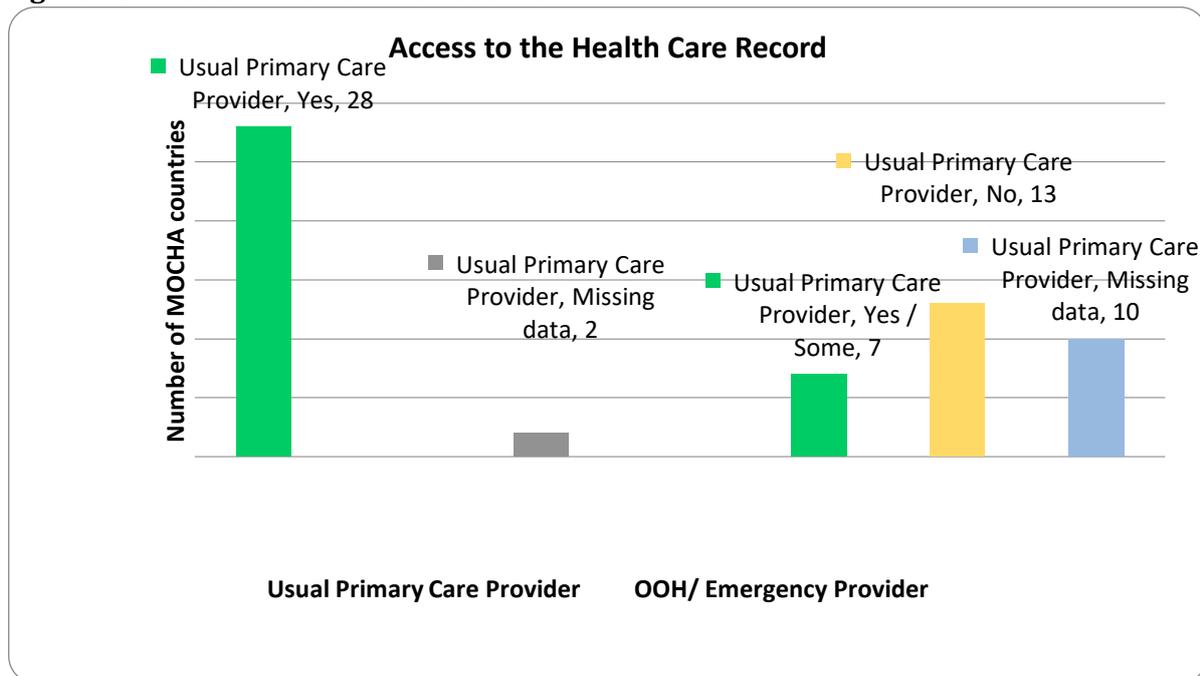
		Round 1 (n=28) & Round 4 (n=23)		Round 4 (n=23)	Round 4 (n=23)
		Will the healthcare professional have access to the child's records		If the child is referred and/or admitted to hospital with an asthma attack, how is communication, in both directions, between primary and secondary care usually achieved? (e.g. a written letter, an email, a phone call?)	Nationally recognised and standardised proforma for communication between primary and secondary care? (response given only if specifically indicated by Country Agent)
		Own GP or Paediatrician	OOH# GP service or ED <sup>s</sup> (response given only if specifically indicated by Country Agent)		
1	Austria	Yes	No	No data	
2	Belgium	Yes		No data	
3	Bulgaria	Yes	No	<b>Referral:</b> Written letter <b>Discharge:</b> Written letter	<b>Referral:</b> Yes <b>Discharge:</b> Yes
4	Croatia	Yes		<b>Referral:</b> Written referral or form <b>Discharge:</b> Written letter	<b>Referral:</b> Yes <b>Discharge:</b> Yes
5	Cyprus	Yes	No	<b>Referral:</b> No communication <b>Discharge:</b> Written letter	
6	Czech Rep	Yes	No	<b>Referral:</b> Written letter <b>Discharge:</b> Written letter	<b>Referral:</b> Yes <b>Discharge:</b> Unclear
7	Denmark	No data		No data	
8	Estonia	Yes	Yes - EHR <sup>^</sup>	<b>Referral:</b> Written letter or EHR <sup>^</sup> referral <b>Discharge:</b> EHR <sup>^</sup>	<b>Referral:</b> Yes <b>Discharge:</b> Yes
9	Finland	Yes	No	<b>Referral:</b> Written letter <b>Discharge:</b> unclear	<b>Referral:</b> No <b>Discharge:</b> No
10	France	Yes	No	No data	
11	Germany	Yes		No data	
12	Greece	Yes	Parent-held child health book <i>Note: EHR<sup>^</sup> is under development</i>	<b>Referral:</b> Phone call <b>Discharge:</b> Written letter given to parents	<b>Referral:</b> No <b>Discharge:</b> No
13	Hungary	Yes	No	<b>Referral:</b> Written letter <b>Discharge:</b> Written letter to GP and parents	<b>Referral:</b> Yes <b>Discharge:</b> Yes
14	Iceland	Yes	Yes - EHR <sup>^</sup>	Response unclear	<b>Referral:</b> Yes <b>Discharge:</b> Yes
15	Ireland	Yes	OOH GP Service: Yes ED: No <i>Note: national EHR<sup>^</sup> is under development</i>	<b>Referral:</b> Written or electronic referral. GP will ring hospital if concerned <b>Discharge:</b> Written letter to GP and to parents	<b>Referral:</b> Yes <b>Discharge:</b> No

16	Italy	Yes	No	<b>Referral:</b> Written letter <b>Discharge:</b> Written letter	
17	Latvia	Yes	No	<b>Referral:</b> Written form and/or phone call <b>Discharge:</b> Written form	<b>Referral:</b> No <b>Discharge:</b> No
18	Lithuania	Yes		<b>Referral:</b> Written letter <b>Discharge:</b> Written discharge summary to GP	<b>Referral:</b> No <b>Discharge:</b> No
19	Luxembourg	Yes		<i>No data</i>	
20	Malta	Yes	Parent held record of milestones and immunisation	<b>Referral:</b> Written letter and GP may ring hospital if concerned <b>Discharge:</b> Written or Electronic discharge summary to GP and printed copy to parents	<b>Referral:</b> Yes <b>Discharge:</b> Yes
21	Netherlands	Yes		<b>Referral:</b> Written letter <b>Discharge:</b> Written discharge summary to GP	<b>Referral:</b> Yes <b>Discharge:</b> Yes
22	Norway	Yes		<b>Referral:</b> Written letter <b>Discharge:</b> Written discharge summary	<b>Referral:</b> Unclear <b>Discharge:</b> Unclear
23	Poland	Yes	No	<b>Referral:</b> no data <b>Discharge:</b> no data	<b>Referral:</b> No <b>Discharge:</b> No
24	Portugal	Yes		<b>Referral:</b> Written or electronic referral <b>Discharge:</b> Electronic discharge summary	<b>Referral:</b> Yes <b>Discharge:</b> Yes
25	Romania	Yes	No	<b>Referral:</b> Written letter <b>Discharge:</b> Written discharge summary given to parents	<b>Referral:</b> No <b>Discharge:</b> No
26	Slovakia	Yes	No	<b>Referral:</b> Written letter <b>Discharge:</b> Written discharge summary	<b>Referral:</b> No <b>Discharge:</b> No
27	Slovenia	<i>No data</i>		<i>No data</i>	
28	Spain	Yes	EHR^ available in some regional areas – not a national programme	<b>Referral:</b> Written and/or phone calls <b>Discharge:</b> Written or electronic discharge summary	<b>Referral:</b> No <b>Discharge:</b> No
29	Sweden	Yes	EHR^ available in some regional areas – not a national programme	<b>Referral:</b> Written or electronic referral <b>Discharge:</b> no data	<b>Referral:</b> No <b>Discharge:</b> No
30	United Kingdom	Yes	No	<b>Referral:</b> Written referral. GP will ring hospital if concerned. <b>Discharge:</b> Written discharge summary	<b>Referral:</b> No <b>Discharge:</b> No
#OOH: Out of Hours \$ED: Emergency Department ^EHR: Electronic Healthcare Record					

### Access to Health Care Record

Twenty-eight countries indicated that the child’s usual primary care provider would have access to the child’s healthcare record, shown in Figure 13. However, of these, only seven countries (28%) reported that Out-of-Hours (OOH) providers or Emergency Departments (ED) would have access or some access to the healthcare record. Access to the record is enabled by the presence of an electronic healthcare record (EHR). Estonia and Iceland have a national cross-sectoral EHR which is accessible by both primary care and secondary care providers. Spain and Sweden have a similar model at a regional level, but national interoperability is not possible with these systems as yet. [Note: an examination of EHR systems in MOCHA countries is being conducted by WP8, and consequently this task is not exploring this process in depth.]

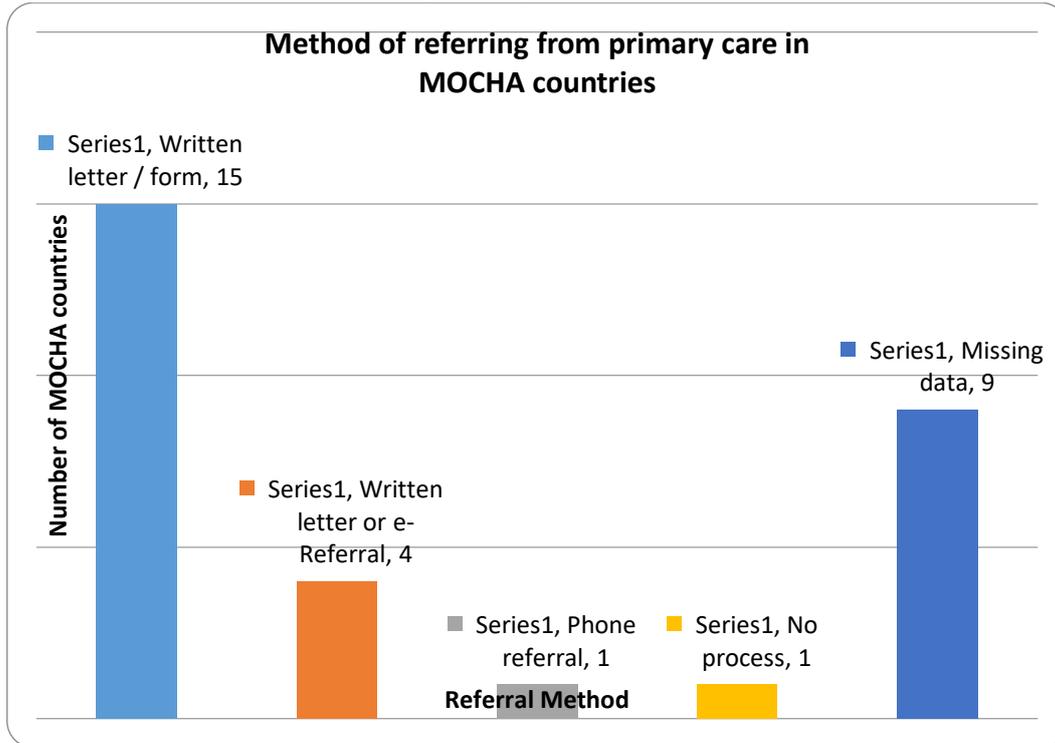
**Figure 13: Access to Healthcare Records**



### Referral and Discharges Processes

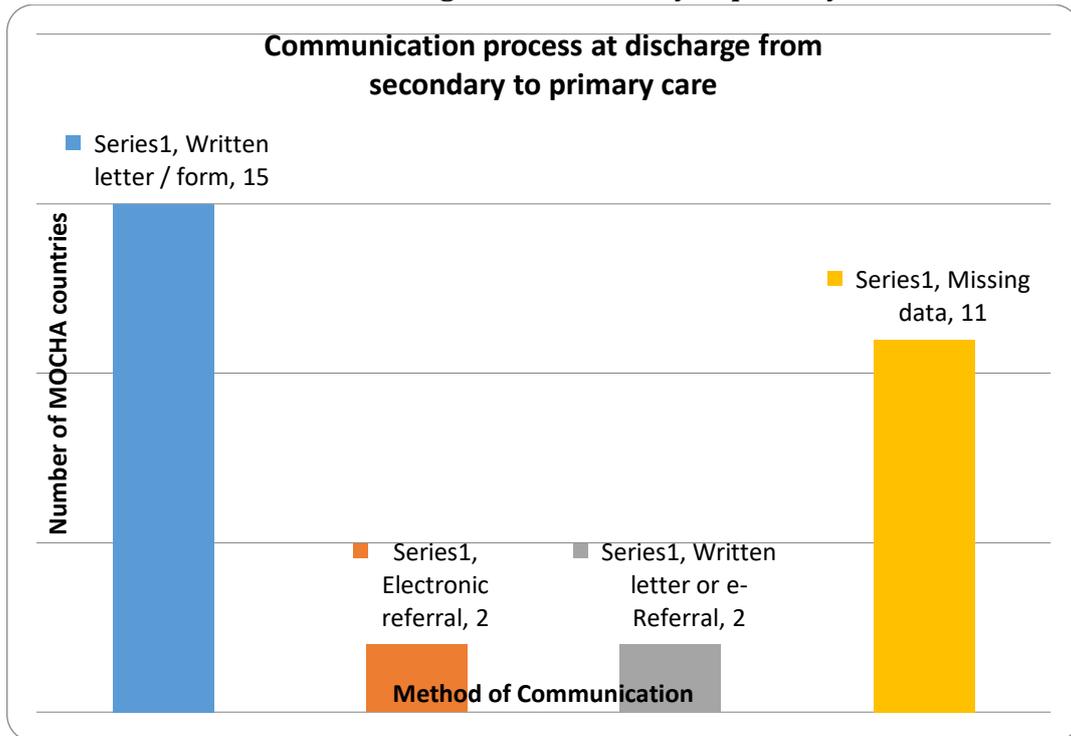
In the event that a child is referred and/or admitted to hospital with an asthma attack, Country Agents were asked to describe how communication is usually achieved, in both directions between primary and secondary care. Of the 23 countries which responded to this round of questions, the majority (15, 65%) reported that a written letter or form is the usual mode of referral from primary to secondary care. Four countries use a combination of written letter or electronic referral, and one country (Greece) uses a phone referral approach. One country (Cyprus) indicated that a referral communication process does not exist. The Country Agents in four countries indicated that GPs would follow up a written referral with a phone call if they were particularly concerned about the child. This is illustrated in Figure 14.

**Figure 14: Method of referring from primary care in MOCHA countries**



Country Agents were asked to describe the means by which communication occurs from secondary to primary care following a child’s discharge from hospital. Nineteen countries responded to this question and the majority (15, 79%) reported that a written discharge letter is the communication process used. Of these, two countries (Greece and Romania) indicated that the discharge letter is given to the parents only and they in turn will communicate with the primary care provider. Two countries (Estonia and Portugal) use an electronic discharge format, while Malta and Spain use a combination of written or electronic discharge communication from secondary care to primary care. This is shown in Figure 15. Country Agents were not asked whether referral and discharge processes in their countries are informed by medication reconciliation guidelines.

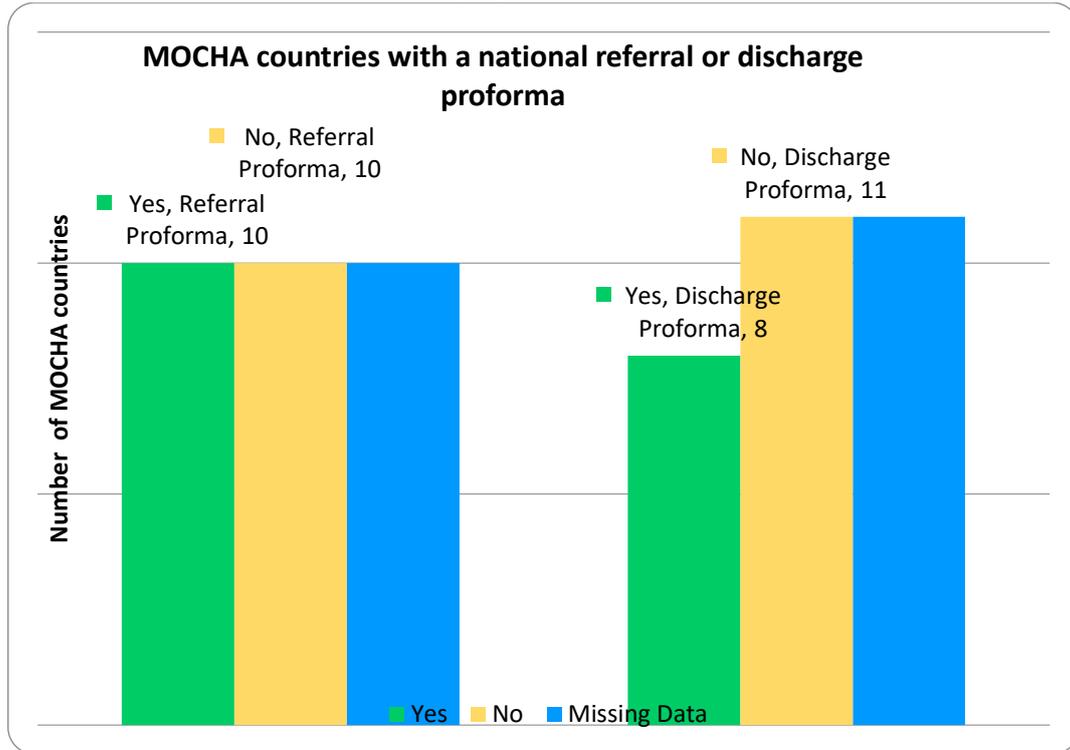
**Figure 15: Communication at discharge from secondary to primary care**



***National Standardised Referral and Discharge Proforma***

When asked if their countries had a nationally recognised and standardised proforma or template for referrals and discharges, 10 countries indicated that they have a referral proforma (Bulgaria, Croatia, Czech Republic, Estonia, Hungary, Iceland, Ireland, Malta, Netherlands and Portugal) A nationally recognized discharge proforma is in place in 8 countries (Bulgaria, Croatia, Estonia, Hungary, Iceland, Malta, Netherland and Portugal). Overall, nationally recognised proformas for both referral and discharge processes are in place in eight of the responding MOCHA countries. In Estonia, the referral and discharge processes are integral to the EHR. This is shown in Figure 17.

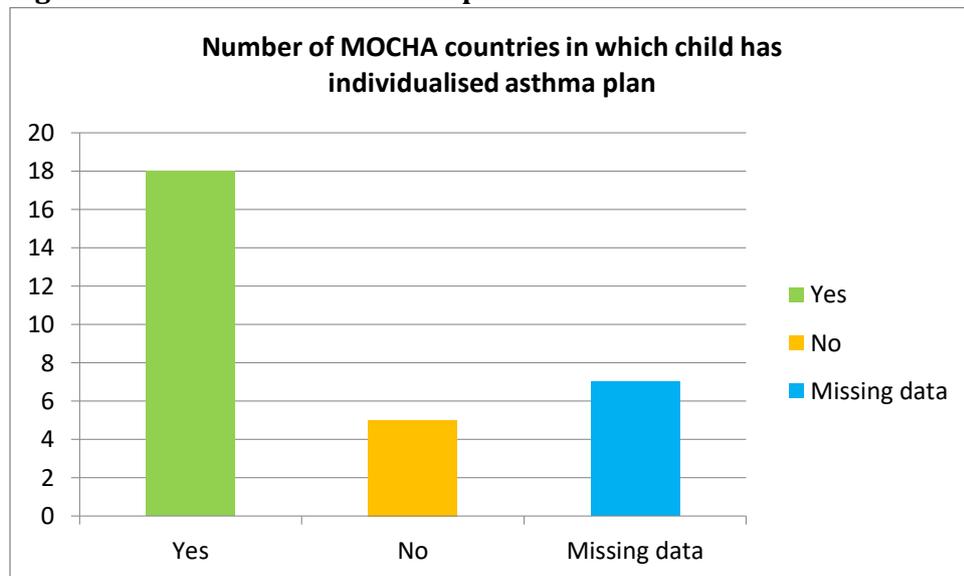
**Figure 17: National referral or discharge proforma**



**Individualised care**

Country Agents were asked if children have a written individualised asthma plan, and if so, who is involved in its development. Of the 23 countries which responded, the Country Agents of 18 countries (78%) indicated that children have an individualised asthma plan. Five countries of those which responded indicated that an individualised plan is not developed for the child with asthma. This is outlined in Figure 18.

**Figure 18: Individualised asthma plan**



The Country Agent responses revealed different models involved in the development of a child’s individualised asthma plan. Predominantly the plan is developed by the Specialist Physician, for example, an allergist or pulmonologist, or the primary care GP or paediatrician. The level of

parent involvement in the development of the plan is variable. Of the 18 countries which responded to these questions, two countries (11%) (Finland and the United Kingdom) indicated that a collaborative approach between medical personnel, parents and schools was used to develop the plan for the child. In a further two countries (11%) (Ireland and Spain), the plan is developed between the specialist physician or primary care provider and the parents, who in turn link with the school to implement it. The findings would suggest that in the majority of countries, a plan is developed by the specialist or primary care provider, and then subsequently the parents engage with the school to implement the plan. Country Agents were not asked if children are involved in the development of their own asthma plans, and there is no data in the Country Agent responses about this.

The clinical scenario in this question related to a ten year boy. Country Agents were asked about the usual practice in their countries in relation to a child of this age holding medication in school. The majority of the 21 countries which responded to this particular question (15, 71%), reported that the child would be able to hold the medication himself, while one country indicated that the medication would have to be handed to an adult. Five countries (24%) indicated that there are variable practices in their countries, which are influenced by an assessment of the child’s ability to self-administer the medication, the local school policy and the wishes of the parents. This is shown in Figure 19.

