

Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

WP9: Validated Optimal Models of Children's Prevention-Orientated Primary Health Care

Public Priorities for Primary Care for Children

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Public Priorities for Primary Care for Children

A report on public preferences for patient-centred and prevention oriented primary child health care models for children

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Contents

1.	Introduction	7
	Aim of the Project	8
2.	Defining attributes of Quality of Care	9
	2.1 The MOCHA working model	9
	2.2 From Quality Frameworks to Attributes of Quality	10
	2.3 From Attributes of Quality of Primary Care to Definition of Outputs	14
	2.3.1 Affordable	14
	2.3.2 Accessible	14
	2.3.3 Acceptable	15
	2.3.4 Appropriate	16
	2.3.5 Continuous	16
	2.3.6 Coordinated	17
	2.3.7 Equable	18
	2.3.8 Empowering	19
	2.3.9 Transparent	19
	2.3.10 Confidential	20
3.	Research Questions	21
4.	Methods	23
	4.1 Design	23
	4.2 From Output Definitions to Operationalization of Attribute-items of Quality of Child	
	Primary Care	
	4.3 The questionnaire	
	4.3.1 Background Characteristics	
	4.3.2 Health Status and Health Care Consumption	
	4.3.3 Quality of the Primary Care System	
	4.3.4 Prioritization of Attribute-items of a Child Oriented Primary Care System	
	4.3.5 Translations	
	4.4 Sampling Methodology	
	4.5 Respondent Sample	
	4.6 Ethics	
	4.7 Data Analysis	
5.		
	5.1 Background Characteristics	
	5.1.1 Representativeness of the Samples of the five Countries	31

POCHA end report

	5.1.2 Comparison of the Samples of the Countries	31
	5.1.3 Health Care Consumption	32
	5.1.4 Health Status	33
	5.2 The Quality of Primary Care for Children	35
	5.2.1 Overall Satisfaction Score	35
	5.2.2 Quality of Primary Care for Children	36
	5.2.3 Differences in Quality of the Primary Care System between five EU Countries	36
	5.3 Public Priorities for Assessment of Quality of a Child Oriented Primary Care System	40
	5.3.1 Agreement in Priorities between five EU countries	40
	5.3.2 Differences in Priorities between five EU countries	40
	5.4 Priorities for Improvement of the current Quality of Care in five EU countries	43
	5.4.1 Priorities for Improvement of the current Quality of Care in the UK	43
	5.4.2 Priorities for Improvement of the current Quality of Care in the Netherlands	44
	5.4.3 Priorities for Improvement of the current Quality of Care in Germany	45
	5.4.4 Priorities for Improvement of the current Quality of Care in Spain	46
	5.4.5 Priorities for Improvement of the current Quality of Care in Poland	47
6.	Conclusions	48
	6.1 Main Findings	48
	6.2 Strengths and Limitations	49
	6.3 Recommendations	50
R	eferences	51
A	ppendices	53
	Appendix 1. List of attribute-items, themes and descriptions	53
	Appendix 2. The POCHA questionnaire	55
	Appendix 3. Combinations of attribute-items used in the experimental design	71
	Appendix 4. Location quota used for sampling per location in each country	73
	Appendix 5. Categories and distribution of educational level for each of the five countries	75
	Appendix 6. Priorities per country	76

1. Introduction

The health of our children is of utmost important not only for themselves and their families, but for the whole society. As future workers, parents and carers, these children are the ones that will build the world of the future. Health services for children are structured differently throughout the European Union, and there is little research into what works best. Therefore, the MOCHA project (Models of Child Health Appraised) performs a systematic, scientific evaluation of the types of primary care services for children that exist in Europe (http://www.childhealthservicemodels.eu/). The project aims to identify the optimal models of children's primary health care, to analyse what factors will help the results of this knowledge be adopted across Europe, and to provide indicators for policy makers of the health and economic gains that can be achieved.