**Figure 19: Handling asthma medication in schools**

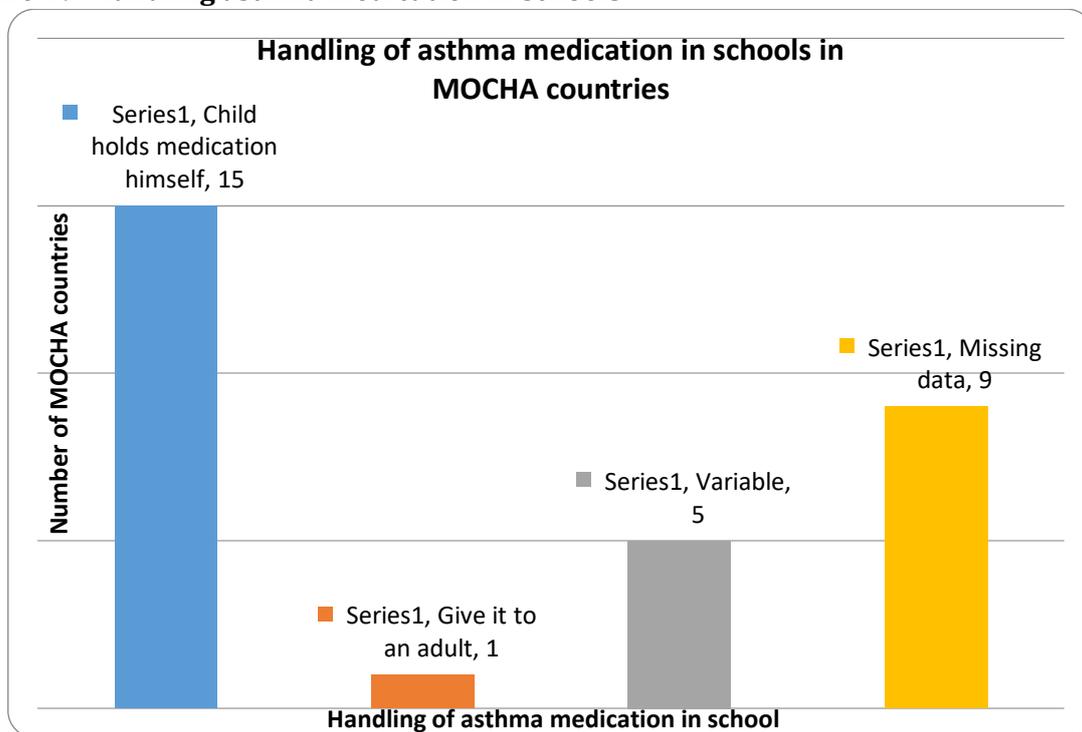


Table 8 summarises the approaches to individualised asthma care in the different MOCHA countries.

**Table 8: Approaches to individualised asthma care in the different MOCHA countries**

		<b>Will the child have an individualised asthma plan</b> <i>(based on national or school policy)</i>	<b>Who is involved in developing the plan</b> <i>(response given only if specifically indicated by Country Agent)</i>	<b>Can Jakob hold the medication himself or is he required to give it to an adult in school</b>  <i>Himself / Adult / Variable</i>
1	<b>Austria</b>	No		Himself
2	<b>Belgium</b>	No data		No data
3	<b>Bulgaria</b>	No data		No data
4	<b>Croatia</b>	Yes	School doctor and School Nurse	Himself
5	<b>Cyprus</b>	No		Himself
6	<b>Czech Rep</b>	Yes	Prepared by Specialist Physician or GP	Himself
7	<b>Denmark</b>	No data		No data
8	<b>Estonia</b>	Yes	Prepared by Specialist Physician GP can amend if necessary	Himself
9	<b>Finland</b>	Yes	Prepared between Specialist Physician and Primary Care and School Health	Himself
10	<b>France</b>	No data		No data
11	<b>Germany</b>	No data	Prepared by Paediatrician	No data
12	<b>Greece</b>	Yes		Himself
13	<b>Hungary</b>	Yes	Specialist Paediatric Physician	Himself
14	<b>Iceland</b>	No		Unclear
15	<b>Ireland</b>	Yes	Specialist Physician or GP, and Parents. Parents and School then review plan	Variable – depends on school policy
16	<b>Italy</b>	Yes	Specialist Physician or Primary Care Paediatrician	Himself – under supervision of trained adult
17	<b>Latvia</b>	Yes	GP (mostly) or Specialist Physician	Himself
18	<b>Lithuania</b>	Yes	Specialist Physician	Himself
19	<b>Luxembourg</b>	Yes	Specialist Physician or Paediatrician	Variable – depends on the ability of the child
20	<b>Malta</b>	No		Give it to an adult
21	<b>Netherlands</b>	Yes – not specific to school setting	Specialist Physician or GP develop plan. Parents link with school	Himself
22	<b>Norway</b>	Yes	GP	Variable – GP will assess child's ability
23	<b>Poland</b>	No data		No data
24	<b>Portugal</b>	Yes	Specialist Physician or Nurse	Himself
25	<b>Romania</b>	Yes	Specialist Physician or Primary Care Physician	Himself
26	<b>Slovakia</b>	No		Variable – depending on ability of the child
27	<b>Slovenia</b>	No data		No data
28	<b>Spain</b>	Yes	Paediatrician and Parents	Variable – depending on parents' decision and agreed plan with school
29	<b>Sweden</b>	Yes	GP or Specialist Physician	No data
30	<b>United Kingdom</b>	Yes	Doctor, School staff and Parents	Himself

## **Conclusion**

Case studies can be used to identify and describe primary care models, and their characteristics and qualities. This is an important approach for the MOCHA project, as extant research specifically on primary care models for children is sparse. The use of case studies allows the project to highlight and identify elements of a model from a child's perspective.

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## Chapter 5

### Aggregated Records and data suitable for model analysis

Simon de Lusignan, Harshana Liyanage, Filipa Ferreira, Stacy Shinneman

This work is taken in part from the internal deliverable D5.1, which describes the creation of the MOCHA MIROI tool: **Technical Requirements Analysis WP5 deliverable reporting technical requirements of child health studies**, Simon de Lusignan, Harshana Liyanage, Filipa Ferreira, Stacy Shinneman. The MOCHA project recognises the need for large data sets as an invaluable tool in identifying models of primary care, as well as a source of triangulation of findings, and testing of MOCHA hypotheses.

#### Main findings

- We have identified a large number of potentially relevant databases via the MIROI research tool.
- Out of 116 databases identified, only 14 were directly focused on children. In others, children were either part of a 'whole population' data collection, or grouped with other ages. In other words, many of the data items are not specific to children or to child primary care
- 28% of databases report requiring over 12 months to obtain data
- Although gender was well recorded in the majority of databases, ethnicity and socioeconomic status was less well recorded
- There is a real need for accessible, relevant, timely and comparable data about children in Europe.
- Europe is at an early stage of marshalling big data sets into a use environment in which they can be utilised to evaluate health provision, such as child health models.
- This collation of potentially useful datasets is believed to be unique.

#### Methods

Working closely with the UML Business Modelling Team (See Chapter 6), a similar process to that of UML was established in order to identify large data sets. This was based on the Accessible Modelling of Complexity in Health (AMoCH) methodology (1), which allows abstraction of real-world phenomena based on our information needs and uses the UML business modelling techniques described in Chapter 6 to a large extent (2).

In common with other sections of the MOCHA project, three 'tracer conditions' were used to help develop the process:

- Asthma
- ADHD Care
- Child centred health care policies

A research specific process was used to identify large datasets for each of these areas, and then to identify what these datasets told us about the primary care systems in the EU and EEA countries.

A first step was to identify the datasets in each country that were specific to, or at least relevant to, children and primary care services. To do this, a first task was to identify what kind of data source would best tell us about primary care in each country. Resulting from this, a research instrument was designed to identify the data sources. This was named the MOCHA International Research Opportunity Instrument (MIROI).

Understanding the data flow diagrams using the AMoCH methodology allowed us to understand the dynamics of the socio-technical systems in our areas of interest, which in turn gave us a basis for specifying the criteria that needed to be considered when selecting databases for research studies. The MOCHA International Research Opportunity Instrument (MIROI) Instrument was developed to identify candidate data sources in each participating MOCHA country, so that the project can eventually obtain comparable information from analysis of electronic health data sources that would indicate the effects and outcomes of the various different child health care models in Europe.

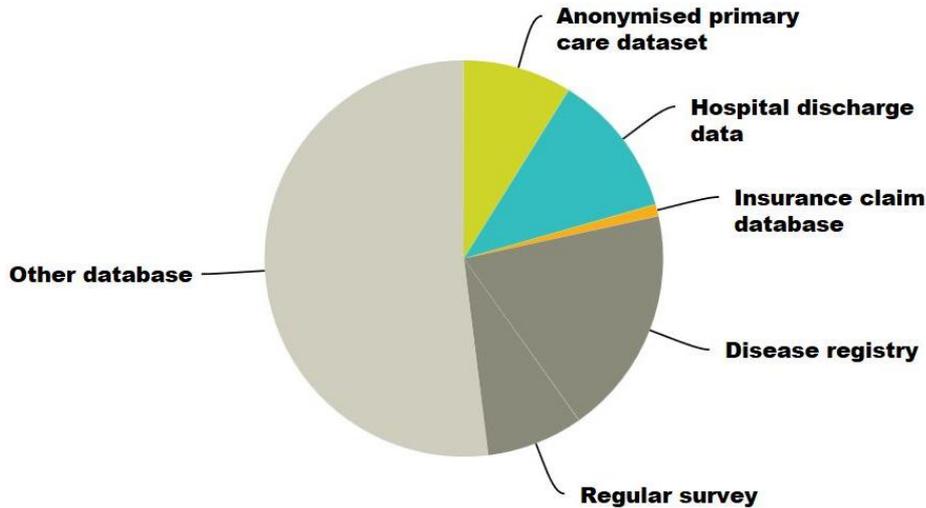
Survey questions relating to the readiness of data sources for conducting various research projects in generic health data were developed using previous experience and formed the basis of the MIROI survey instrument. It consists of 23 questions, which collecting basic information about a database, such as database contact details, population, data quality and governance. The MIROI survey was sent out to all Country Agents in the MOCHA project (See Introduction), and the responses compiled to identify what were the six (or more) most important and relevant child-health databases in each country.

### **Triangulation and Validation**

The development of the MIROI tool was successful in identifying a large number of databases that were of potential relevance to the project, and which are relevant to the primary care systems in the EU and EEA. The results were placed in an online repository hosted by the EMIF project (<https://emif-catalogue.eu/>)

When asked to choose the type of database by source of data upload, over half of the databases returned were described as 'other' by the Country Agents, and their utility to the MOCHA project in terms of describing children's health outcomes, or to triangulate findings within the project was not immediately obvious. This is shown in Figure 20.

**Figure 20: Type of database (by source data upload)**

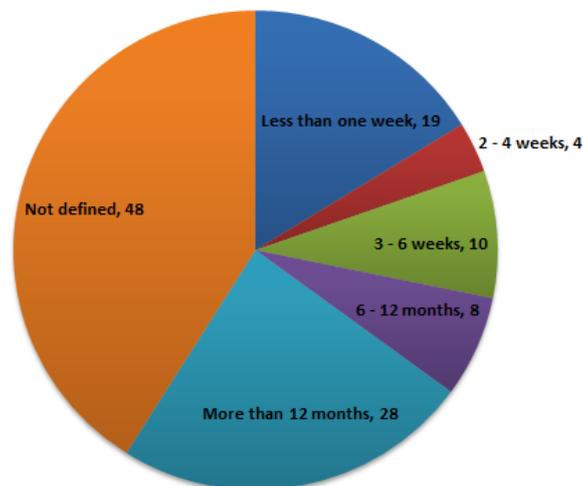


To further investigate database classifications, the MIROI provided asked the survey responder to select one or more terms that classified the data contents of the database. In these responses, 25 out of 133 responses were classified as ‘other’; only 38 databases of the 133 were specifically related to primary care.

An important factor in using large data sets for the purposes of the MOCHA project is the time lag between the data event, and its availability in statistics (question 10). In 54 of the responses, the time before data can be released for analysis was unclear, not available, not defined or not provided. Of the remaining responses, 63 databases reported a time lag of less than one year. Twenty-eight databases were reported to have time lags of 10 days or less, while 11 databases were reported to have time lags of 1-3 years.

Figure 21 shows the identified databases, and the time lag between the data event and availability of the data.

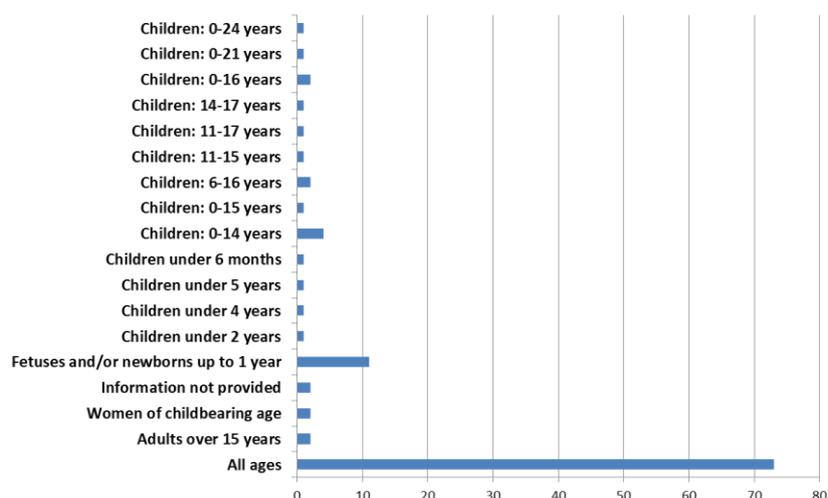
**Figure 21: Time lag/ delay between data event and data availability for analysis**



### Summary of Population and Age ranges covered

Most databases responded covered the whole country being represented (102/133). However, the active patient population was largely dependent on the nature of the databases concerned. From the 133 databases, 90 cover all age ranges while 36 were specific to children. The age range of the databases is shown in Figure 22.

**Figure 22: Age range covered by the databases identified via MIROI**



An important element of the MOCHA project is to identify equity of access to primary care. Identification of access and equity within databases is important for triangulation and validation of our results. However, not all databases recorded important elements of equity. Table 9 describes the equity variables that are contained in the MIROI identified databases.

**Table 9: Equity of access issues in databases identified via MIROI**

	Yes	No	Not provided
Does database contain data items - gender?	99	15	2
Does database contain data items - ethnicity?	41	74	1
Does database contain data items - socio-economic group?	42	73	1
Does database contain data items - small area locator?	78	36	2

Of crucial importance is not only the identification of the databases in Europe, but also the policy of accessing the data they contain. In terms of whether there is a written policy governing data access, 95 databases have a written policy, 30 databases do not have a written policy and 8 responses did not provide information on the written policy. This is shown in Table 10.

**Table 10: Data access policy for databases identified via MIROI**

In general, is there open access to data?	Number of responses
Unclear	43
Yes, with restrictions	39
Yes	22

No	7
Yes, for aggregated data	3
Yes, with authorisation	3

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## Chapter 6

### Conceptual representation of business models using UML

Daniela Luzi, Fabrizio Pecoraro, Oscar Tamburis

This work is taken from the MOCHA internal deliverable D1.4: Daniela Luzi, Fabrizio Pecoraro, Oscar Tamburis **Integrating a conceptual representation of business model with UML**. Institute for Research on Population and Social Policies (IRPPS-CNR), Rome, Italy; and the MOCHA internal deliverable D1.8: Daniela Luzi, Fabrizio Pecoraro, Oscar Tamburis , **UML business process description for minor illness and acute care condition (Asthma)**.

#### Main findings

- The process of business modelling allows us to identify the main strengths of children primary care services and highlight potential gaps in the varying structures and processes of care that exist across the 30 EU and EEA countries. The use of this technique was tested for feasibility in its application to the MOCHA project.
- A new methodology has been developed enriching the UML diagrams with a conceptual view represented by a rich picture focused on three maps of building blocks. They identify three main pathways in child care: well-being monitoring, disease management and social support.
- The conceptual model allows the identification of a set of homogeneous macro-activities (building blocks) that facilitate the comparison in the delivery of child primary care services across countries as well as the interface between primary, secondary and social care.
- The UML use case diagram makes it possible to provide a functional diagrammatic picture of primary health delivery models on the basis of clinical guidelines that represent a benchmark to compare health care business processes.
- The UML activity diagram gives a dynamic description of the interaction between actors derived from the responses to MOCHA Country Agent questions “in real-life context”.
- In mild acute conditions, or in simple long-term illness, during normal opening hours in most European countries parents are likely to take their child in primary GP/Paediatrician practices that is generally an assigned family doctor.
- Access to a hospital emergency service is widely reported as a valid alternative in both scenarios, presumably when parents are particularly concerned with their child health status. This is particularly highlighted by CAs in the asthma scenario.

#### Methods

UML is a standardized modelling language used for the description of software engineering processes, but this technique also has the potential to produce a consistent and scientifically sound description of the primary care systems in Europe, which are based on a range of inter-linking processes. As such it addresses MOCHA purposes to give a functional diagrammatic picture of the model in each country, accompanied by a word description of each primary care health delivery method.

The first challenge was to develop a conceptual model that could be used as the basis of process description. To achieve this within the objectives of the MOCHA project, we added a preliminary phase to the UML -base description that would set the criteria of comparable process descriptions. Table 11 describes the methodology based on the combination of the conceptual

model and the UML diagrams. This shows the main steps followed to identify homogeneous parts of the processes within primary care that can facilitate the comparison between national health systems.

**Table 11: Main methodological steps, highlighting the main aim of each step, the method used to achieve it as well as the input information required and the results obtained.**

		#	Aim	Method	Input	Result of the step
Model level of refinement 	Conceptual model	1	Identify the main components that influence the child care from the MOCHA perspective	Rich picture	MOCHA objectives, Vision of child care	Determinants of care, set of macro-processes relevant for the process-oriented analysis, main actors and organizations involved
		2	Identify the macro-processes and macro-activities that describe the child care	Map of building blocks	Rich picture	For each macro-process, identification of the generic workflow and of the linked macro-activities, i.e. building blocks.
	UML model	3	Identify the activities, the actors involved and their relationships of a specific health issue	Use case diagrams	Macro-processes, Guidelines	For each macro-activity, each use case diagram identifies possible actors and roles involved. They are based on relevant guidelines but not dependent on a specific national health system.
		4	Identify similarities and differences between countries in terms of: <ul style="list-style-type: none"> <li>• Activities performed</li> <li>• Actors involved</li> <li>• Settings of activities execution</li> <li>• Timeline</li> </ul>	Activity diagrams	Use cases, Case studies, National norms and regulations	For each use case, a set of activity diagrams is defined grouping countries with similar process performance. They identify the sequence of activities and messages exchanged, the actors involved and their relationships and interactions.

The conceptual model is based on two main perspectives. The first one, at a high level of abstraction, is called *rich picture* and is developed to identify the main components that influence primary care for children. To achieve our specific task the *rich picture* focuses on the business process description, identifying the macro-processes that are relevant for the analysis.

The second perspective, the *map of building blocks* is a refinement of the rich picture that specifies the macro-processes that describe the generic workflows and related macro-activities. This is used to isolate homogeneous, comparable parts of the process (the so called building block) that have to be taken into account when analysing the different national care provision.

This conceptual stage is the starting point to apply and develop the UML models that are relevant for the process description. In particular, the *UML use case diagram* describes a single, previously identified building block identifying the actors interacting in the execution of the activities performed in a given use case based on the management of a specific health issue. The development of the use case diagram is based on relevant guidelines but is not dependent on a specific country health system.

Finally, once the actors and activities of a specific building block have been identified, *UML activity diagrams* are used to group similar country-based performance of the process, so that their descriptions can help in identifying similarities and/or differences in the provision of child care, specifically in terms of: activities performed, actors involved, where it is executed and timeline.

### **Development of a rich picture**

The concept of rich picture generates from the “Soft System’ methodology” (SSM) developed in the 1980s by Peter Checkland and colleagues (1, 2, 3), who proposed a methodology of system engineering that is able to capture a holistic, real-world complex view of a given situation – whether this is a program, issue, initiative or a specific setting. The building of a rich picture is one of the first steps of SSM methodology and consists of a “compilation of drawings, pictures, symbols and text that represent a particular situation or issue from the viewpoint(s) of the person or people who drew them” (4). This conceptual model has been adopted by different teams in the health care context (5, 6, 7, 8).

There are no fixed rules to be applied or syntax to be agreed on; however, a rich picture is generally developed by identifying primary stakeholders, their interrelationships, their concerns, and the structures and processes that outline the context at a high-grained level of description (9).

Within the MOCHA project, the rich picture centres on primary care for children and considers the main processes along with the different components that influence child health. The process of creating a rich picture helps us to identify the boundaries of the health care system that is to be analysed and compared with others across the European Union and EEA. The identified processes resulting from the rich picture are further detailed in the map of building blocks.

### **Maps of building blocks**

The concept of the building block has been used in various scientific approaches, including the World Health Organisation<sup>1</sup>. A building block is created in order to understand users’ needs in complex contexts where an information system and/or an organisation is embedded. It is generally used to capture high-level software functionalities from an implementation (10, 11, 12) and an architectural point of view (13, 14, 15), independent of technology and implementation choices. A common feature of building blocks is that they are easily re-usable and replaceable in a different part of the software development. This flexibility makes building blocks also suitable for the high-level description of business process fulfilling the purposes of our task.