Primary health care (PHC) refers to the concept elaborated in the 1978 Declaration of Alma-Ata, which is based on the principles of equity, participation, inter-sectoral action, appropriate technology and a central role played by the health system (6). In their study on European primary care, Kringos et al. (2010) define primary care as "the first level of professional care service, where people present their health problems, and where the majority of the population's curative and preventive health needs can be satisfied."(5). Primary care is generalist in nature, client-centered and focused on the person with questions about his health in his or her social context. Based on a systematic literature review, Kringos et al. (2010) identified four dimensions related to the primary care process: accessibility, continuity, coordination and comprehensiveness (7). Ideally, primary care services should be easily available close to where people live with no obstacles to access at the time of need. Primary care should provide continuity of care over the life course. Primary care should coordinate the different teams of health professionals that collaborate in the care for a certain patient. Finally, primary care should feature preventive care throughout the life course, including prevention of disease or health problems, lifestyle advice, and physical and mental illness prevention (5, 8, 9).

Primary care for children fits within this generic picture, but has to accommodate the physiological and intellectual development of the child; 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.

The MOCHA project comprises a multidisciplinary study of appraisal of primary healthcare for children and young people in all 30 EU/EEA countries. The focus of appraisal of the forms of primary care for these age groups within the MOCHA project is on the following health services: general practice/family practice (generalists seeing patients of all ages), primary care paediatrics (seeing only child patients), community nursing (often including home visiting), and school health services.

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 categorized into: 1) models that are led by a primary care paediatrician; 2) models that are led by a general practitioner; and 3) mixed models, usually with additional health professionals available for consultation.

Using lead practitioner as basis for distinguishing models has some utility but is clearly an oversimplification of the necessary criteria for appraisal. 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 (10).

The aim of the ninth work package in the MOCHA-project is to use the findings from the other work packages and further develop the optimal, sustainable and cost-efficient patient-centred and prevention oriented primary child health care models. Important in developing these models is to have information on views of stakeholders, professionals in health care as well as citizens who pay and/or make use of the system, on the vital changes necessary and achievable in policies to improve the primary child health care systems. In this report we focus on the general public's views on the primary care model for children in their country.

Aim of the Project

The ninth work package in the MOCHA project comprised several tasks. The main goal of the task, described in this report, was to elicit formative values from the general public in five European countries, to determine public priorities in the assessment of the quality of a child-oriented primary care system. We have achieved this goal using the following steps:

- 1. In the first step we identified and defined the relevant outputs of a child-oriented health care system from a child, youth and carer centred perspective, as adopted in the MOCHA working model.
- 2. In the second step, the nine outputs of a child-oriented health care system were operationalized in 40 attribute-items in plain language as much as possible. Through an iterative process within the MOCHA project team, between one and nine attribute-items were operationalized for the nine outputs in order to cover the full description of each output.
- 3. In the third step, a descriptive, cross-sectional, quantitative study, using a questionnaire, was used in a representative sample of the general public in five European countries to measure the public's experiences and/or perceptions of the quality of the currently provided primary care for children, and to elicit preferences with respect to the children's primary care

2. Defining attributes of Quality of Care

The aim of this chapter is to define the relevant outputs of health systems from a child, youth and carer centred perspective, as adopted in the MOCHA working model, in the first phase of the MOCHA project.

2.1 The MOCHA working model

The MOCHA working model is a combination of the model of Bronfenbrenner (1979)(11) and the Donabedian framework (1988)(12, 13) (table 2.1). The Bronfenbrenner model is focused on the environmental factors which can affect the development of (children's) health. The Bronfenbrenner model consists of four levels, namely 1) microsystem, 2) mesosystem, 3) exosystem, and 4) macrosystem(11). The Donabedian framework aims to define attributes of the quality of health care services. In this framework, the health care system is defined by means of its structure, process and outcome) (13).

Table 2.1. The levels/attributes of health and high quality health care according to Bronfenbrenner (1979) (11) and Donabedian (1980) (13).

Model	Aim	Levels/attributes		
Bronfenbrenner	Influence of environmental factors on the health development of children	 Microsystem (family), Mesosystem (relation school and family) Exosystem (schoolpolicy, job parents) Macrosystem (social, political, cultural factors and organization educational system) 		
Donabedian	Studying health care services and evaluating the quality of health care	 Structure (governance, economic conditions and workforce development), Process (access, continuity, coordination and comprehensiveness) Outcome (quality, efficiency and equity) 		

In the MOCHA working model, the four levels of the Bronfenbrenner model are represented in the "lollipop" on the left side (figure 2.1). The attributes of the Donabedian framework are represented on the right side in the blue box of the MOCHA working model as potential outputs of the health care system from a child, youth and carer centred perspective. These attributes of quality of care are: affordability, accessibility, acceptability, appropriateness, continuity, coordination and equitability of care and empowerment as a result of care (figure 2.1).