In our approach a *map of building blocks* is a first refinement of the rich picture, and focuses on the identification of the main processes to be analysed in the provision of child primary care for each country. Each map is a still high-level conceptual description of our vision of child primary care, representing one of the main tracer health care pathways a child may experience throughout his/her psychophysical development.

The map consists of a core process that represents the main workflow composed by a sequence of building blocks executed in parallel or in series to accomplish a well-defined objective. Decision points are also included in the workflow to determine alternative as well as parallel paths within a process flow depending on the condition applied. Generally, the condition depends on the result of a specific building block, on the health status of the child and/or on the determinants of health. Additional building blocks (known as linked building blocks) are included in the map representing macro-activities that can be executed in certain circumstances and anytime within the main process. They may also represent macro-processes that are executed in other settings of child primary care, for instance performed by specific health care services and/or other stakeholders. In this way we can represent interacting macro-process

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<sup>1</sup> The concept of building blocks has been also adopted by the WHO within a framework that describes health systems in terms of six core components or “building blocks”: service delivery, health workforce, health information systems, access to essential medicine, financing and leadership/governance (WHO, 2010).

that for instance can describe interfaces between primary and secondary care or primary and social care services.

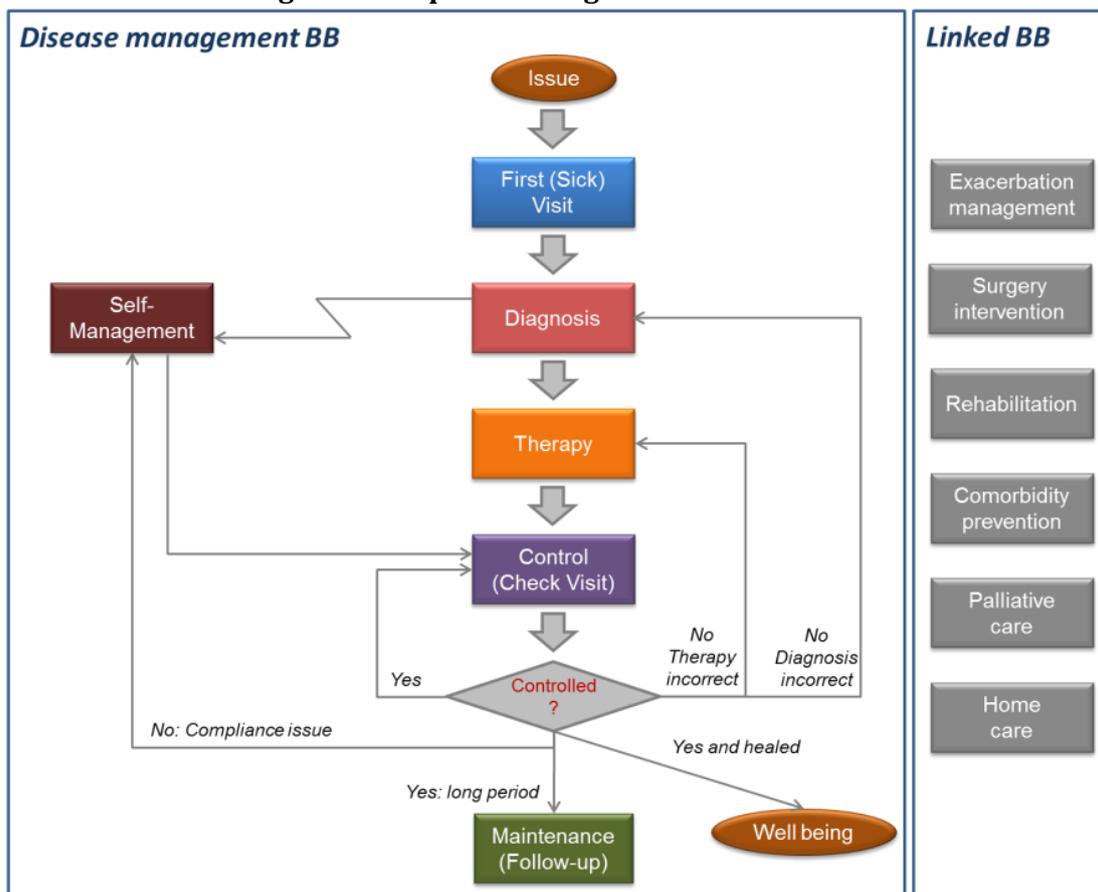
Thus, a building block acts as a meaningful and self-consistent component of a health care process. Every building block consists of:

- an entry point: an event that triggers the process, e.g. child experiencing an episode of care;
- a set of activities: that describes the interaction between different actors (carers, care recipient, family other third parties) eventually including a technological support to pursue an aim and/or address a concern;
- an exit point: that shows that the process is concluded, e.g. the diagnosis is confirmed.

The intrinsic homogeneity of the structure of the building block makes it able to be “isolated” from the specific process and, when possible, re-used in similar moments in different scenarios (for instance related to different pathologies).

An example of a map of building blocks, Figure 23, describes how a child with a health issue navigates the primary care system that can be generalized in each country. The process begins with a ‘sick visit’ – where a set of activities is begun in order to diagnose, refer and treat a condition. In the MOCHA project, asthma diagnosis and management is used as a tracer condition.

**Figure 23: Disease management map of building blocks**



A list of building blocks and related meaning is provided in the tables 12 and 13. When available, sources of definitions are reported.

**Table 12: Building blocks of disease management.**

Name	Description	Source
First sick visit	A visit focused on one particular acute problem, such as earache, sore throat, fever, vomiting/diarrhoea.	<a href="http://www.dukechildrens.org/services/primary_care/visit_types/#sick_child_visit">http://www.dukechildrens.org/services/primary_care/visit_types/#sick_child_visit</a>
Diagnosis	The process of identifying a disease, condition, or injury from its signs and symptoms. A health history, physical exam, and tests, such as blood tests, imaging tests, and biopsies, may be used to help make a diagnosis.	NCI dictionary of cancer terms
Therapy	Treatment intended to relieve or heal a disorder	Oxford dictionary
Control visit	A visit focused on the evaluation of the child health status that checks the validity of the diagnosis and the effects of the therapy.	
Maintenance /follow-up	Monitoring a child's health over time after treatment, after a chronic disease has been diagnosed	
Self-management	Set of recommendations given by the health care provider to support the psychophysical child development (for example, appropriate diet for age, breast feeding, etc.)	

**Table 13: Additional building blocks linked with disease management**

Name	Description	Source
Exacerbation management	Set of activities that manage the increase in the severity of a disease or its signs and symptoms.	
Surgery procedure	A procedure to remove or repair a part of the body or to find out whether disease is present. An operation.	NCI dictionary of cancer terms
Rehabilitation	A process to restore mental and/or physical abilities lost to injury or disease, in order to function in a normal or near-normal way.	NCI dictionary of cancer terms
Comorbidity prevention	Set of activities aiming to prevent the coexistence of two or more diseases	
Palliative care	Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of palliative care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment. Also called comfort care, supportive care, and symptom management.	NCI dictionary of cancer terms

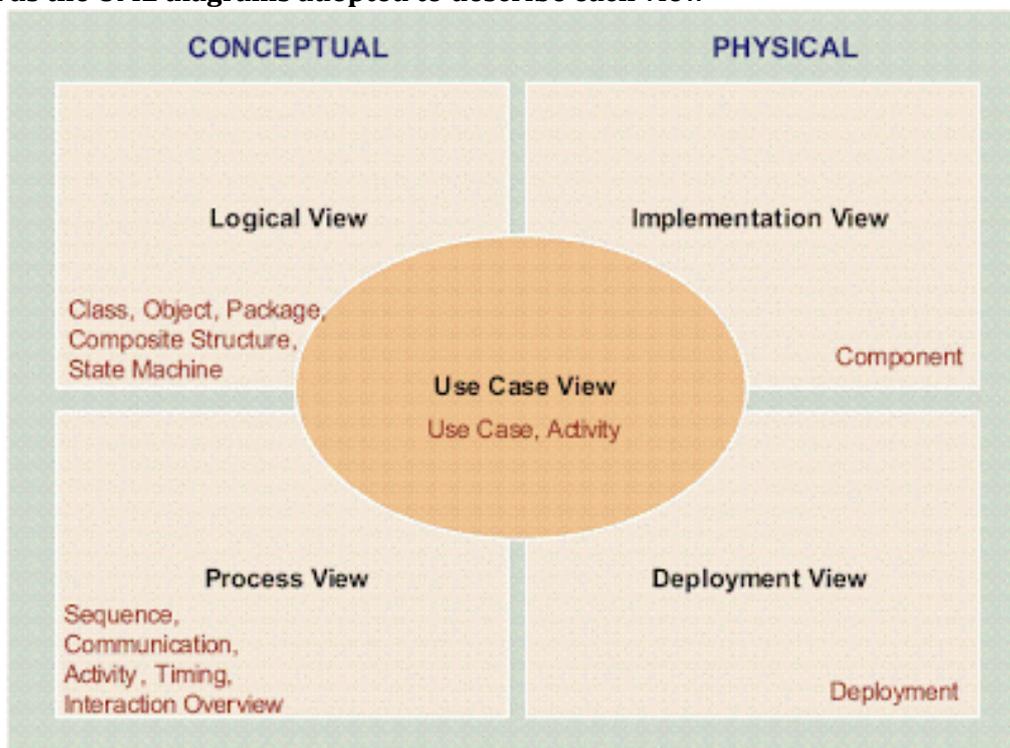
### Unified Modelling Language (UML) model

The UML is a general-purpose, developmental, modelling language in the field of software engineering. It is intended to provide a standard way of visualising the design of a system (16). UML combines techniques from data modelling, business modelling, object modelling and component modelling and can be used across different implementation technologies throughout the software development life-cycle, both from a technological and methodological point of view (17). UML is based on a semi-graphical and a semi-formal notation, using precise semantics. The different aspects of the system under analysis are described by the use of different diagrams (note that currently UML version 2.5 has 14 types of diagrams) to describe the structure (static description) and the behaviour (dynamic component) of the system. Diagrams are selected by taking into account the viewpoint of the relevant stakeholder in describing and evaluating the

functioning of complex systems. In particular, UML provides the following views and for each view it indicates the relevant diagrams to be developed (See Figure 24) (18, 19):

1. **Logical view:** refers to the functionalities provided by the system to end-users;
2. **Development view:** illustrates a system from a programmer's perspective and is concerned with software management. This view is also known as the implementation view;
3. **Process view:** deals with the dynamic aspects of the system; explains the system processes and how they communicate, and focuses on the runtime behaviour of the system;
4. **Physical view:** depicts the system from a system engineer's point of view. It is concerned with the topology of software components on the physical layer, as well as the physical connections between these components;
5. **Scenario (use case) view:** the description of an architecture is illustrated using a small set of use cases, or scenarios that describe sequences of interactions between objects and subjects, and between processes.

**Figure 24: The UML different views highlighting the conceptual and physical perspective as well as the UML diagrams adopted to describe each view**



(from <http://everspring79.blogspot.it/2008/09/uml-41-view-materials.html>).

For the purposes of our task, the scenario (use case) view is a suitable perspective to describe the business process modelling of primary care systems. The application of the use case and activity diagrams are appropriate to describe the interaction between the different stakeholders as well as to describe the activities performed in each identified case study/scenario, as reported by different researchers (20, 21, 22, 23, 24).

### ***Use case diagram***

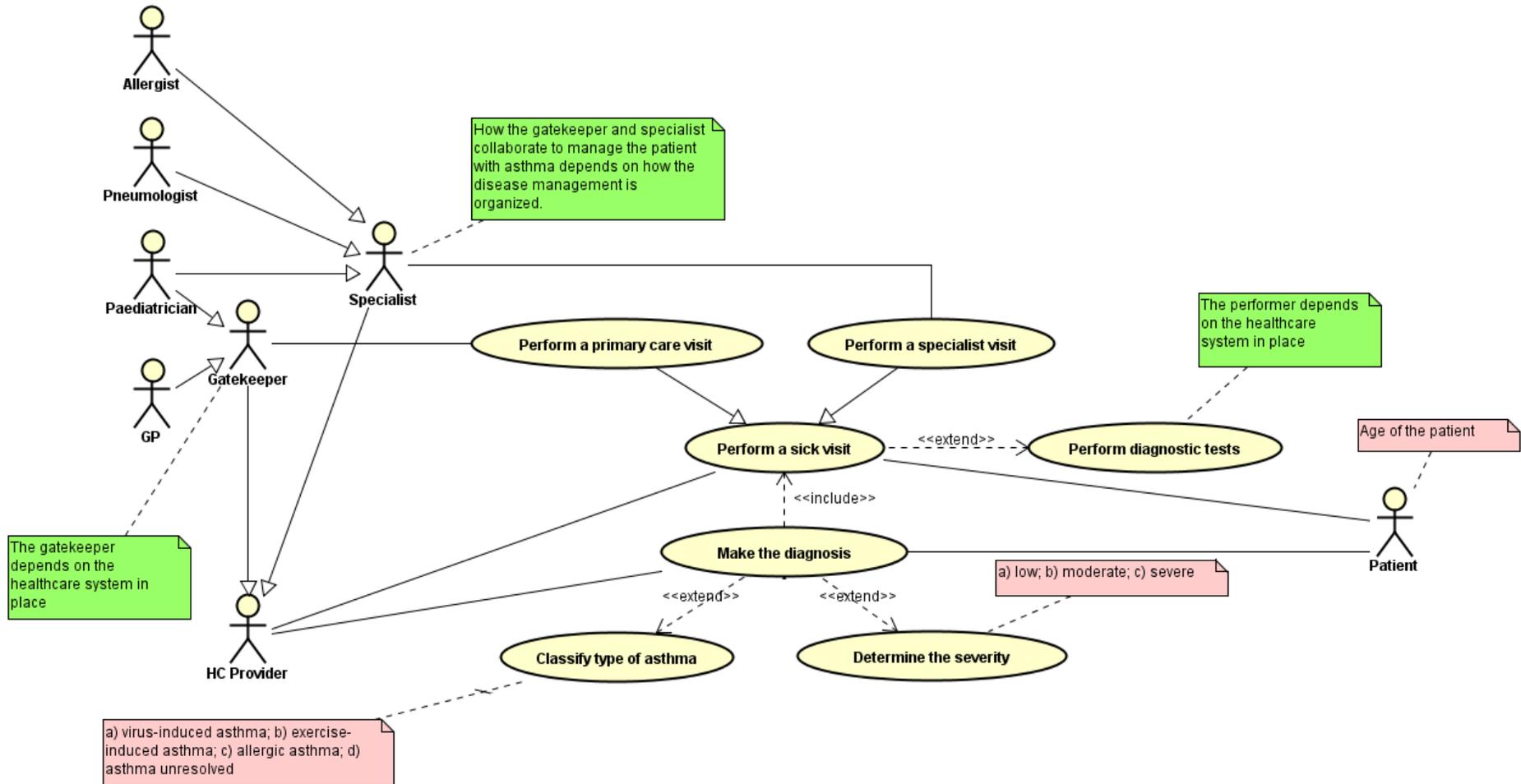
In software engineering, use case diagrams represent missions, task or goals of the different stakeholders involved. The main purpose of the use case diagram is to list the actors and the use cases and show which actors participate in each use case. The behaviour of each use case is expressed using models of dynamic view such as the activity diagram. A use case diagram contains the following main components:

- The actors, usually individuals involved with the system defined according to their roles and responsibilities. For instance, an actor can be a person, an information system or a device that interacts with the system.
- The use cases, which are the specific functionalities or services provided by the system and performed by actors within and around the system.
- The relationships between and among the actors and the use cases.

Within the MOCHA project the Use Case diagram identifies the actors who interact in the execution of each identified building block as well as the activities performed. It can be focused on a specific disease or type of intervention. Its description is based on available clinical guidelines that are “systematically developed to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances” (25). Considering that clinical guidelines are commonly agreed by the scientific community and are therefore important to assess the quality of care, they can be used as a benchmark to compare health care business processes. Other sources that can be used to define a use case diagram are, for instance, evidence-based literature review and/or intervention programs. This can be seen in Figure 9.

The main actors involved in this part of the process are the patient and the health care (HC) providers. The HC providers are divided into two relevant actors in terms of gatekeeping. A gatekeeper can be a General Practitioner (GP) or a primary care paediatrician; depending on the health care system in place (for instance, Italy has a primary care paediatrician-based system, whereas the UK has a GP-based system). The gatekeeper is responsible for the first visit of the child as well as for the diagnosis that is *included* within the activities of the sick visit. Using the tracer case of asthma, two important use cases that *extend* the diagnosis activity are the classification of type of asthma and the determination of its severity – these necessitate the input of a specialist physician such as a Pneumologist or Allergist. In some cases, a primary care paediatrician may be a specialist in asthma, for instance if he/she belongs to a secondary care organization, a hospital or an emergency room. To enrich the diagram, notes are included to provide additional information. For instance, in diagram shown in Figure 25 the age of the child is a fundamental variable that determines the type of instrumental test that can be performed. Another example is related to the primary care provider, who performs the diagnostic (instrumental) tests (i.e. spirometry) depending on the healthcare system. Finally, as described above, also the identification of the gatekeeper depends on the care system in place, such as paediatrician-based system in Italy and GP-based system in UK.

Figure 25: Use case diagram of a 'sick visit'.



### ***Activity diagram***

The activity diagram is a graphical representation that defines activities as well as actions to be performed in a stepwise manner to model both computational and organizational processes (i.e. workflows) (16). In software engineering, the activity diagram is mainly adopted to model business processes captured by a specific use case or scenario at a more detailed level, where each actor involved in the execution of the use case is represented also highlighting the actions carried out. An activity diagram contains the following components:

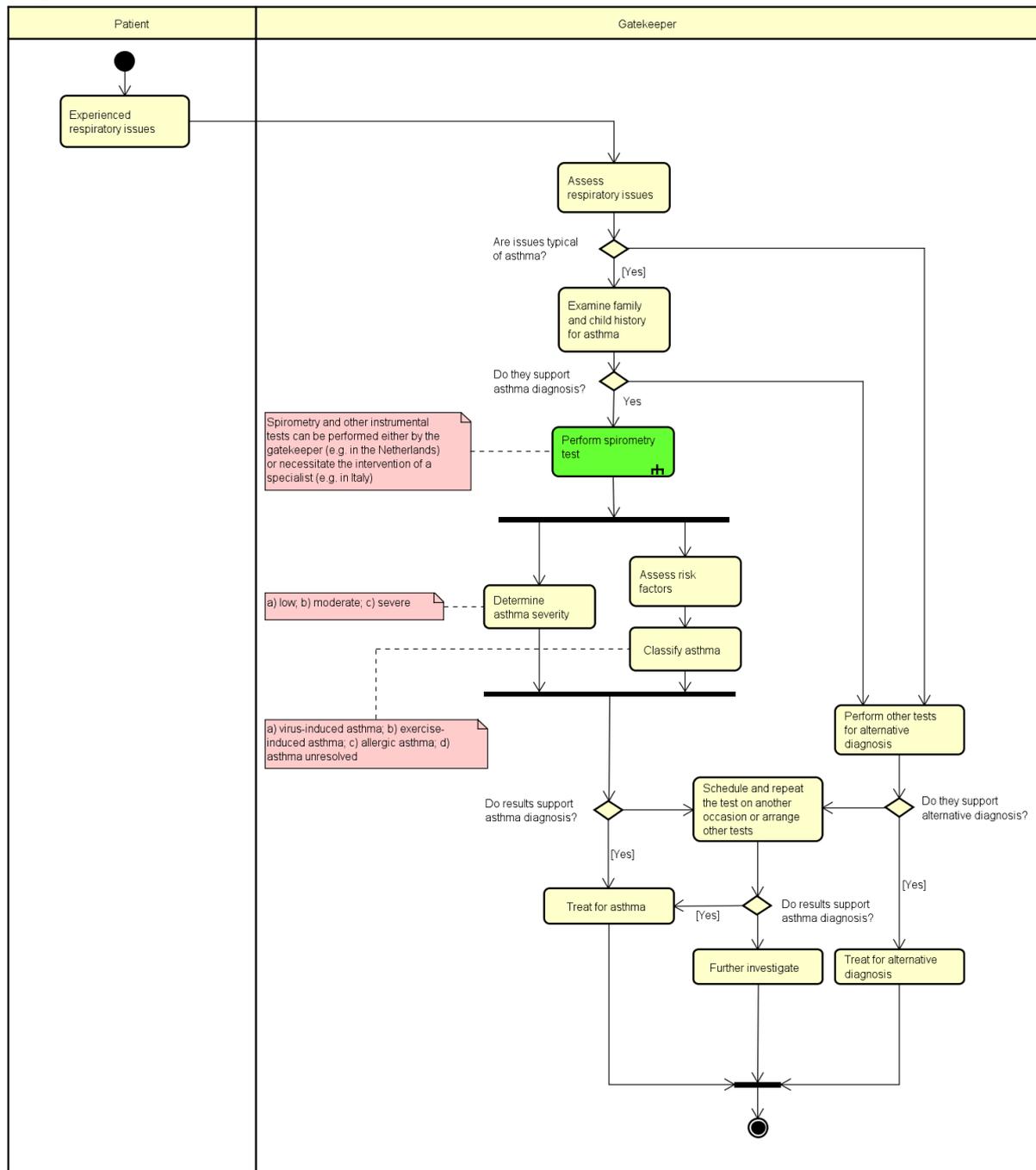
- Actors who represent a specific user or a system interacting with other stakeholders (as described in the use case diagram, actors can be human beings, information systems, medical devices, etc.). This component reflects the actors associated with the specific use case to be described.
- Activities carried out by each actor in a stepwise sequence.
- Messages that can be sent or received, specifying the interaction between two actors.

In a MOCHA perspective, this diagram describes the sequence of activities performed and messages exchanged by the different actors as well as triggering conditions of a set of activities within the building block. The descriptions of activity diagrams are based on the case studies provided by the Country Agents (See Introduction, and Chapter 4). On the basis of these descriptions we are going to group and then compare countries that have similar procedures, use similar services, and are based on similar caregivers for the provision of care.

Figure 26 shows the activity diagram for the use case selected: *make a diagnosis*. The diagram is based on a 10-year old child who has occasionally experienced wheezy attacks. To enable a diagnosis to be made the child has to perform a spirometry test.

Once the gatekeeper has assessed the child's respiratory symptoms, in addition to the child and family's risk factors for asthma, a spirometry test can be performed alongside other relevant tests to determine the type and the severity of disease; or signpost to additional tests or tests that are specific to other pathologies. This diagram features notes that specify information that cannot be reported using the symbols of the UML formulae. In this case they reflect the different types and severity of asthma.

**Figure 26: Activity diagram specifying the sequence of activities performed during the diagnosis use case**



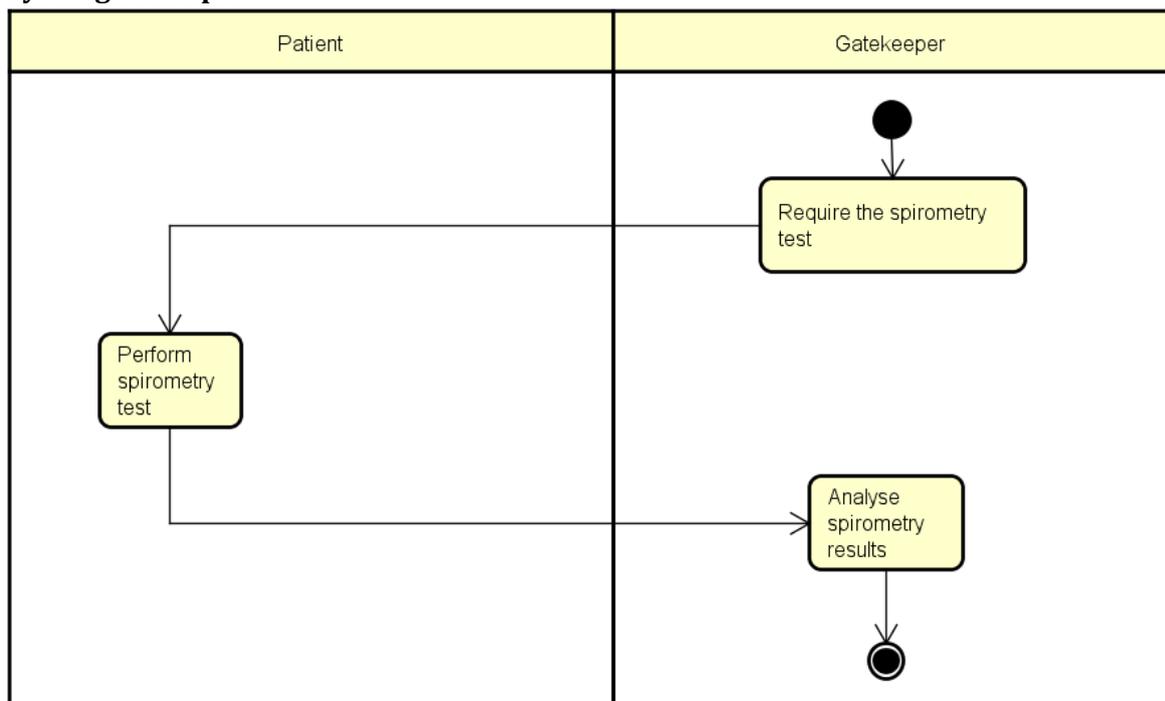
In this activity flow, the event *perform the spirometry test* is reported in green and as a core activity using the UML formula. In our example, this activity is an important part of the macro-process as the spirometry test can be performed directly by the gatekeeper or by a specialist. Therefore, we can distinguish the countries in these two groups and compare the activities performed in each one.

In Figure 27 the child is required to execute the spirometry test directly during the first sick visit performed by the gatekeeper. In this case the gatekeeper can also analyse the results of this test and make the diagnosis at the first onset of the health issue.

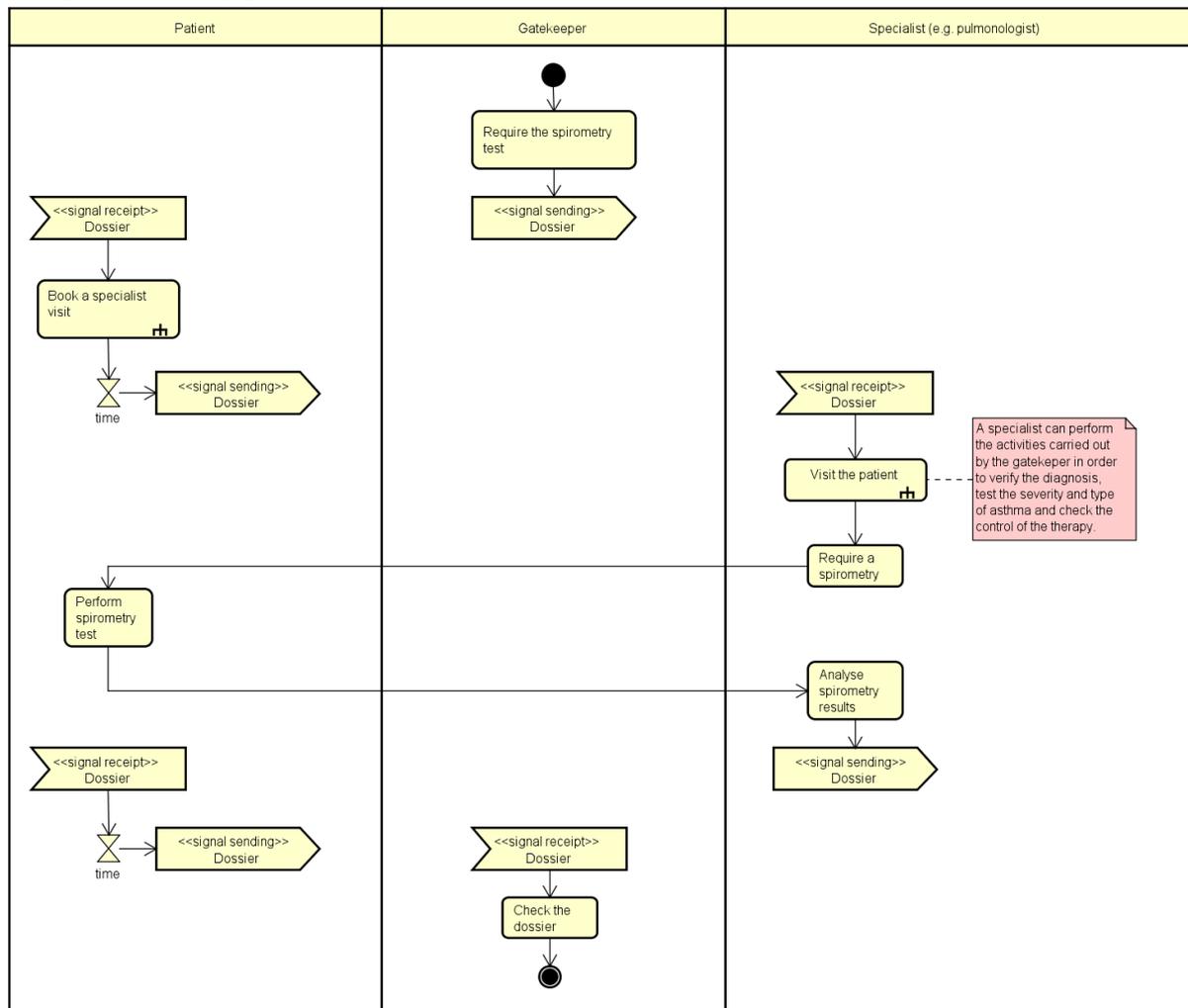
Conversely, in the scenario modelled in Figure 28 the spirometry is performed by a specialist – this may happen in countries where the gatekeeper is not equipped with spirometer or is not qualified to perform this task. Thus, the diagram introduces the third actor (specialist). In this scenario, the gatekeeper requires the family of the child to book a specialist visit during which the required test is performed. This implies collaboration between the two health care professionals, as well as the inclusion of administrative procedures related to the booking and eventually payment for the specialist visit.

The two processes are compared not only on the basis of activities performed and actors involved but also on the time required to perform the diagnosis. In the second scenario this implies the need for including waiting time for a child to access primary care as well the secondary care visit, as shown by the hourglass reported in Figure 28.

**Figure 27: Activity diagram describing the performance of the spirometry test executed by the gatekeeper**



**Figure 28: Activity diagram describing the performance of the spirometry test involving the specialist (e.g. pneumologist)**



### Applications of the methodology

The business modelling process was applied using three tracer scenarios, as outlined by the Country Agents (See Introduction) in their countries. The three scenarios were:

- Access to care for mild fever and rash
- Access to care for moderately severe asthma attack
- Management of chronic illness in school setting

#### *Access to care for mild fever and rash*

In the case of access to care for a child with mild fever and rash, the questionnaire focused on a 2-year old child in a typical family who quickly develops a mild fever, and rash on Wednesday late afternoon (during usual business hours). The parents decide they want their child to be seen by a health professional within 24 hours.

Based on the answers of the CAs the following main activities were identified:

- Access to OH (Office Hour) Primary Care (PC);
- Use of child medical record;

- Visit payment.

The study of the answers provided further details about how the general access to care process is organized, and it was possible to identify information concerning:

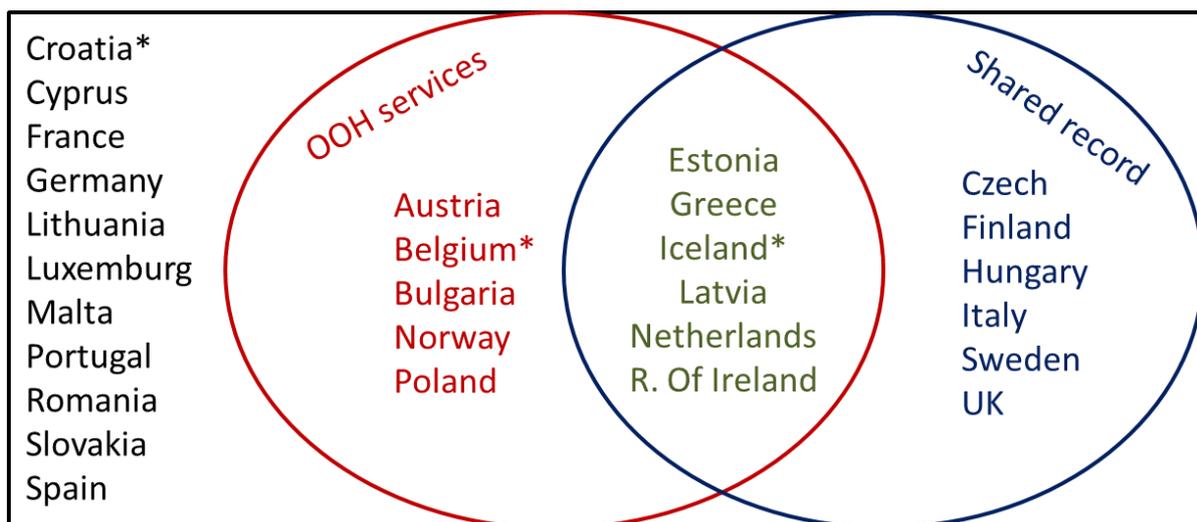
- Request appointment for Primary Care visit;
- Delivery of Out-Of-Hours (OOH) PC services;
- Delivery of home visit (usually in the case of a severe child condition).

Given that access to primary care OH services occurs very similarly across the 30 countries, the selection criteria for the classification of countries into groups were based on the following aspects:

- Availability of Out-Of-Hours (OOH) Primary Care services;
- Availability of EHR among providers and settings.

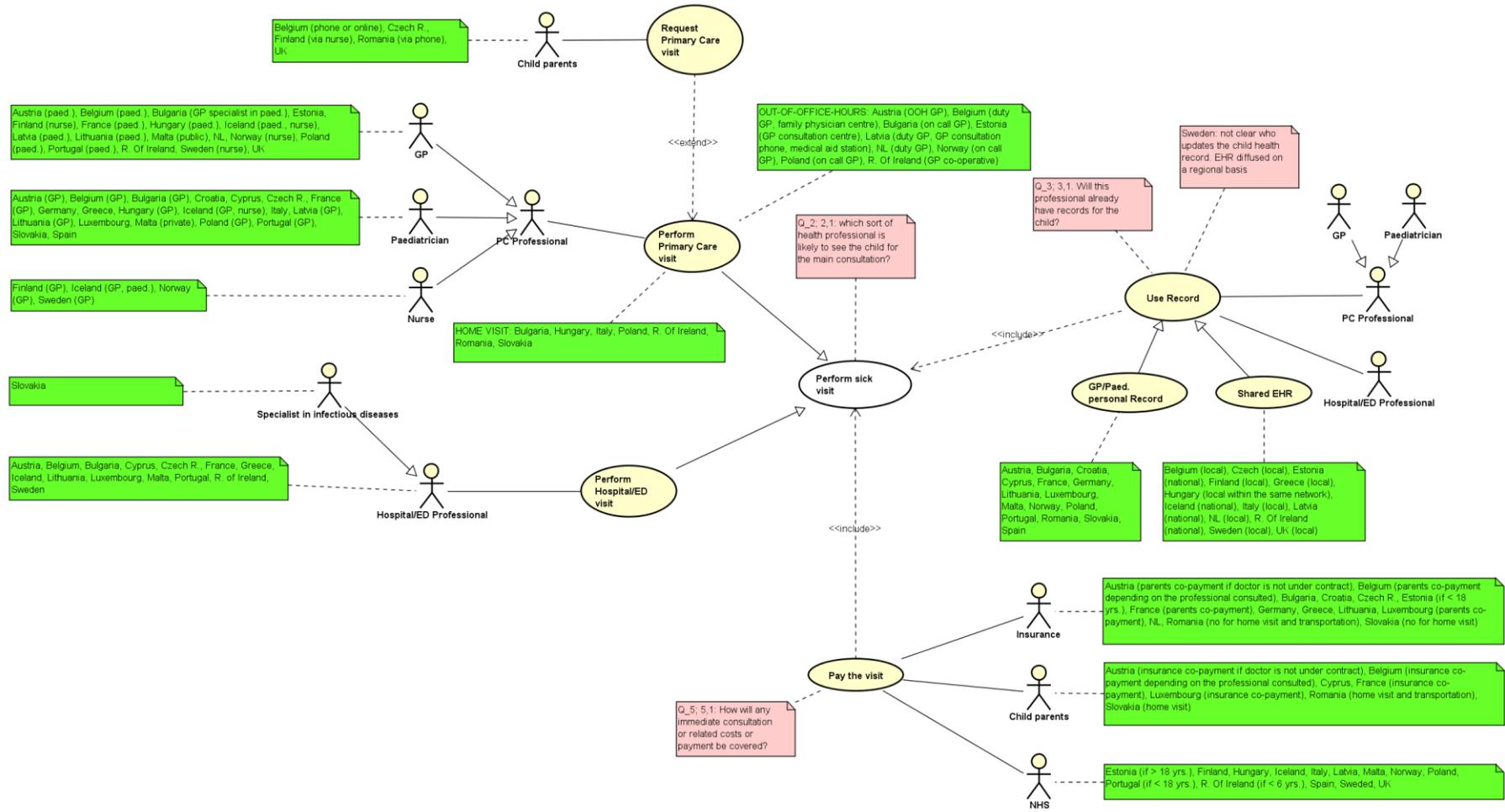
On the basis of these criteria countries were grouped according to similar practices. Six countries (Estonia, Greece, Iceland, Latvia, Netherlands and Ireland) provided out of hours (OOH) services and share information among providers using local and/or national electronic health records (EHRs). Both these services are not provided in eleven countries (Croatia, Cyprus, France, Germany, Lithuania, Luxembourg, Malta, Portugal, Romania, Slovakia, Spain). The remaining countries are split between those with OOH primary care services (Austria, Belgium, Bulgaria, Norway, Poland) and those with information shared using local and/or national EHRs (Czech R., Finland, Hungary, Italy, Sweden, UK). This is shown in Figure 29.

**Figure 29: Clustering of countries based on similar practices of access to care for mild fever and rash**



Further to the clustering of countries, the Use Case Diagram in Figure 30 shows the activities of the MOCHA countries related to the case study of a child with mild fever and rash. Green notes specify the type of actors involved in the related activity in each country, while pink notes map the questions to the Country agents.

Figure 30: UML Use Case Diagram: Access to care for mild fever and rash



### ***Access to care for a moderately severe asthma attack***

The second questionnaire considers the access to care of a child with a moderately severe asthma attack. The answers from the MOCHA Country Agents identified the following main activities:

- Access to open-hours Primary/Secondary Care;
- Use of child medical record;
- Use of (standardised) communication documents between Primary and Secondary Care in case of child referred and/or admitted to hospital (e.g. written letter, email, phone call, etc.).

Further scrutiny of the Country Agent answers provided further details about how the general access to care process is organized, and it was possible to acknowledge information also concerning:

- Delivery of Out of Hours (OOH) primary care services.

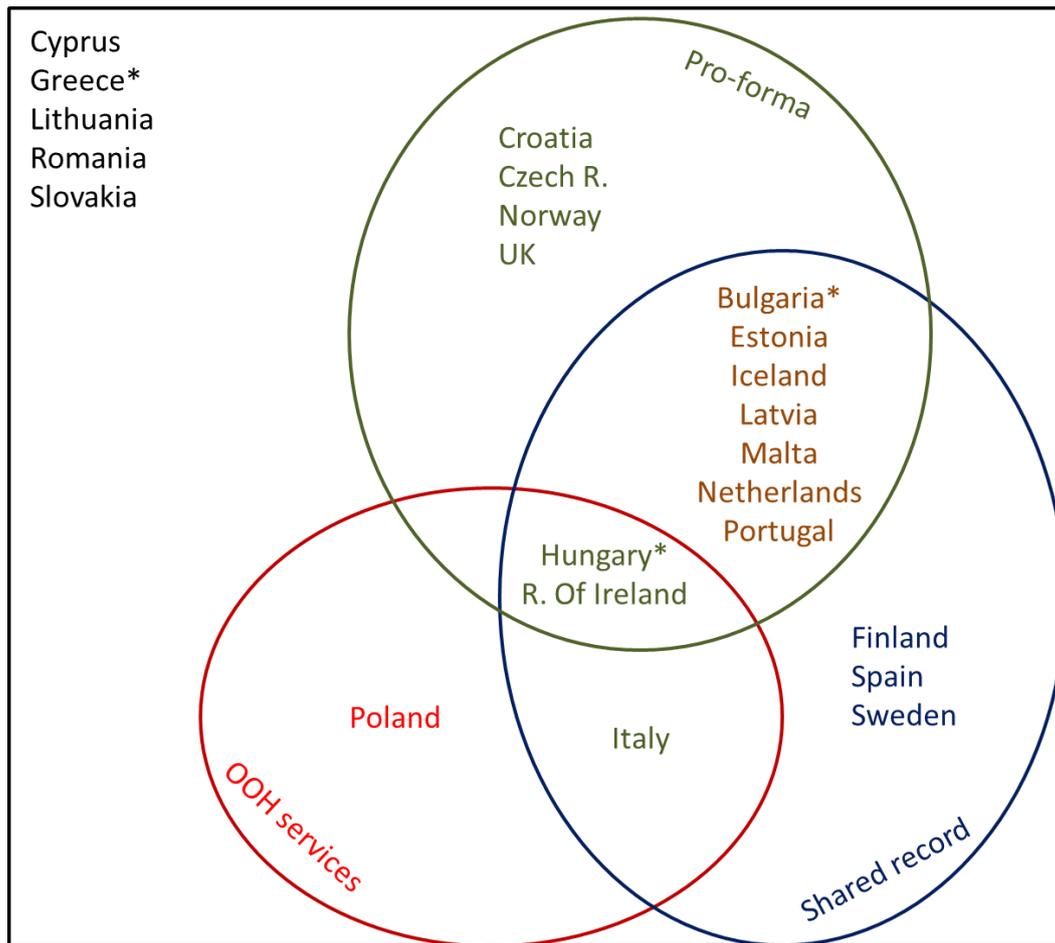
Access to office hours care for children with a moderately severe asthma attack occurs in most European countries in primary GP/Paediatrician practices. Access to hospital emergency services is of course always possible, presumably when parents are particularly concerned with their child's health status. Compared with the previous scenario, the indication of accessing this service has been reported more frequently by CAs as an alternative access to primary care. Moreover, some CAs (Bulgaria, Estonia and Slovakia) report the possibility for parents to directly take the child to a secondary care professional without being referred from a primary care professional. Czech Republic considers this case only for repeated events. Four CAs (Italy, Latvia, Lithuania and Netherlands) report that parents may be referred to the specialists from another care level.

As in the previous scenario, the access to primary care OH services occurs very similarly across the 30 countries; accordingly the selection criteria for the classification of countries into groups were based on the following aspects:

- Availability of OOH primary care services;
- Availability of EHR among providers and settings;
- Use of recognised and standardised pro-forma for the communication between primary and secondary care.