MOCHA WORKING MODEL Life course determinants of child health and primary care quality

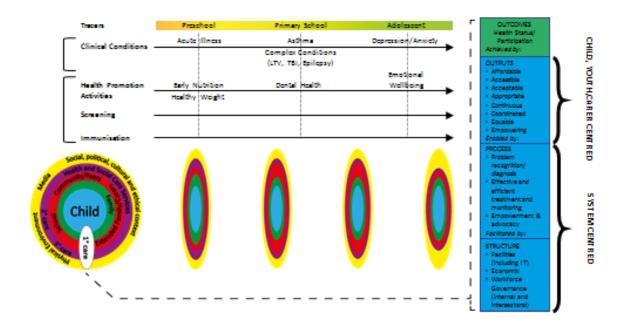


Figure 2.1. The MOCHA Working Model

We first sought to define the potential outputs of primary care for children by looking at definitions within the study of Kringos et al. (7). We added definitions from other literature sources if definitions were missing in the study of Kringos and/or because the factors as adopted in the MOCHA working model do not fully overlap with the terminology as described by Kringos. A more detailed critique of appraisal frameworks for primary care has been carried out by WP1 (Autan M, Alexander D, Rigby M, Blair M in preparation). The common features of macro, meso and micro level determinants and a logic model which attempt to link structures, processes, outputs and outcomes are common features. The Kringos framework has been the best tested in a European context and hence has been selected for use in this study despite some of the limitations expressed above in terms of lack of child specific focus.

2.2 From Quality Frameworks to Attributes of Quality

In their systematic literature review of the core dimensions of primary care, Kringos identified ten core dimensions (7). Included were three dimensions of structure, being 1. governance; 2. economic conditions; and 3. workforce development. Moreover, four dimensions of the primary care process were included, being 4. access; 5. continuity of care; 6. coordination of care; and 7. comprehensiveness of care; and three dimensions of the outcome of a primary care system, being 8. quality of care; 9. efficiency care; 10. equity in health. Table 2.2 presents the core dimensions of the Primary Care System according to Kringos et al. (7). There is a direct match of the potential outputs of the MOCHA working model with regard to terminology with three of the four process dimensions of the primary care monitor of Kringos (accessibility, continuity, and coordination). The affordability and acceptability of primary care are subdomains of "Access to Primary Care" in the Primary Care Monitor, while they are separate domains in the MOCHA

working model. Equable in the MOCHA model seems to be a combination of "equality in access" and "equity in health" in the Primary Care Monitor. There is no direct match between the appropriateness of care as stated in the MOCHA working model, although intuitively it seems to relate to the quality, efficiency and comprehensiveness of care in the Primary Care Monitor. The term empowerment is not in the Primary Care Monitor.

Table 2.2. Core dimensions of the Primary Care System according to Kringos et al., 2010(5). Blue terms can be matched to the child, user and carer centered outputs of child primary care system as defined in the MOCHA working model. For the starred (*) dimensions only a limited description is given because their impact on the output of the Primary Care system is outside the view of users of the system.

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Core Dimensions	Definition			
Governance*	The vision and direction of health policy exerting influence through regulation, advocacy, collecting and using information.			
Economic conditions*	Operationalized in health care funding system, health care expenditures, primary care expenditures, employment status, remuneration system and income of primary care workforce			
Workforce development*		care professionals that make up the primary care ition that they take in the health care system.		
Access to care		ilability, geographic accessibility, affordability, ation of primary care services, and accommodation of ity in access.		
	Availability of PC	The volume and type of primary care services relativ to population needs		
	Geographic accessibility of PC	Remoteness of services in terms of travel distance for patients		
	Affordability of PC	Financial barriers patients experience to receive primary care services, such as co-payments and cost-sharing arrangements		
	Acceptability of PC	Patient satisfaction with the organization of primary care		
	Utilization of PC	Actual consumption of primary care services		
	Accommodation of accessibility	The manner in which resources are organized to accommodate access (e.g. appointment system, afterhours care arrangements, home visits)		
	Equality in access	The extent to which access to primary care services is provided on the basis of health needs, without systematic differences on the basis of individual or social characteristics		
Continuity of care	Operationalized in longitudinal continuity of care, informational continuity of care and relational continuity of care			
	Longitudinal continuity of care	Having a long-term relationship between primary can providers and their patients in their practice beyond specific episodes of illness or disease		
	Informational continuity of care	An organized collection of each patient's medical information readily available to any health care provider caring for the patient		
	Relational continuity of care	The quality of the longitudinal relationship between primary care providers and patients, in terms of accommodation of patient's needs and preferences, such as communication and respect for patients		
oordination of care	Reflects the ability of proof of health care	rimary care providers to coordinate use of other levels		