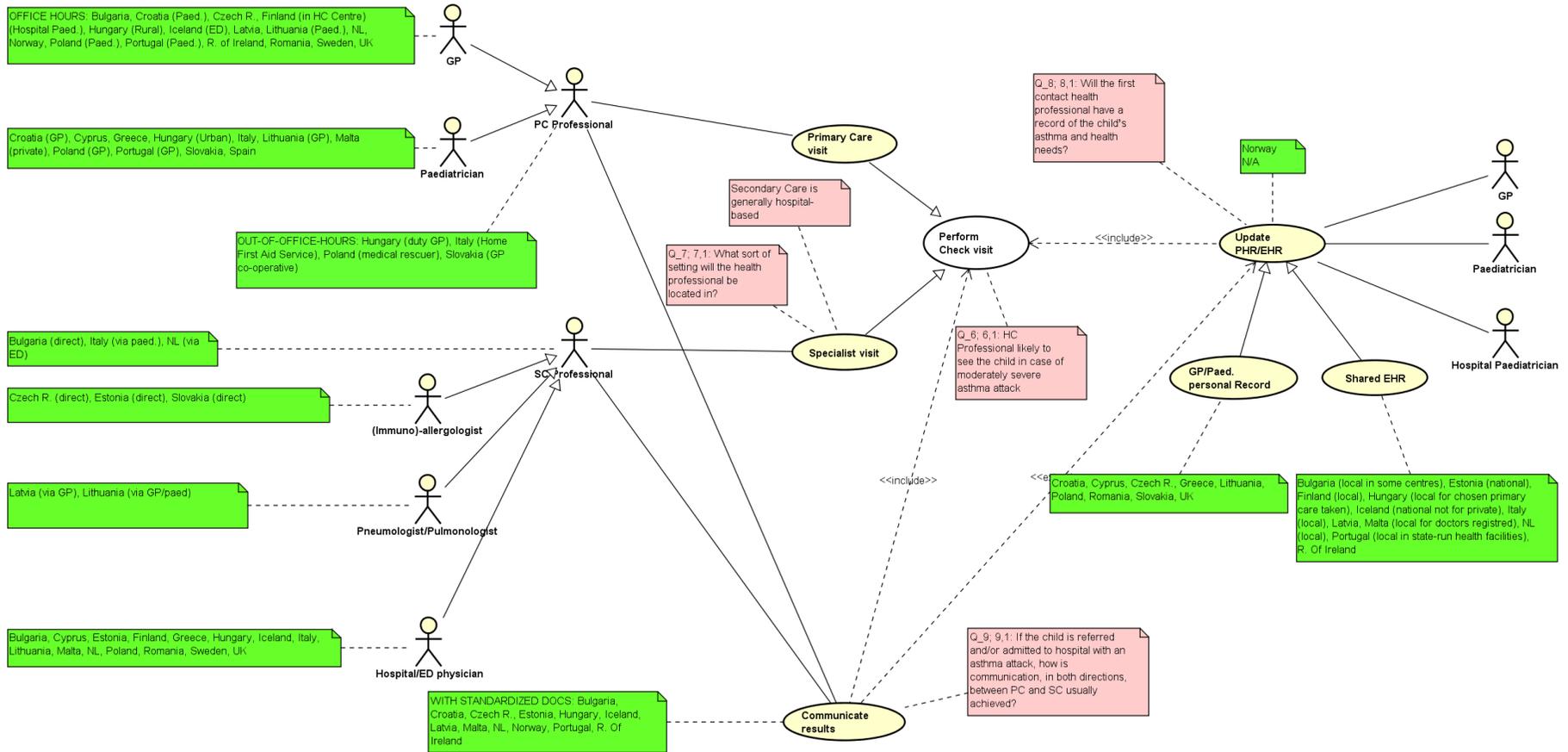
On the basis of these criteria countries were grouped according to broad similarities in process. Two countries (Hungary and Ireland) provide out of hours services, share information among providers using local and/or national EHRs and have standardized pro-forma for the communication between primary and secondary care. In five countries, these features are not available (Cyprus, Greece, Lithuania, Romania, Slovakia). Among the other countries: Bulgaria, Estonia, Iceland, Latvia, Malta, Netherlands and Portugal provide OOH services and standardized pro-forma, but do not share information with local and/or national EHR, while Italy provides OOH and shared EHR without standardized pro-forma. The remaining countries are split between those with only standardized pro-forma (Croatia, Czech R., Norway, UK), those with information shared using local and/or national EHR (Finland, Spain, Sweden) and Poland that provides OOH primary care services. This is shown in Figure 31.

**Figure 31: Clustering of countries based on access to care for a moderately severe asthma attack**



Further to the clustering of countries, the Use Case Diagram in Figure 32 shows the activities of the MOCHA countries related to the case study of a child with a moderately severe asthma attack.

Figure 32 UML Use Case Diagram: Access to care for moderately severe asthma attack



### **Management of chronic illness in school setting**

The third questionnaire considers the case study of a 10-year old child who has a 2 year history of asthma and takes regular medications (by using an inhaler) for this. When in school setting, on occasions he will need to use an inhaler when he does physical exercise in the gym or playground. Based on the Country Agent answers the following main activities were identified:

- Development of policies for the treatment of asthma attack at school
- Production of the school written plan;
- Management of an inhaler for non-severe asthma attacks;
- Support for the child in case of medical emergency;
- Inform parents if any treatment is provided to the child at school.

Further study of the answers provided further details about how the general care plan management process is organised, and it was possible to acknowledge information also concerning:

- Request to create the school written plan;
- Implementation of the school written plan.

The answers allowed the actors to be grouped into three main categories according to their belonging organization and/or level of care (actor type):

1. *Healthcare Professional* that comprises Primary and Secondary Care Professionals (GP/Paed./Nurse).
2. *School Professional* including (trained) teachers, the school director and more in general school staff/personnel members.
3. *School Care* that comprises school doctors and nurses.

When it was not possible to establish whether an actor belongs to primary or secondary services, the actor type was reported as general Healthcare professional.

In many cases, the Country Agent's answer reported the same activity for more than one actor, and combined in several ways: For example, in Italy, the written plan is produced by Specialist doctors in treatment centres OR primary care paediatrician AND the Local Health Unit. In the majority of cases, the written plan is produced by Healthcare Professionals. School Care actors are involved in Croatia, Finland, Ireland and the UK. Parents participate in the production of the plan in six countries (Finland, Greece, Iceland, Ireland, Spain and UK).

The use case diagram depicted in Figure 33 models two main scenarios: 1) the production of the care plan that specifies the actions to be taken at school for a child with asthma; 2) the adoption of medical and emergency procedures to manage an asthma event occurring at school.

In the first scenario (upper part of the diagram) the main use case is *Produce the school written plan* that is a generalization of the use case *Produce the care plan* where all the actions and information needed to look after a child with asthma are defined and reported. The production of the school plan is generally performed by a healthcare professional and a member of the school staff, upon agreement with child parents. Moreover, as highlighted by the relationship *include* the production of this plan is based on policies developed at national and/or school level. Different actors (for example, healthcare professional, school director, or the child's parents/guardians) can be involved in the application of the written plan. An example of this application is specified in the second scenario that is modelled in the bottom part of the diagram and represented by the use case *use inhaler* that specifies in case of asthma attack whether the

child can manage it by himself or whether the treatment is performed by an adult (teacher and/or nurse). Note that the relationship *include* pinpoints whether the school can support the child in the delivery of this treatment by providing supervision through a school teacher. This is one of the actions put in place by the school to support the child in the event of medical emergency, as highlighted by the generalization relationship between the two use cases. Finally, the use case *Communicate information about the treatment* specifies when the parents should be informed, if any treatment is given to their child. This is generally performed by a member of the school staff or by the specialist (this is an *extended* use case given that in some situations the communication is an optional activity).

## **Triangulation and Validation**

The UML modelling language allows the MOCHA project to make comparisons between very different models of care, by modelling particular activities based on how a child interacts with the health service in three main pathways: wellbeing monitoring, disease management and social support. Each UML model is derived from the responses to MOCHA Country Agent questions – and, therefore, is not based on any pre-defined models of care, which are very difficult to identify (See Chapter 1).

This methodology has never been used as a way of mapping children’s primary care services in Europe; but it allows the comparison of the complex primary care provision for children in the European Union and EEA, and as such, contributes to the ultimate MOCHA objectives of identifying optimal models of child primary care.

The methodology also specifies how UML use case and activity diagrams can be adapted to compare the business processes across countries, identifying the sources of information on which the descriptions are going to be based. In particular, the use case diagram provides a snapshot of the actors and activities related to a building block, and relies on clinical guidelines that represent a benchmark to compare health care business processes.

Activity diagrams benefit from the MOCHA case study approach to highlight differences and similarities in activities performed, actors and services involved as well as timelines “in real-life context” (26).



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## Chapter 7

### The contextual determinants of child health policy

Kinga Zdunek, Peter Schröder-Bäck, Mitch Blair, Michael Rigby

#### Main findings

The identifying cultural factors that influence primary care child health policy yielded an extremely rich variety of concerns and protests about child health in Europe. What has been drawn from this is a map of the important actors, influences and determinants that affect or stimulate changes in child primary care policy. These consist of:

- The child as a central, causative actor, accompanied by executive actors – acting in both the proximal and distal environment of the child
- Contextual determinants of changes in policy in child primary care services – in terms of human and non-human factors
- Socio-cultural determinants of changes in policy in child primary care services
- Structural determinants
- International determinants
- Specific events
- Vehicles of public expression

The interaction of all these different elements is both complex and enlightening in terms of cultural influence on child health systems.

A number of themes emerged from the responses from the Country Agents. These have been identified as:

- Vaccination debates
- Disabled children's rights
- Child abuse
- Lifestyle changes
- Societal changes and effects on a child's mental health
- Child poverty and homelessness
- Provision and access to child health care and services
- Functioning of the health care system

All primary care systems are subject to the influence of public opinion shaped by multiple political social and cultural influences. In this report, we examine child-centric determinants of health policy in terms of their context. This allows us to verify to what extent they are present and influential in the content and processes of primary care child health policy. The main objective of the study was to explore the contextual determinants of child health policy taking into account socio-cultural background factors. To do this we aimed to identify the most influential factors or topics of public concern which have been perceived to have most shaped recent national health policy in each country. Figure 34 shows the change in the child actor over time, in terms of autonomy and decision-making, and the influences that combine to shape child health policy in primary care.

**Figure 34: Child Centric Health Policy**



## Methods

This study was a qualitative analysis, inspired by a constructionist approach based on a positivistic grounded theory. The methodological procedure applied was based on a hybrid approach linking inductive, data-driven perspective of Charmaz (1, 2, 3) with elements of deductive coding which was based on the classification of contextual determinants of Leichter (4) and incorporated into the research path. The mixed character of the approach was applied due to the nature of the research group and to adjust the project overall methodology. The emerging data is the result of scientific reactivity to analyses, comparisons and interpretations. It also recognises the previous experience and knowledge of the researcher.

We asked each of the MOCHA Country Agents (See Introduction) to identify between three and five important issues related to child primary care services, which were widely discussed in the news, media and by the public in their country in the past five years (2011-2016).

The Country Agents were sent a semi-structured survey instrument. Each respondent was asked to describe the case, specify the object and area of public concern, indicate the broader context of the case and identify the level of discussion as well as the vehicles of public expression and the outcomes of the case.

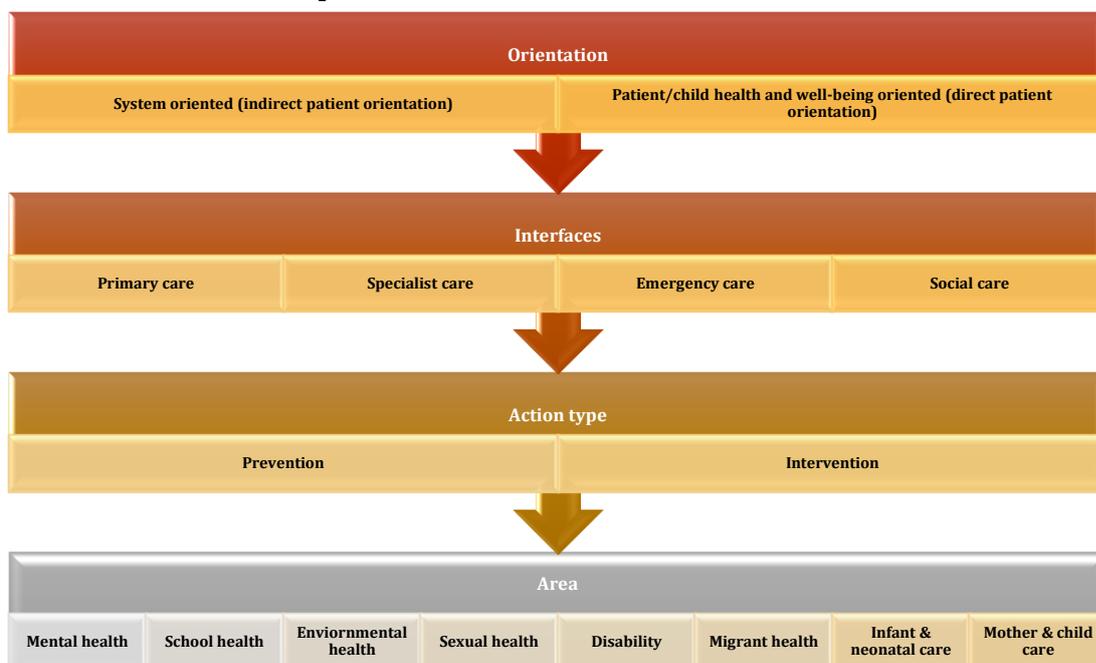
The representatives of 22 countries respond to the question and there were 65 cases characterising different areas of public concerns in various European countries. However, the goal was not to measure quantitatively the amount of cases of particular character, but to indicate the issues which across Europe may influence child-centric activities.

### Triangulation and Validation

This work breaks new ground in research into the models of child health systems in Europe, in that the diversity of contextual influences have never been mapped in such a way in the past. Along with the governance of systems this knowledge together with the focus on the formal political structures and processes highlighted in Chapter 9 will inform the development of optimum models (or, more accurately, elements of a model) of health care in taking account of the important factors that influence decisions about what should the health service be focused on and how it operates or should function. The MOCHA research topics i.e. type of health condition or system characteristics selected for further study by the researchers themselves acts as a useful comparison with findings.

From analysis of these concerns, a number of main areas of concern in Europe were identified. It was evident that there is a broad range of child health problems that are in the public consciousness; although there are issues of primary importance assigned to each example, there are significant overlaps between different areas within particular cases, and this enabled a generic structure to be developed of the areas of child health care and policy that are of most interest. The interaction of the child with the health system observed in these cultural issues are considered via different domains within health care system; such as primary care, specialist care, emergency care and/or social care. Within those domains two levels of activity were observed: prevention directed the attention to the well child embedded in the family context, broadly understood social environment context or preventive care context; and intervention which places the child with long-term illnesses and/or complex healthcare needs in the centre. This is shown by Table 14.

**Table 14: Main areas of public concerns of child health**



### The child as the central actor

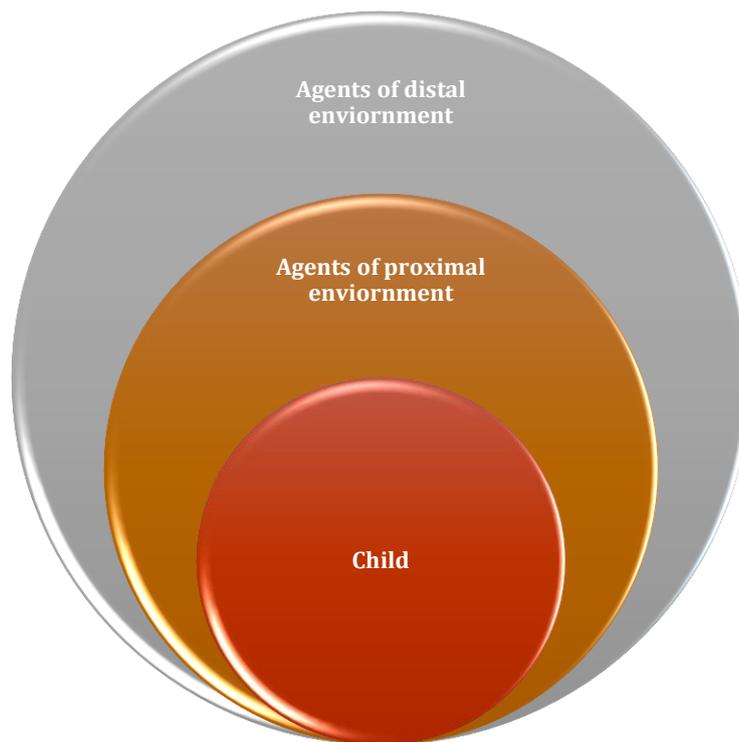
Children are the main object (both direct and indirect) of debates and discussions related to child primary health care across most of the European countries. This may take different forms:

- The child as an object of a child-centric health policy decision is the well child (embedded in the family context, broadly understood social environment context or preventive care context);
- The child with long-term illnesses and/or complex healthcare needs is at the centre of the debate.
- There is heterogeneity because of the differences in child health issues according to life stage from prenatal period via infancy to adolescence.

Although the child itself is not usually an active participant in the discussion on the shape of policy for child primary care services, the child's role as the subject and cause of societal action means they are a **causative actor**.

The causative actor (the child) is surrounded by a large network of representatives. As these actors have a greater ability to act and represent the interest of the child they are defined as the **executive actors**. We consider them as the **agents** of the child circulating around in the proximal or distal child's environment. The proximal environment of the child is understood as the direct milieu of the child on the micro level whereas distal refers rather to indirect surrounding on meso- and macro-level. The difference between distal and proximal environment of the child is expressed by the type of relationship. In the proximal perspective, the agents are capable of constructing the direct relationship whereas the agents of distal environment are rather acting on the basis of indirect contact (See: Figure 35).

**Figure 35: The child as the central actor in the process of shaping child health policy**



### **Actors of proximal environment**

- The principal actors of the child's proximal environment are parents. They are often vocal in discussions about their child's situation. In many cases, they are supported by involved **caregivers** within **social care** and **healthcare services**. They also more often than other agents are considered as both causative and executive actors. Parents can be agitators in the case of inequality or perceived poor treatment of their children. Parents represent the child's voice via informally organised groups or with the support of parents' associations, medical doctors or journalists.
- Other actors who closely surround the child include **family members, acquaintances, friends, neighbours and school environment** as well as the **general practitioners** or others representatives of the health system who are the "listeners" and "observers" institutionally empowered to act in the name of the child.
- **Teachers and the school environment** as the agents of the child act based on regular everyday contact – an example of teachers acting on behalf of the child was evident in Greece, where teachers as well as parents and raised the issue of fainting episodes at school due to hunger.

### **Agents of distal environment**

- **Health care professionals based within or representing the health care system.** In some cases, health professionals took an active role in discussions about child health from a direct or indirect focus point.
- The voices of **professional groups working within the health care system for children** are also an important distal actor. The strength of the system affects its ability to respond adequately to those who use the service, including children.
- **Non-governmental sector and society.** Non-governmental organisations in many cases are the platform for exchange of common views for representatives of health professionals, parents and carers and other interested persons who wish to ensure that the child health and well-being is protected.
- **Governmental sector and national services (State involvement).** Representatives of state, such as the Ministry of Health, other government departments and national institutions are part of the distal environment of a child's place in a health system as they tend to provoke debate, in the form of introducing new policies, or new solutions to problems.
- **Individual authorities.** Initiatives undertaken by the state were often supported by individuals acting independently, for example, an ombudsman charged with protection of children's rights and health, or in joint committees.
- **Research centres and mass media.** Research centres play a crucial role as prior sources of information on the phenomena discussed in public. In addition to this, a substantial role can be played by mass media in the discussion.

### **Contextual determinants of changes in child primary care health policy**

Health policy is not isolated from contextual reality. Actions undertaken in the area of child health care are influenced by two groups of interdependent factors that trigger the onset or exacerbation of the public concerns.

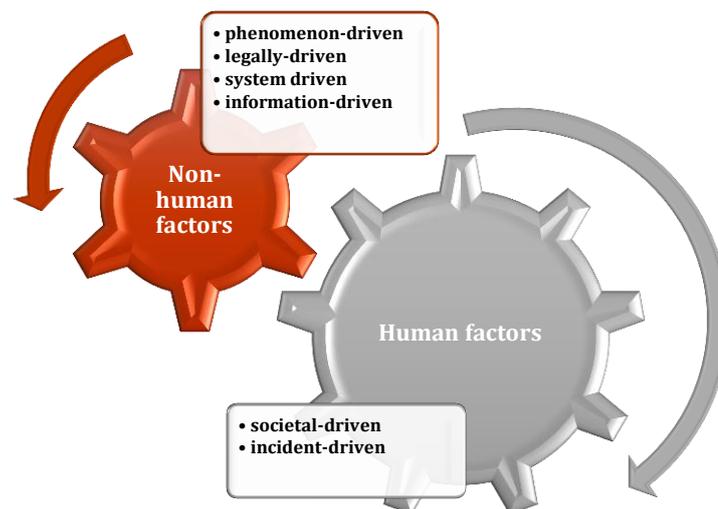
- The first group include actions by the public that are societal-driven and of incidental experiences which stimulated incident-driven initiatives.

- The second group consists of phenomenon-driven, information-driven, procedurally/legally-driven or system-driven actions.

The category groups which emerged from the collected data were divided into two types of constantly interrelating factors: **human factors** and **non-human factors** (See: Figure 36).

In all cases, we observed subcategories of positive and negative triggers: for example, those which drive health policy changes into adverse health effects (negative driver) or towards advantageous health effect (positive driver). As can be seen in Chapter 8, differentiating between positive/negative identification and effects is a contextual challenge. What is positive or negative is fluid, depending on national assumptions and prioritised values to the individual or society

**Figure 36: Interdependence of the triggers of the child health policy change**



### **Human factors**

The **human factors** which trigger child health policy change, and provoked wider social reaction were linked with **societal-driven initiatives**. Human factors identified by the countries included: access to neonatal care in areas of Norway; the objection of Czech parents to the introduction of mandatory vaccination; the protest by Austrian mothers about discrimination in the education system against children with complex and chronic illness or disability; journalists identifying over medication of children in Romanian State Care; and paediatricians who object to the practice of closing wards at weekends, thus threatening the health and lives of children in need.

Some of the human factor events are **incident-driven**, meaning that a particular situation or event stimulated public discussion and concern. Often, these are of ethical character, as was seen in the debate in France about confidential access to contraception for teenage girls; euthanasia, or a child as a 'victim' of extreme parental decisions about diet and lifestyle, as seen in a case in Italy.

## **Non-human factors**

There were four types of **non-human factors** that triggered societal movements towards changes in child primary care health policy: phenomenon driven, information importance, procedural solutions and system performance.

- The **phenomenon-driven** triggers prove that the large scale processes can significantly affect child health status at micro level, and require responsiveness at macro level. Examples of phenomenon-driven triggers include the wave of migration into and within Europe and the economic downturn as the consequence of the global crisis. This has led to important debates about unaccompanied child migrants in the UK and Finland; and in Greece, the economic downturn was of particular relevance, where the problem of food insecurity was widely discussed after reports of school children fainting in class, and child poverty and homelessness became an element of concern in other countries, including Spain and Ireland.
- **Information importance** was a feature of the discussion on vaccination and anti-vaccination movements. This particular discussion exposes the importance of rigour in scientific and institutional reports, as well as statistical data. In contrast, the bulk of information-driven causes were positive in tone. Reports from the HBSC survey started raising awareness on the issue of obesity prevalence correlated with the low proportion of time dedicated to physical education and eating plans at school in Malta. The problem of bullying was underlined by the HBSC study in Latvia, and the issue of chronic conditions in adolescents in Austria.
- In terms of **procedurally/legally-driven** triggers, the implementation of new legislation, guidelines and procedures can trigger changes in policy relating to child primary care services and resulting societal protests. Included in this category are objections in Croatia when the rights of disabled children were infringed; the changes in post-graduate education for doctors in the Czech Republic, which resulted in paediatric general practice no longer being recognised as a specific discipline; and changes in terms of eligibility for Discretionary Medical Cards, inadvertently creating inequity and discrimination in Ireland.
- **System performance** triggers are mainly concerned with how poor organisation and infrastructure may provoke severe health risks, which indirectly refers to health system functioning and organisation. This was seen in an example given from Romania, where a fire in an intensive therapy ward for premature babies revealed a problem of service deficiency connected to austerity policies, which stimulated a heated public discussion on a national level. When a new vaccine against meningococcus appeared in Lithuania, many parents wanted it, but there was only limited access. Conversely, the lack of trust in the authorities' competence is expressed by anti-vaccination movements, which advocate freedom of choice in vaccination of children.

## **Socio-cultural determinants**

**Socio-cultural** elements in the public contextual issues were identified from the Country Agent responses. They also took into account the wider context described by each Country Agent.

The **Societal activation** level has an influence on child health policy as well as care and often is driven by public sensitivity to child-related issues. Activation can be in two forms. On the one hand, it can be because of an occurrence or lack of an occurrence. The example of strong public activism was the desire for free choice in vaccination in the Czech Republic. **Awareness** of the

problem or awareness of its impact is correlated with access and availability of information. This was evidenced by a Spanish case of child poverty and its impact on wellbeing; and the Austrian case of children with chronic conditions being inadequately cared for by the health and educational systems.

The issues of awareness may be indirectly correlated with **communication**. The epidemic outbreak in Romania and lack of clarity in terms of informing the public about the progress and results of investigations did not contribute to a growth in public confidence, but in contrast intensified the lack of trust in the authorities and reinforced a crisis in social capital. On the other hand, the lack of *direct communication between hospital/health care, school and other social services* in Norway reflected the passivity of the social environment to the problem of child abuse problem, resulting in the death of an 8-year old boy. This lack of **trust** in scientific authority was also seen in Italy, where organisations opposed to vaccines have promoted campaigns and have resulted in a large reduction in the percentage of children vaccinated against mumps, rubella and measles. National debates about vaccination often are accompanied by the issue of the right to **freedom** to refuse mandatory vaccination without the risk of financial sanctions or limited access to the services.

**Contextual change** is another factor influencing the child health policy and care. By contextual change, we understand shifts in the proximal and/or distal child environment, and phenomena at macro or micro level. The examples based on which we extracted this category were correlated with, amongst others, an early intervention named "*Frühe Hilfen*" in Austria, which responded to child welfare concerns by aiming to improve development and opportunities for children and families. In Portugal, contextual change can be seen in the improvement of living conditions in the last four decades which has negatively affected the prevalence of obesity. More generally, changes are linked to the modernization of everyday life, as evidenced in Iceland's concern about child and adolescent obesity, and changing family structures, identified by problems in parenting and resulting violence and bullying in the school setting was identified in Latvia. Digital media and its use by children and at school is a component of modern **lifestyle** interpreted as set of behaviours which directly or indirectly may affect positively or negatively the child health status. Lifestyle is also an important component to be taken into consideration while defining child health policy priorities. This can be seen in discussions of obesity (for example in the United Kingdom, Austria and Portugal) and its relationship to 'screen time', sedentary behaviour and reduction of physical exercise as part of the school day and active transportation to school (which was identified as an issue in Portugal).

The **attitudes** and **beliefs** not only affect lifestyle choices at micro level but also drive national debates. For example, in Finland, a discussion on sexual education became a larger debate on tolerance and religion. As well as debates on same-sex marriage; religious, cultural and issues of tolerance also influenced the debates on contraception for adolescent girls and child poverty. In Malta, religion was cited as a factor in child poverty in the sense that a reduction in religious values has led to increased marriage breakdown and an increase in the immigrant population in the country.

Tradition is usually strongly embedded in the history of a country. Thus, **history** was extracted as separated category of data. As in most of cases, the impact of the past policies and solutions, as well as inherited traditions, may be twofold. On the one side, archaic policies and attitudes allowed issues such as child abuse to go unrecorded, as was reported by Iceland, or in countries that formerly lived under a communist regime found that their systems of care were archaic and not fit for purpose in the modern world – as seen in the Czech Republic's system of care for vulnerable children: or the legacy of previous traditions of organising care in residential units

also affected child care in Romania. Similarly, in Croatia, the rights of children with disabilities was a concept relatively new to society.

On the other hand, some issues correlated with the historical traditions in organisation of child health care may be interpreted in terms of having a positive influence on the issue. For example, in Spain, the discussion on establishment of a *minimum childhood vaccination schedule* was accompanied by the removal of pneumococcal and varicella vaccines, which traditionally were included in the vaccination schedule.

In Netherlands, the socio-cultural background of obesity was discussed in terms of **socio-economic status**, low socioeconomic status, financial debts, low level of education, unemployment, immigrant status or single parent houses are also perceived to be risk factors for childhood obesity.

Migration and changes in traditional family patterns led to the emergence of discourse about **tolerance**. In Finland, where the sexual education curriculum included homosexuality, social attitudes carried weight Finland also reported the issue of asylum seekers, particularly unaccompanied minors as an issue of tolerance. The problem of unaccompanied asylum seekers (UASC) was also discussed in the United Kingdom: *“While there is clear concern for the wellbeing of these children, the current political climate is less favourable toward immigration - captured by the anti-immigrant rhetoric spouted by pro-Brexit campaigners in the UK and the growth for far-right parties across Europe. Since Brexit, there has been an increase in the reported number of hate crimes suggesting that there is an anti-immigrant sentiment within the UK which is not positive for those who are advocating for greater care for UASCs”*.

### **Structural determinants**

Among the determinants of child health care and policy some were structural determinants, in other words, they refer to the interrelated components of the system organisation. As our research focuses on the child health the health care system, relationships with other systemic elements are crucial. Thus we created two groups – internal determinants that relate to the structure of health care and policy, and external determinants that relate to indirect influences on health care and policy.

### **Internal structural determinants**

These comprised important elements such as access to care and provision of care. The cases identified by the MOCHA Country Agents highlighted issues of organisational culture, workforce and organisational functioning of the system.

**Access to care as** a contextual determinant of child health care and policy was seen in the case reported by Norway, where a ten-month-old boy died on the way to a central hospital in an air ambulance. He was unable to be treated near to where he lived in the North of Norway; no air ambulance was available when needed, and life-saving equipment on the air ambulance failed. The public concern in terms of access to specialist care and medication was raised in Iceland, where the problem of over-medicalization for ADHD was raised. Contextually, the issue was linked with *“good access to child psychiatrists and gradually improved access within secondary primary healthcare to diagnostic services for ADHD, including psychologists”*. In Greece, local controversy was related to concerns raised by the medical profession about child mental health and was largely related to the hardship of economic situation. In contrast to the case in Iceland, in Greece the problem of access to care was *“linked to health reform and austerity measures, which have reduced the number of available services, the amount of state subsidy for these services, the number of professionals such as special education assistants, “shadow” teachers etc.”*.

In Latvia, concern about high maternal and perinatal mortality was linked with to issues of accessibility of healthcare, regional restructuring of perinatal care and a lack of health care professionals, particularly in rural areas.

The issues of access to care are related to those of **provision of care**. Public and professional concern in Estonia was raised after it emerged that in the development plan proposal of the Estonian Health Insurance Fund for 2017-2020, did not include the provision of paediatric services in county hospitals for cost reduction purposes; meaning paediatric services would only be available in major Estonian hospitals. The contextual baseline for the Finnish health care system reform was also linked to a debate about limiting access to services. The proposal was to merge the current 300 municipalities (who are currently in charge of health and social care provision) into 18 regions.

Restructuring of services was also the source of the discontent in Ireland about the changes of eligibility for Discretionary Medical Cards. In Ireland, decision-making about services was centralised, and discussion about the Discretionary Medical Cards was linked with centralisation of a process to determine eligibility for free health care (and) led to significant public debate about how the State should support children with complex or long-term healthcare needs.

Data collected from the MOCHA Country Agents also underline the importance of **workforce**. In the Czech Republic, the debate about modification of the proposed system of post-graduate care for medical doctors was strongly linked to the large number of paediatricians in the country; with the high proportion of doctors aged 55-75 years; the risk of a drain of healthcare professionals to other countries; and the debate on income of medical professionals. In Latvia, the problem of workforce shortages was stressed as important factor in the high maternal and perinatal mortality rates. During the nursing strike in the Child Health Centre in Warsaw, the largest specialist children's hospital in Poland, the workforce demands were strongly highlighted. The context of the case referred to two associated arguments: the insufficient number of medical personnel and the low wages of Polish nurses.

This case introduced another contextual factor which was coded as the lack of organisational culture as a symptom of **organisational dysfunctionality of the system**. In the Romanian case, the deficit of such was explained by weak leadership, which did not maintain technical equipment adequately. This was accompanied by lack of respect for safety procedures, including shortages of appropriate equipment. Additionally, *“the medical leadership did not stand up against the political ruling which aggravated the medical personnel shortage so much that it clearly endangered patients’ lives”*. This situation brought about the discussion about the capability of the Romanian emergency system to respond to emergencies in terms of basic equipment, workforce issues, and the presence of inappropriate procedures and protocols. Overall inefficiency of the health system was to some extent evident in the case of the striking Polish nurses. The strike began in a hospital for specialised, difficult cases – and soon became national debate. It arose because of funding procedures, which prevented managers from raising wages or hiring new staff – the problems arose from years of neglect and lack of reform in the Polish health services.

### **External structural determinants**

Indirect factors also have an influence on health policy decisions and resulting change in primary care services for children. The external structural determinants identified in this exercise are factors on macro level which influence how problems are solved and issues negotiated area of child primary health care. These data reveal strong determinants in the form of the economy and finances as well as policy and politics.

Child health issues are contextually influenced by **political initiatives**. In Estonia, the formulation of a new government affected the discussion on mandatory vaccination and its potential links with national family benefits. The political debates accompanied the public discussion on health care on unaccompanied asylum seekers in Finland and the United Kingdom. Direct political involvement with child health issues was observed in cases linked to globally prioritised issues; for example Malta's concern with childhood obesity. Conversely, a lack of political awareness of the challenges facing disabled children was a feature of the protest in Poland.

The level of political awareness is expressed by the initiatives undertaken at the **policy** level. This may be expressed by implemented legal solutions, such as the reduction of children's exposure to passive smoking was addressed by a formal document and the promise to increase the price of cigarettes and make them harder to obtain. The Polish government also introduced an Act on food safety and nutrition to tackle the problem of childhood obesity. Changes in law can also stimulate protest, as was seen in Croatia, where parents claimed laws were changed to their disadvantage. .

We also observed the important impact of **economic** and **financial factors**, which often mutually intensified the effects of each other. Austerity policies in Greece or Spain were the consequence of economic crisis. These impacted heavily on those in lower socioeconomic classes. Greece reported that unemployment was causing intense social problems that had a direct impact on children. In Spain, the introduction of a new vaccination scheme was seen as evidence of priority given to public spending cuts rather than to child public health, cuts which directly led to an increase in child poverty levels. Spending cuts to healthcare as a result of financial and economic difficulties was also reported as determinants affecting child health policy in Portugal, Romania and Ireland.

### **International determinants**

Membership of European regional and global organisations facilitates diffusion of information, and obligates respect of shared values and commonly agreed rules. As such, they have a not insignificant impact on child health policy and care.

Globally published **evidence** may be data that is, not available nationally, but which illuminates the existence of a problem. International comparison drives discussions and resolutions to problems. . Many countries stressed the importance of global reports and comparison studies, such as the Health Behaviour in School-Aged Children (HBSC) ([www.hbsc.org](http://www.hbsc.org)) study or World Health Organisation analyses, as important sources of information which provoked or supported national discussions on important topics such as childhood obesity. The importance of evidence in planning child health policy and care was observed, while many national and international initiatives and debated were supported by locally published data and statistics.

The existence of global and national reports correlates with the **cross-nationality** of many issues of child health policy and care. Issues such as obesity, vaccination, child abuse or care for migrant children are not contained within a country's border but connected to global changes of lifestyle, increased self-awareness of health and increased awareness of children rights. This has been linked with the institutionalization of child care and shifts in European normative systems. Often such cross-national comparison resulted in exchange of views and ideas and learning from the experiences of other countries in order to build their own reality.

The development of regional integration organisations, which encourage voluntary renunciation of autonomy in some areas, requires regional harmonisation and unification. The need to adapt European rules at a national level stimulated debate the Czech Republic about

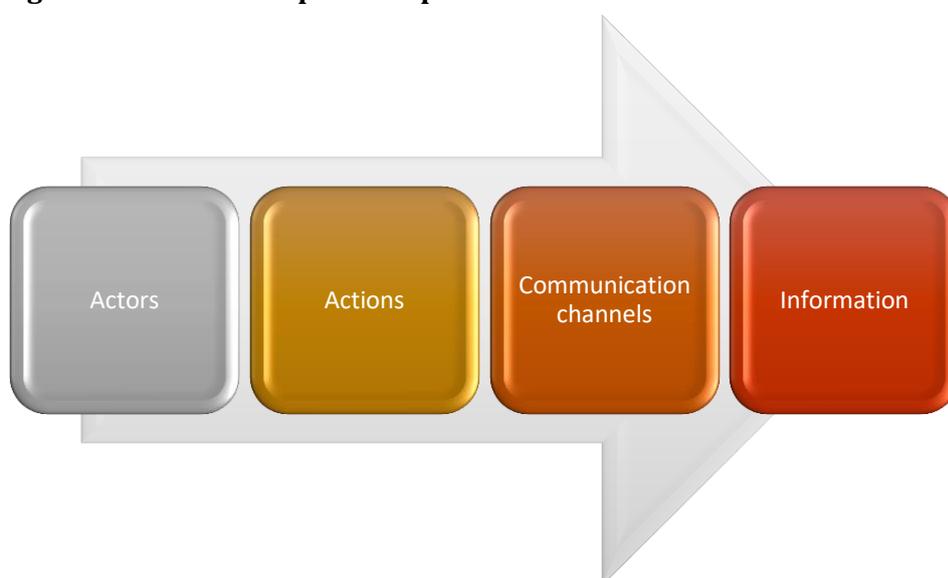
changes in the organisation of child and adolescent health care. European legislation was adapted by the Latvian government to reduce children's exposure to passive smoking Croatia, as one of signatories of the UN Convention on the Rights of Persons with Disability in 2007, was obligated to respect its rules. This led to the frequent citing of the UN convention once rights of children and carers were changed to their disadvantage in the country. Other global processes and movements which affected national discussions involved the global economic crisis. This influenced the functioning of child health care and policy in most European countries. Spain, Portugal, Greece, Malta and Ireland, in particular, struggled with the problem of child poverty and homelessness. The global humanitarian crisis and the plight of unaccompanied asylum-seekers was identified by the UK and Finland as an influential issue. In addition, the situation of migrant families has worsened in also in countries affected by the economic crisis. Globalisation has also contributed to diagnosis and treatment options, in particular, medication. In Iceland, it has been credited with facilitating the gradual increase in the use of methylphenidate for ADHD. Globalisation and global advertising strategies were seen as causes of poor mental health in Germany, in terms of the use of digital media and a potential negative impact on children and adolescents.

### **Vehicle of public expression**

The means by which the public express their dismay or support of an initiative or system change can also support or hinder the process of policy development. In addition, public expression can also stimulate change – without debate as to the intended (or unintended consequences of the resulting action).

Public expression can take place by the actors directly involved. Others have expressed their opinions through actions – such as a strike as in the case of the nurses in Poland. The means of communication is changing. Although professional groups and official media outlets still have a large influence, new means of communication – particularly social media, are fast becoming powerful in their ability to gather support for a campaign. Information, also, is becoming more readily available, whether this is via official data available on government internet sites, or through social media or other channels. As a result, the public opinion and trends are becoming an increasing influence on decisions about health systems. This is shown in Figure 37.

**Figure 37: Vehicles of public expression**



## Conclusion

The importance of context in the process of child health policy making is more significant than ever. Changes within the last two decades, such as proliferation of actors; the reconfiguration of the actors' power; and new context of health has caused a shift from **health governance** to **governance for health**. This process has also shed new light on the factors which influence child health policy-making.

The determinants described by this chapter have a regulatory function towards child health care and policy, in that they stimulate public action, which often is a reaction to public discontent. Multiple societal voices are more frequent participators in the process of child health policy making; and as a result have led to the implementation and/or introduction of new procedures, actions plans and guidelines; influenced the level of awareness, intensified scrutiny, increased access and availability of services, provoked introduction of structural changes or withdrawn unfavourable changes. In conclusion, cultural context has a broad institutional impact.

## Acknowledgements

Acknowledgement is paid to the Country Agents of the MOCHA project as identified on the project website (<http://www.childhealthservicemodels.eu/partners/>). Their contributions ensured that the findings of this report are based on detailed and local indigenous knowledge. Text in *italic font* refers directly to Country Agent comments.

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## Chapter 8

### Incentives, penalties and societal effects

Helen Wells

This work has a strong linkage to equity issues, as models use forms of compliance that may inadvertently penalise groups of disadvantaged and vulnerable individuals.

#### Main findings

- Levers are ways in which providers and recipients of health services are persuaded to act in particular ways, which contribute to the notion of 'common good'.
- The most common form of leverage is financial – applying both to provider and recipient (parent as responsible for the child)
- Levers are used in almost all countries of the EU, yet there is very little evaluation of their effectiveness or perverse effects, and evaluations that exist are generally focused on economic measures of success and failure, not health and wellbeing outcomes.
- Incentives for vaccination and take up of preventive care in pregnancy and early years were amongst the commonest schemes
- Non-monetary incentives are rare and designed to increase engagement with health care services
- In some cases disincentives as penalties exist to support improved vaccination rates or eligibility for childcare
- The majority of Country Agent answers that reported levers were part of a mixed system of delivery. As such, it was not possible to identify a purely incentivised method of delivery, but to observe a range of incentives being available to increase the level of provision of certain key deliverables in each country context. This makes it difficult to identify confidently the effects of incentives (or indeed penalties) where outcomes driven by levers cannot be satisfactorily disaggregated from outcomes produced through other means.
- Levers are based on assumptions that are themselves uncertain in validity and strength – including that financial incentives will motivate behavioural change; that such behavioural change will deliver improvements in health; and that policy makers can distinguish between those aspects of clinical activity that would benefit from financial incentives, and those that would be affected adversely.
- There is little documented evidence of the “human” effects of manipulating behaviour in desired directions.

Incentives and penalties seek to exploit short-term thinking to encourage 'good' choices and bring rewards into the more tangible short term future. Levers are used across a range of social contexts where the state seeks to influence behaviour, such as in personal financial incentives that encourage health promoting behaviour (for example, stopping smoking while pregnant). In terms of child health, incentives are directed at the service providers (encouragement to provide vaccinations) or to the child via the behaviour of the parent – such as additional benefits if all health visits are attended; or social security payments dependent on vaccination status. It is an imprecise science, as we know that even short-term benefits can be ignored or rejected as a 'price' to pay for continuing with unhealthy but enjoyable behaviour.” (1). There may also be unintended adverse outcomes, even of an otherwise successful incentive – for

instance, financial incentives awarded to service providers for achieving delivery targets may make it more difficult to recruit practitioners in areas of deprivation as they have to work harder for the same income; financial penalties may hit hardest families already under stress such as single parent families, those with a chronically ill member, or those with low paid jobs who need to work long hours.

## Methods

In order to establish what levers are in use that are related to child primary health care models in the EU and EEA, the MOCHA Country Agents (See Introduction) were asked to provide examples of levers in their country, that were related to primary health care for children. This was done by sending out a semi-structured questionnaire, in which the Country Agents were asked to list the incentives and penalties in their country; and to specify any evaluations that had been conducted on the use of incentives and penalties within schemes specifically.

A range of levers were identified by the MOCHA Country Agents. These were analysed in terms of the type of lever described, whether they were focused on the provider or the recipients of health care.

They were also assessed in terms of the evaluation of effectiveness of the levers.

## Validation and Triangulation

A range of levers were identified by the MOCHA Country Agents (CAs) as being in operation across Europe<sup>2</sup>. This mapping of levers, penalties and incentives has to our knowledge, never been carried out before, and gives a picture of the sometimes 'hidden' influences on health behaviour and on health systems functioning.

Responses were not received from all countries, and some responding CAs submitted very brief returns that indicated only that no such schemes were in operation in their country. The various lever types were explored in the context of the wider literature on each form of lever.

- The most common form of leverage was financial leverage (applying to either provider or recipient)
- To a lesser extent, access (to various services) was controlled by the state (and variously represented) to secure desired outcomes
- In a minority of cases, goods were offered in exchange for compliant behaviour.

The most notable finding was that evaluations of these types of incentives were broadly non-existent. Where evaluations were noted, these had been outcome- or process-based and therefore adopted more simplistic measures of success and failure which were largely measured in financial or uptake terms and were almost exclusively quantitative.

The majority of Country Agent answers that reported levers were part of a mixed system of child primary care delivery. As such, it was not possible to identify a purely incentivised method of delivery, but to observe a range of incentives being available to increase the level of provision of certain key deliverables *in each country context*. This makes it difficult to identify confidently the effects of incentives (or indeed penalties) where outcomes driven by levers cannot be satisfactorily disaggregated from outcomes produced through other means.

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<sup>2</sup> A total of 22 countries responded to the questions sent out in round 5.

### **Incentives for providers**

- **Payment for performance (P4P)** incentive approaches were in evidence in Croatia, Estonia, Latvia, Lithuania, Portugal, Spain and the UK. Whilst Dutch primary care physicians receive 10 Euros per flu vaccination administered to adults, this incentive does not apply to children. The use of incentives for healthcare providers in Slovakia ceased in 2012, and payment dependent on career specialisation was in evidence in the Czech Republic.
- **Financial incentives for minimum levels of preventive actions.** Incentives for vaccination of children appear reasonably common and, along with the UK example of incentives for healthcare providers who successfully reduce smoking and increase breastfeeding in their target populations, are examples of incentives that rely on the healthcare provider's ability to bring about a change in behaviour in another person. This adds another layer of complexity to the idea of levers, where one person's benefit is dependent on the behaviour of another.
- **Other incentives:** In Austria, incentives such as training opportunities, free workshops, free consulting offers, and access to network meetings have been offered to Kindergartens that participate in *Netzwerk Gesunder Kindergarten Oö* (Healthy Network Kindergarten Upper Austria). Countries that require vaccination of children for access to childcare similarly exploit parents' need for childcare as an indirect lever to obtain healthcare goals.

### **Sanctions for providers**

- Most of the responding countries reported some sort of sanctioning system operating in respect of healthcare, though many were reported as being in place to respond to instances of malpractice and substandard care.
- In Croatia penalties can be given for failing to provide services (preventative, diagnostic, curative to referred persons), though these sanctions were reported as being rarely used. Romanian providers are penalised for failings in delivery or instances of mis-prescribing by the withholding of payments (not, seemingly, incentives) and through reduced promotion prospects and denied access to training courses. It is possible to see all the examples of P4P, above, as examples of financial sanctions when bonuses are withheld, and this is particularly likely to be the interpretation where basic payment amounts are deemed insufficient for general operation. In such situations, the additional funds may not be seen as an optional extra (a genuine 'bonus') but as a necessity. The Latvian and Spanish responses characterised the P4P as an example of a financial penalty, as well as an incentive, for example.

### **Incentives for recipients**

Although such considerations introduce considerable complication, levers from the user perspective target the rationality of an adult for the indirect benefit of a child.

A range of incentives for recipients of healthcare services were identified by Country Agents. Most of the incentives offered related to the behaviour of the parent or guardian in relation to their child's health. As such the child's body was the means for achieving the incentive (or avoiding the penalty) but the decision about what happened to the child was that of the parent or guardian. The term 'recipient' therefore generally refers here to the adult actor in what is

actually a triadic relationship between parent, child, and provider. In a very small number of cases the child themselves was the target of the incentive.

- **Free healthcare for children:** Free provision is arguably the most significant financial incentive operating in relation to child health – or, alternatively it could be viewed as the removal of the financial penalty of paying for access, depending on perspective; or just part of normal service provision. When provided free of charge, child healthcare need not come at the expense of another choice - to eat, or pay rent for example, or to forego luxuries. Free healthcare, generally provided by a national insurance system, was reported as an ‘incentive’ in Estonia, Latvia, Finland, and the Netherlands. In Lithuania various healthcare and preventative programmes are provided for free by Government, whilst in Norway health checks, and health centre services are free for all children. Portuguese children receive free dental checks, consultations, vaccinations, and school health services (with additional free services for children with specific health problems). In many countries (including Cyprus, Ireland, Norway, Portugal, UK) many vaccinations were reported as being free of charge, though other more explicit forms of lever were also commonly applied to this example, such as the penalty of being unable to attend childcare without previous vaccination. Some countries have indicated that free vaccination services are an incentive, but this can only be regarded as such when other services – such as visiting the primary care physician – require a form of payment or co-payment. Where all services are free, vaccinations can be regarded as normal service provision.
- **Financial incentives targeting expectant mothers and new-born children.** Several financial incentive schemes target expectant mothers and those with new born children, including the Austrian ‘mother child passport’ scheme, where obtaining a family allowance is conditional on completion of five medical examinations during pregnancy and five in the first 14 months of a child’s life. In Finland an expectant mother has to attend at least one health check at a maternity clinic prior to the 5<sup>th</sup> month of gestation to receive the Finnish maternity package (*Äitiyspakkaus*). Incentives to encourage breastfeeding are available in Croatia, and (locally) in the UK some pregnant smokers in Scotland have been offered grocery vouchers if they provide smoke-free breath tests at weekly check-ups. In Norway, social media campaigns encourage physical activity, with “gift vouchers” made available for those that demonstrate involvement.
- **Non-monetary incentives.** Some incentives offered have a financial value but are not offered in monetary form. As noted above, the considerable goods (clothes, a sleeping box, toys, a book etc.) available to new parents as part of the Finnish maternity package are conditional upon engagement with healthcare providers at key points of the pregnancy. Plans to introduce a similar scheme (goods for new parents) in Scotland from 2017 will, it is hoped, encourage engagement with healthcare services. In the Netherlands, some health care organisations have operated an ‘Ipad lottery’ for girls who get all three HPV vaccinations.
- **Behavioural incentives.** In some countries, services such as free or low cost of parenting programmes, specialist support groups and homework clubs were made available to parents in disadvantaged communities or to parents of children with certain disabilities (such as language impairment) to encourage participation with the health service. In other countries, childcare or full benefits were only available to children who had been vaccinated. These are in effect incentives to adopt certain behaviours. As with most incentives, the counter-interpretation is that they are denied to those who fail to adopt those behaviours and hence the line between incentives and penalties is once

again blurred. Countries that employed such incentives include Ireland, the Netherlands, the Czech Republic, Hungary, Romania, and Lithuania.

### **Penalties for recipients**

Whilst it is, as noted above, possible to see most incentives as potentially withheld punishment, and withheld incentives as sanctions, there are some examples of overtly penalising practice that relate to parental decisions about their children's health.

- **Fixed penalty or fine/cessation of financial benefits.** The most common example is the fixed penalty or fine for failure to comply with mandatory vaccination programmes. Fines were reported to be issued in the Czech Republic (up to Euro 380), France, and Slovakia (Euro 250) for failing to get a child vaccinated. This is also possible in Croatia, but no sanctions have been issued. In France, social security payments are withheld if the child's healthcare certificate is not up to date. In some cases, French parents are also liable to a potential criminal conviction, or even imprisonment for failing to engage with the mandatory vaccination programme for children, which can be construed as a form of child abuse, as is the case in Hungary.
- **Smoking bans.** Various countries in Europe (and beyond) have banned smoking in cars where children are present in order to reduce the harmful effects of passive smoking to children. Whilst this is not specifically related to child healthcare provision, it represents an interesting example of the creation of an offence (the outlawing of a behaviour) for the sole purpose of achieving a healthcare goal. It also relies upon the involvement of criminal justice actors in the pursuance of public health ends. England and Wales introduced a ban on smoking in vehicles with passengers under the age of 18 in 2015, with a fine of £50 being associated with the offence. Scotland introduced a ban in 2016, which applies to cars carrying children under 18, and attracts a fixed penalty fine of £100. In Cyprus, smoking in cars carrying children under 16 is banned and attracts a fine of Euro 85, whilst in France the age is 12 and the fine is Euro 68. In Italy the fine is up to Euro 650 and the ban applies to cars carrying both children and pregnant women. Malta is scheduled to introduce a ban on smoking cigarettes and e-cigarettes in cars carrying anyone under the age of 18 in 2017, with this offence attracting a fine of Euro 50. In Finland, both tobacco products and e-cigarettes are banned in cars carrying children under 15. A ban is apparently planned in the Netherlands, where smoking in school playgrounds will also become illegal in 2020, and is also proposed in Wales.

### **Effects of incentives and sanctions**

The concept of levers and nudging is uncomfortable, because, as noted by Bodemer, "*nudging* assumes that people's choices must be guided because mental capacity limitations result in decisions that are systematically inferior to the normative standards implied by those who nudge" (2).

We may know what is best in terms of physical health, but a social science perspective is better placed to consider wellbeing more generally, within personal context. The physical patient, or indeed the physical healthcare provider, may know what is best to do, but in the context of being a parent, a worrier, a debtor, a welfare recipient, a colleague, a carer or any other number of equally significant identities, decision-making processes come under pressure. Reviews and evaluations that focus only on easily measurable financial or other quantitative indicators of

effects risk overlooking the qualitative, less easily measured and more subjectively 'human' effects of manipulating behaviour in desired directions.

Much of the published material on models of individual behaviour and change is based on theory rather than practice, and there is little consensus on the elements of successful interventions" (1). Equally, in the provider context, Kringos et al note that "primary care providers' remuneration systems are in almost all European countries topped up by various performance-related financial incentives to influence physician behaviour" (3), and yet, "[e]xisting reviews also reported a lack of evidence on the incidence of unintended consequences of P4P. Despite this, new programs continue to be developed around the world at an accelerated rate. This uninformed course risks producing a suboptimal level of health gain and/or wasting highly needed financial resources." (4). With such approaches "proliferating" according to Van Herck et al. (4), many authors have cautioned that there is only limited evidence about what works in terms of leveraging the behaviour of healthcare providers (1, 5).

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## Chapter 9

### **The Political and constitutional context - A Heuristic Governance Framework for Effective & Good Implementation Planning of Models of Child Primary Health Care**

**Peter Schröder-Bäck Timo Clemens, Kyriakos Martakis, Kinga Zdunek, Helmut Brand**

Given the concepts and insights of Governance for Health, this chapter aims to answer the question: “what political, constitutional and other criteria and factors of governance are relevant for developing and exchanging models of best practice in Child Primary Health Care across Europe?”

“[G]overnance for health is defined as the attempts of governments or other actors to steer communities, countries or groups of countries in the pursuit of health as integral to well-being through both whole-of-government and whole-of-society approaches. It positions health and well-being as key features of what constitutes a successful society and a vibrant economy in the 21st century and grounds policies and approaches in such values as human rights and equity. Governance for health promotes joint action of health and non-health sectors, of public and private actors and of citizens for a common interest. It requires a synergistic set of policies, many of which reside in sectors other than health as well as sectors outside government, which must be supported by structures and mechanisms that enable collaboration. It gives strong legitimacy to health ministers and ministries and to public health agencies, to help them reach out and perform new roles in shaping policies to promote health and well-being.” (1)

#### **Main findings**

- The literature review revealed that no governance concepts exist specific to developing and implementing child health policy.
- To appraise models of primary care, the different sectors and levels of governance must be taken into account. These vary from country to country – and even from region to region.
- Multilevel and inter-sectoral governance offer a helpful two dimensional framework for research, policy analysis and policy development. These governance concepts help to understand what actors and institutions are of relevance for developing child-centric health care approaches within healthcare but also outside healthcare (such as in the education sector). A third dimension is added with the leading values for good governance.
- Non-state actors work alongside the standard health care actors, which are often public or semi-public. Lobbyists, civil society, NGOs and so on play an important role in governance, and are fundamental elements of context in which models of child primary care are developed and implemented.
- Multi-level Governance as a concept is useful to understand the networks and interactions in which decisions and implementations take place; particularly in an inter-sectoral perspective for a model of primary child health care which is seeking to address current and future child health needs
- Recognising the **Good, Intersectoral, Multisectoral (GIM)**-governance framework including stressing the normative element of governance – what values contribute to the

concept of “good governance” – is likely to facilitate the spread and implementation of good practices of child-centric health policy approaches across different governance models in the EU, as the variety of relevant stakeholders and institutions can better be mapped and taken into account

## **Methods**

This explorative section offers a framework on governance that has a heuristic value for further analyses, developments and implementations of child primary health care practices – it should be clarified at this point that Governance at the policy level is different from Clinical Governance of care delivery, or Organisational Governance of delivery bodies. Methodologically this section is built on a literature research and review on concepts and keywords from approaches of Intersectoral Governance (IG), Multilevel Governance (MLG), Health System Governance (HSG) in the context of (Child Primary) Health, knowledge on governance and child primary health care in European Primary Care. The concepts of IG, MLG & HSG were the areas of focus, rather than on other conceptions like smart governance, hierarchical governance, vertical governance, networked governance (2) or micro-meso-macro governance (3) so as to stay more relevant to the task of identifying the current models of primary care for children and the issues that surround them.

The literature was searched and reviewed using PubMed, Scholar, Google and snowball sampling. There was no limitation to the publication with regard to year of publication or type of paper. Only articles in English language were taken into account. The main relevant findings are presented according to the key concepts identified. The Dimensions of governance were first listed, and then assessed by the author to allow the construction of a concise framework.

Case studies on injury prevention have been used as exemplars of the dimensions of governance. Child primary care is an important core element of child safety, and treatment of injury, and as such is a pertinent case study for use in MOCHA. The use of such case studies is important to illustrate and apply the framework of governance developed in MOCHA.

## **Triangulation and Validation**

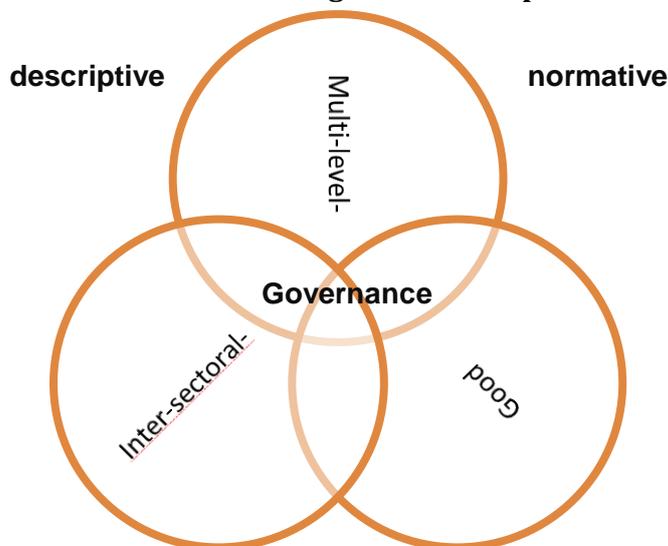
Understanding concepts of governance is essential for the MOCHA project to move towards effective, and realistic, appraisal of the models of child primary health care in Europe. This work makes explicit the elements that form notions of governance, and shows how governance is likely to influence child primary health care policy and models. The identification of the processes and actors in the governance of health systems allows us to identify the influences and pathways of change. This, combined with our research into cultural influences (See Chapter 7) and the intended and unintended effects of elements of governance in the form of levers and nudges (See Chapter 8) gives us a strong baseline for the future work in MOCHA. This work contributes to the model by which the appraisal and true understanding of the context of child primary health care can take place.

### **Key concepts of governance**

Governance is a complex notion. Even though there is consensus as to its importance, understanding of what governance means and consists of can change according to different cultures and nations. We have identified certain key concepts that contribute to governance.

- The literature suggests that there is overlap between many of the aspects and criteria related to governance. In terms of governance of policy and health care, some elements are decentralised – this means that the authority of governance is dispersed to different levels (supra-national, national, or regional for example) (multi-level governance). This dispersal goes on to reflect governance in other sectors, all of which contribute to the determinants of child health (= intersectoral governance).
- Values are an important element of governance. However, these are mentioned in different contexts, and may have different meanings. The dimension of ‘good governance’ is both descriptive, for example, in terms of mapping who decision-makers are and what are the values that decision-making do follow; and normative, in the sense of prescribing norms and values decision makers should follow .
- Previous work has shown that for primary care governance, these different aspects of governance are all relevant. Furthermore, they can overlap – as one identifies the actors e.g. in intersectoral governance as to what sectors they belong to but also in multi-level governance and in good governance. This is shown in Figure 38.

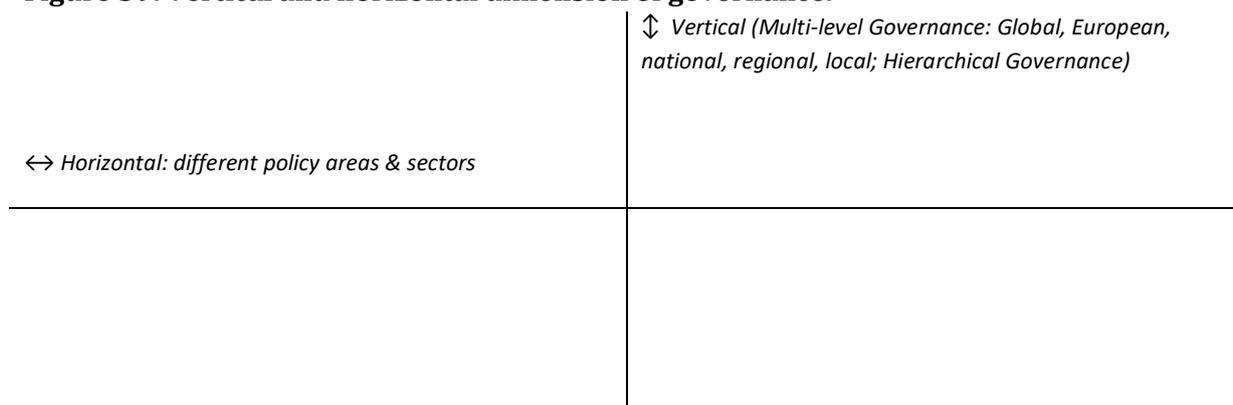
**Figure 38: Commonalities in governance aspects**



### **Dimensions of Governance**

Multi-level governance and intersectoral governance together offer a two-dimensional framework, which has been described by Kickbusch and Gleicher (1) as horizontal and vertical. This can be visualised in a two-dimensional matrix to which we add the related model of “hierarchical governance” as used by Kuhlmann and Larsen (4), shown in Figure 39. Further aspects of governance (and good governance / policy capacity and so on), however, need to be integrated to create a more comprehensive framework of governance and how it relates to child primary health care services.

**Figure 39. Vertical and horizontal dimension of governance.**



### Governance and primary care

In addition to the different aspects and criteria of governance in general, it remains to be seen how governance plays a role in primary care. The decentralisation of governance to regional and local authorities (5) means that decision-making and operational governance takes place at different, subnational levels. Multi-level governance (MLG) is thus a relevant point of interest. Other aspects of Primary Care Governance or Governance of the Primary Care System (PCG) encompass professional standards, clinical guidelines and even patient rights (5). Kringos et al. (6) found *eight features of Primary care Governance* that refer to the structure, process and outcome of the primary care system. These aspects reflect the dimensions of governance previously discussed, as summarised in Table 15.

**Table 15: Features of Primary Care Governance following Kringos et al (6) and their correspondence to other general governance approaches.**

Features of Primary Care Governance (6)	Correspondence to Governance Concepts
Health (care) goals	e.g.: Transparency (7)
Policy on equity in access to primary care service	e.g.: Equity (Council of the European Union 2006)
(De)centralization of primary care management and service development	e.g. MLG
Quality management infrastructure in primary care	e.g.: Quality (8)
Appropriate technology in primary care	e.g.: Quality (8)
Patient advocacy	e.g. Participation of affected interests (7)
Ownership status of primary care practices	e.g.: Accountability, Transparency (7)
Integration of primary care in the health care system	e.g.: Quality (8), intersectoral and multilevel governance

### The Actors in Multi-Level Governance

Governance relies on the actors that implement health models. In any health system there are a multitude of actors and policies that exist in different levels of governance. Each participant acts in different levels of governance, and makes different connections and relationships with each other depending on the external context. These connections may take the form of advising, assessing, cooperating, educating, enforcing, financing/funding, informing, monitoring, and recommending among others. They can also be associated in different ways, such as a linear

connection where one actor gives advice to the other, but also may associate in a collaborative way (9). This combines to create the overall governance. Table 16 gives an example of the actors and policies in terms of multi-level governance. Other dimensions of governance, such as values and specific sectors will have a similar variety of actors and policies.

**Table 16. Example of actors and policies / decisions on different levels in multi-level governance of child safety**

<i>Level</i>	<i>Public / State Actors [main relations / connections to other actors]</i>	<i>Non-State Actors / Private [main relations / connections to other actors]</i>
<b>Global</b>	<ul style="list-style-type: none"> <li>UN (e.g. MDGs, Sustainable Development Goals) [<i>advising, setting targets</i>]</li> <li>UNICEF [<i>advising, setting targets</i>]</li> <li>UNESCO [<i>advising, setting targets</i>]</li> <li>WHO (e.g. Department of Maternal, Newborn, Child, and Adolescent Health; policies like: Declaration of Alma Ata, Ottawa Charter for Health Promotion, FCTC; programmes such as: The WHO Child Growth Standards, Global Plan of Action for Children's Health and the Environment) [<i>advising, informing</i>]</li> </ul>	<ul style="list-style-type: none"> <li>Professional Associations (e.g. World Medical Association) [<i>guiding</i>]</li> <li>Clowns without borders [<i>providing service</i>]</li> <li>NGOs: Red Cross / Red Cressent [<i>providing service</i>]</li> </ul>
<b>European</b>	<ul style="list-style-type: none"> <li>EU (e.g. Common Values for Health Systems; Horizon2020) [<i>regulating, financing, agenda setting</i>]</li> <li>Council of Europe (e.g. policies: European Social Charter) [<i>advising, setting targets</i>]</li> <li>WHO-EUROPE (e.g.: Investing in children: the European child and adolescent health strategy 2015–2020, European Vaccine Action Plan 2015–2020) [<i>advising, informing</i>]</li> </ul>	<ul style="list-style-type: none"> <li>NGOs (e.g. patient / consumer / children advocates, ...e.g.: EACH – European Association of Children in Hospitals) [<i>advising, lobbying</i>]</li> <li>Professional Associations (physician specialists, nurses, ...e.g.: European Medical Association) [<i>advising, educating, ...</i>]</li> </ul>
<b>National</b>	<ul style="list-style-type: none"> <li>National Ministries (Health etc. – see different sectors) [<i>regulating, implementing, enforcing</i>]</li> <li>National Health System (NHS organisations) [<i>providing, financing, ...</i>]</li> <li>National Public Health Institutes (e.g. NICE, RIVM, ...) [<i>advising, assessing</i>]</li> <li>WHO country office [<i>advising</i>], WHO collaborative centres [<i>researching</i>]</li> </ul>	<ul style="list-style-type: none"> <li>Insurances [<i>financing</i>]</li> <li>Professional Associations (physician specialists, nurses, ... e.g.: National Medical Associations) [<i>advising, educating, ...</i>]</li> <li>Pharmaceutical companies [<i>providing, financing, ...</i>]</li> <li>NGOs (e.g. patient / consumer / children advocates, ...) [<i>advising, lobbying</i>]</li> </ul>
<b>Subnational / regional</b>	<ul style="list-style-type: none"> <li>Regional Ministries (Health etc.) [<i>regulating, implementing, enforcing, financing</i>]</li> </ul>	<ul style="list-style-type: none"> <li>Regional Professional Associations (e.g. Paediatric Society of Northern Greece PEVE) [<i>guiding</i>]</li> </ul>
<b>Local</b>	<ul style="list-style-type: none"> <li>Local governments [<i>implementing, financing, ...</i>]</li> <li>Public Health Service [<i>delivering service, </i>]</li> <li>Public hospitals, outpatient / inpatient health care units [<i>delivering service, </i>]</li> <li>Institutes of Social Paediatrics [<i>delivering service</i>]</li> <li>(Public) Schools [<i>educating</i>]</li> </ul>	<ul style="list-style-type: none"> <li>Private hospitals, outpatient / inpatient health care units [<i>delivering service,</i>]</li> <li>NGOs (e.g. local Red Cross, local civic associations) [<i>advising, lobbying</i>]</li> <li>GPs, Paediatricians, other health professions (physiotherapy, occupational therapy, ...) [<i>delivering service,</i>]</li> <li>(Private) Schools [<i>educating</i> ]</li> </ul>

Table 16 showed the overview of sectors for child safety. As child primary care is an important core element of child safety and injury care, the list of actors and policies is pertinent and

relevant to MOCHA. Further specification of the actors in terms of primary health care for children is shown in Table 17, based on Scholtes et al. (10):

**Table 17: Sectors relevant for Child Primary Health Care Services (Based on: 10)**

Sector name	Sub-sectors included within each sector
Advocacy	Advocacy organisations
Communications	Telecom, internet, IT, web security
Community Development	Community and neighbourhood organisations, economic development (infrastructure, rural development programmes), town planning
Education	Primary, secondary, tertiary education, vocational training, adult and continuing education, driving instruction
Emergency services	Ambulance, fire service, coast guard, life guard, lifeboats
Environment	Environmental preservation, pollution control and prevention, natural resource conservation, environmental preservation, parks, open spaces
Food and drink industry	Restaurants, bars, cafés
Health	Primary, secondary and tertiary care, rehabilitation, mental health, crisis intervention (includes suicide prevention), public health, patient organisations
Insurance	Health insurance, care insurance
Media	Production and dissemination of information: Social Media /Networks, television, newspapers, magazines, radio
Recreation	Sport, playgrounds
Research	Universities, research institutes
Social/welfare services	Surveillance, social security, child welfare, child services, day-care, youth services, youth welfare, (youth clubs, delinquency/drop out prevention) family services (parenting courses, family violence shelter), services for disabled, services for elderly, children’s ombudsman

### **Adding the Normative Dimension**

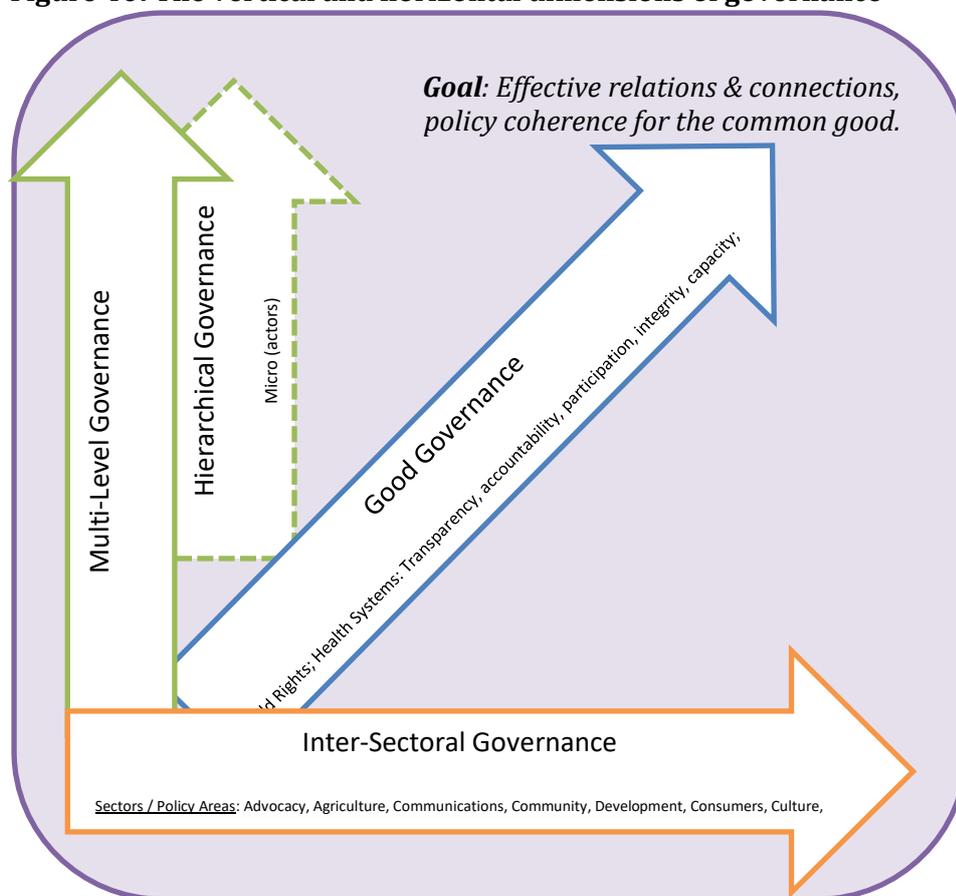
In most definitions of governance – especially the ones talking of *good* governance – values were reflected in addition to other aspects of governance, such as “equity” in the context of primary care. The values of health systems and the EU health (care) systems present values that should be considered in accounts of CPHC governance. As mentioned above, many of the values overlap. Thus, we would like to focus particularly on the formulation of the relevant values for good governance as they were formulated particularly in the Health Systems Governance approach (7), namely: Transparency, accountability, participation, integrity, capacity. And add the specific European Union healthcare system values: Solidarity, equity, universality, access to good quality of care (8); and the child rights based approach, the goal of which is to embed children’s rights in the health care system to ensure that the right things happen, to the right children, at the right time, in the right place, and using the right staff having the right support, to achieve the right outcomes, all at the right cost (8).

### **Visualising the “Good, Intersectoral, Multisectoral Governance” framework**

To summarise the discussion of a framework, we visualise these three dimensions of the Good, Intesrectoral, Multisectoral (GIM) Governance framework that we regard as applicable for child

primary health care. Figure 40 integrates the vertical dimensions and horizontal dimensions of governance, and as a third dimension the values. This “third dimension” clarifies its relevance to the other dimensions. The literature shows a general lack of awareness of relations and connections for effective implementation of evidence-based policies and interventions. Thus, this model reminds us that effective and coherent connections of the various dimensions are extremely important. A goal of governance was said to be the “*common good*” and this is included as a feature of the GIM framework.

**Figure 40: The vertical and horizontal dimensions of governance**



### **Applying the governance framework to case studies**

In order to illustrate and apply the MOCHA governance framework, we have used case studies from injury prevention. These show actors and how they relate to each other in the context of decision making in child primary health care interventions; and implementing them. The case studies show the “levels” to which the actors belong, and whether there is involvement from sectors other than health care. In addition, the values at stake are illustrated.

### **Health care counselling on unintentional child injury**

This case study draws upon a report about how health care counselling on unintentional child injury in maternity and child health clinics in Finland was established (9). The case study shows an inequity across the country, despite national legislation establishing clinics and availability of child health care throughout Finland. Despite national guidelines, the organisation of services on an independent, municipal level does not provide universal and equal access to all citizens. As a result of this inequity, further guidelines have been implemented in cooperation with

national and regional and local level actors from the health care sector. A supervisory national level institute is monitoring the quality and enforces the implementation. Table 18 shows how the different levels of governance in health care must cooperate in order for effective and universal injury prevention to take place.

**Table 18: Health care counselling on child injury prevention in Finland (9).**

	<i>Good</i>	<i>Inter-sectoral</i>	<i>ML / Hierarchical</i>
<i>Legal Background</i>			National Laws establish these clinics  Municipalities independently organise services.
<i>Availability of services</i>	Inequalities in service provisions was a problem.  Universality of services was strived for.		Varied by regions.  To counter inequalities: national ministry of health issues guidelines.  Universality across the country was strived for.  Manuals for all professionals within the country were established.  Further guidelines were developed on national level together with regional authorities.

***Prevention of burns to children in Norway***

The second case study describes an intervention established in Harstad, Norway, which aimed to prevent burns in children. The health care sector (in particular the local hospital) initiated the intervention, and it was aimed at parents and local vendors of cooking stoves. Parents were counselled about installing safety measures, and vendors were asked to sell security shields for stoves; the intervention was supported by the local media (9, 11) Table 19 describes the case study, and shows how cooperation between the different actors, including NGOs, was helpful in reaching the parents and vendors. In essence, it shows the importance of identifying the (potential) actors in advance of such an intervention, and their connection in the form of cooperation, educating and financing is important.

**Table 19: Children’s burns prevention (9)**

	<i>Good</i>	<i>Inter-sectoral</i>	<i>ML / Hierarchical</i>
<i>Funding</i>			National Ministry of Health funded this local initiative.
<i>Implementation</i>	Equity (special focus on immigrants).	NGOs (Red Cross, Women’s organisation), local media, vendors cooperated to implement safety measures	Local level.

**HPV vaccination programmes in Europe**

Elfström et al. (12) researched the organisation of HPV vaccination programmes in Europe in order to . They wanted to establish how the programmes are implemented in different countries; and if and how values such as quality and effectiveness play a role. This large study presented data from 27 countries. However, it was unclear at which level the contact persons were acting. The contact persons answered questionnaires, and were also actors within the governance of the HPV programmes. In the main, respondents came from the health and research sector. As a result, the study remains – despite some hints on regional and district variety – relatively blind in terms of Intersectoral and MLG; despite the fact that different levels of governance other than the national viewpoint are extremely relevant to immunisation and health organisations. Values are mentioned in their study design and also in their results, however, given the additional possibility of immunising boys, many more values and value conflicts are at stake than are (and can be) described and discussed in such a paper.

Elfström et al. implicitly refer to some of the aspects of the GIM Governance. However, to better understand the organisation of the HPV programmes, a systematic use of the GIM Governance framework would help to better understand the interrelations of the different actors and understand the variety in Europe (12). Thus, efforts in different countries would be more comparable, and best practices transferable. Table 20 describes the case study.

**Table 20: Differences in HPV vaccination programmes across Europe – study design and results of Elfström et al. (12) through the lens of GIM Governance. .**

	<i>Good</i>	<i>Inter-sectoral</i>	<i>ML / Hierarchical</i>
<i>Study design of Elfström et al.</i>	Values like quality and effectiveness were drivers of this study	In how far sectorial differences were considered in questionnaire, not clear.  Mainly ministries of health, researchers and programme administrators were contacted.	Vaccines approved by EU.  VENICE study showed heterogeneity of organisation of immunisation programmes: reason to do this study.  European guidelines were considered in designing the questionnaire  Investigate programme organisation but not sure what ministries they contact: national / regional? This might lead to response bias.  Regional diversity within countries was not considered, it seems, in their study design. However, in the results one category is “difference between districts”
<i>Implementation in Europe (Study Results)</i>	Quality, effectiveness, equity.	Health sector (incl. primary care, public health services)  Schools /educational sector (as setting for implementation)  Population registries	European Union guidelines for introduction of HPV vaccination programmes from the ECDC exist.  EMA assesses and approves vaccine, WHO positions towards vaccination  Regional level differences (made explicit for Belgium, Italy and Switzerland).  Differences on district level on vaccine use

## Conclusion

The MOCHA project has identified relevant aspects and values of governance, which can then be applied to different contexts of interventions and implementation in child primary health care. Different examples, such as that of child injury prevention, show the different levels that relevant actors belong to, and if sectors other than health care are involved in governance are at stake. Governance is complex, and this must be taken into account. The MOCHA GIM framework can be used to analyse any number of case studies, and prepares the ground for the implementation of innovative models of child primary health care in Member States.

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## Chapter 10

### Discussion and conclusion

**Mitch Blair, Michael Rigby, Denise Alexander**

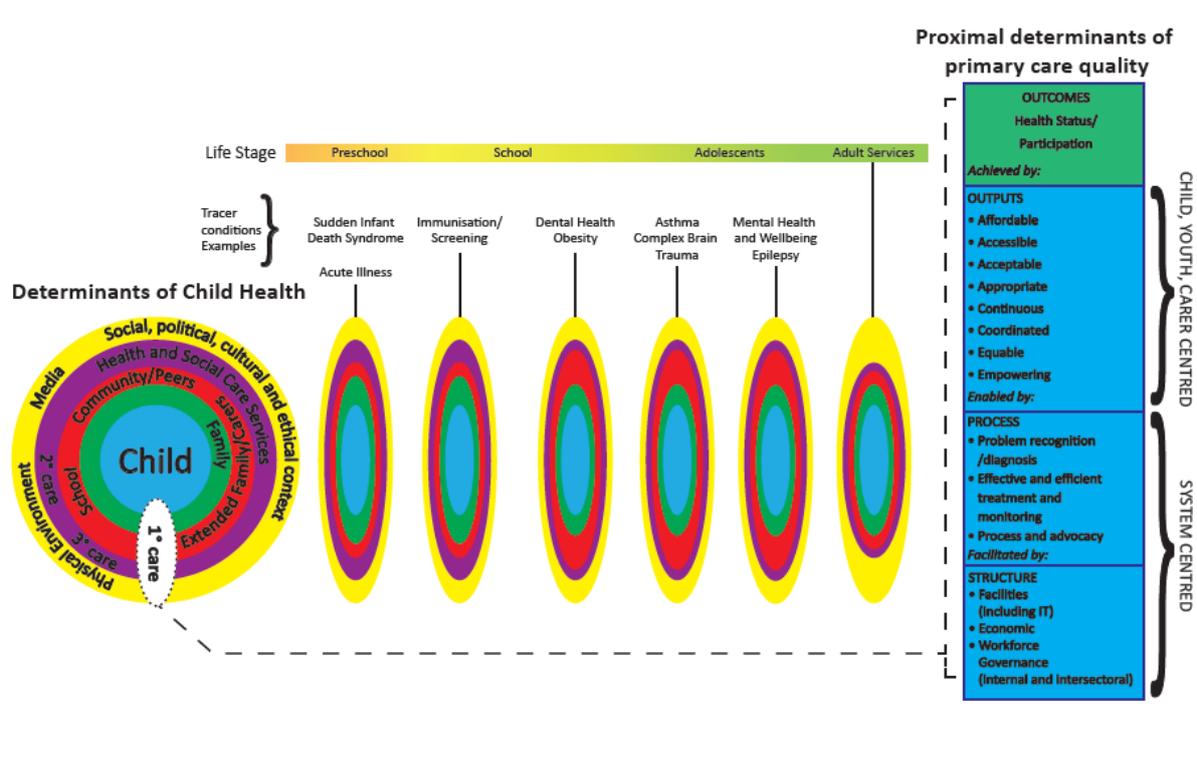
This report demonstrates the complexity of structure and use of primary care for children in Europe. Each chapter approaches the models of primary care from a different perspective. This is essential to reflect the complexity of primary care and to identify the multitude of elements (and confounding factors) that interact within different constructs of primary care systems, and between primary care systems and the health of each individual child.

This work acts as a baseline and framework for MOCHA explorations of 30 European countries, and means of appraising the different interpretations of a model of health that are in place. One of the key aims of MOCHA is to explore how well the various components of the model support optimum outcomes both in terms of child, carer professional and population-based outcome measures. Approaching the investigation from different research and analytic angles using mixed methods allows for triangulation of results, which in turn ensures optimum robustness within the boundaries of the project and appropriate attribution. A number of potential case scenarios/ key clinical conditions have so far been selected to test the various aspects of the models – and the types of scenario will undoubtedly increase as the MOCHA project continues. What has become apparent is that this initial analysis provides a very limited professional-centric conception of typology and other ways of classifying model types need to be developed and tested such as a model of a single practitioner versus a multidisciplinary team; the influence of funding types (insurance versus taxation or mixed), or workforce, skills and competencies based classifications. Responsivity of the model to demand, and appropriateness of provision are important elements in the MOCHA project, reflecting the lifestyle and societal changes and different priorities in healthcare systems that are emerging in the 21<sup>st</sup> century.

#### **Conceptual framework of a model**

The diverse and yet profound influences on children's health and on the role of primary care services as a determinant of health need to be incorporated into a primary care model. The model must accommodate the different needs of a child's life course, and the types of health condition encountered in that journey. This is summed up by the MOCHA conceptual framework, developed as a result of considerable in-project analysis and iteration, as shown in Figure 41.

**Figure 41: The MOCHA Conceptual Framework of a Model**



This model was developed as a result of in depth MOCHA research, analysis and discussion, iteratively over the first year’s work on the MOCHA project. It is broadly based on three theoretical frameworks; Bronfenbrenner’s ecological model of determinants of health (the left hand circle) (2), A modified Kringos model of determinants of quality of primary care (1) (the right hand block) and a lifecourse epidemiological framework of childhood health and disease (the horizontal axis).

The ‘ecological’ circle on the left, which was inspired by the visualisation in the CHILD project (See Introduction), describes the influences on health and health policy decisions. The health services, set within these cultural contexts, influence what is available to schools and to the community in which the health model operates. Within the community setting, a family makes choices and decisions about health based on what is available, knowledge and cultural influences, and finally – potentially influenced by all of these factors is the child. Alternatively, viewed from the inside outwards, it can be seen as the child in the centre, able to influence and make decisions about what is available to him or her in terms of health in the context of the family, who then can influence the needs of the community, school and wider social factors, which in turn affect health services and ultimately, the cultural, media and wider social settings. In practice, both situations occur, in a dynamic process that is constantly in flux.

The variation in the colour scheme over time indicates how the various determinants are weighted for a typical child over time. For example, there is a relatively larger influence of parents and family in the early years, and greater influence of school, peer groups and external influences such as the media, as children grow older. A combination of preventive care, physical and mental health, and short term and longer term conditions have been selected as tracer conditions, examples of which appear in the diagram above the circles. The MOCHA project will extend these, and also balance between long-term conditions, acute conditions, mental health, and the needs of the majority – the generally well child in terms of prevention, pre-disease diagnosis and salutogenic behaviour. In addition to this, the needs of preventive medicine and

improved health literacy are elements of good health in childhood that must be accommodated, as is the important relationship with other services, within the health system for secondary and tertiary care, and externally such as with social care, education and justice among others.

It is likely that further refinement of this framework will be effected to facilitate an effective child, adolescent carer and professional focused appraisal

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