	Gatekeeping system	The level of direct access for patients to health care providers without a referral from a primary care provider		
	Primary care practice and team structure	Such as shared practices, team premises and team size and tenure		
	Skill-mix of primary care providers	Diversification and substitution of primary care providers		
	Integration of primary care-secondary care	Care integration can be achieved through specialist outreach models and clinical protocols facilitating shared care		
	Integration of primary care and public health	The extent to which primary care providers collaborate with practitioners from the public health sector to provide services that influence health		
Comprehensiveness of care	Represents the range of health care needs	services available in primary care to meet patients'		
	Medical equipment available	Range of medical equipment available in primary care practices		
	First contact for common health problems	Range of health problems for which first contact care in primary care is provided		
	Treatment and follow-up of diagnoses	Range of diagnoses for which treatment and follow-up care is provided in primary care		
	Medical technical procedures and preventive care	Range of medical technical procedures and preventive care provided in primary care		
	Mother and child and reproductive health care	Range of mother and child and reproductive health care services provided in primary care		
	Health promotion	Range of health promotion activities provided in primary care		
Quality of care	The degree to which health services meet the needs of patients, and standards of care			
	Prescribing behavior of primary care providers	The frequency at which providers prescribe medicine		
	Quality of diagnosis and treatment in primary care	For example, reflected by the occurrence of avoidable hospitalization for acute ACSCs		
	Quality of management of chronic diseases	For example the prevalence of chronic diseases, receipt of treatment characteristics, and the occurrence of avoidable hospitalization for chronic ACSCs		
	Quality of mental health care	Such as prevalence of mental disorders, and anti- depressant medication, and continuity of mental care		
	Quality of maternal and child health care	Reflected for example by maternal mortality rates, occurrence of preventive screening for pregnant women, and infant vaccination		
	Quality of health promotion	Such as obesity, smoking or alcohol use in the population		
	Quality of preventive care	Such as the occurrence of preventable ACSCs, or cancer screening		
Efficiency of care	The balance between the to come to certain outco	e level of resources in the system used to treat patients mes		

POCHA end report

	Allocative and productive efficiency	Respectively, minimizing patient's opportunity cost of time spent in treatment; maximizing the patient's outcome, minimizing the cost per patient	
	Technical efficiency	A system is technical efficient if it cannot reduce its resource use without reducing its ability to treat patients or to reach certain outcomes	
	Efficiency in performance of primary care workforce	Reflected by basic figures relating to the provision of care, such as number of consultations and their duration, frequency of prescription medicines (unnecessary use), and the number of new referrals to medical specialists	
Equity in Health	Equity in Health The absence of systematic and potentially remediable differences in health status across population groups		

2.3 From Attributes of Quality of Primary Care to Definition of Outputs

In this paragraph, we seek to define all dimensions used in the MOCHA working model in order for their use in the public preference study.

2.3.1 Affordable

Affordable primary care for children can be accessed without inordinate financial barriers, such as high co-payments or cost-sharing arrangements" [definition adapted from Kringos et al., 2010(5)]

Affordable care is part of the accessibility domain in the study of Kringos et al. (2010)(5) and defined as "financial barriers patients experience to receive primary care services, such as copayments and cost-sharing arrangements". Likewise, affordability is a dimension of accessibility in the framework of Levesque et al. (2013): "the economic capacity for people to spend resources and time to use appropriate services". (1) Evans et al. (2013) define affordability as "people's ability to pay for services without financial hardship." (4) In this study, we use the definition provided by Kringos et al. (2010)(5). Healthcare costs in the context of this research include the costs attached to the use of a healthcare service, such as direct and indirect healthcare costs, the costs of healthcare insurance and a patient's deductible.

2.3.2 Accessible

Accessible primary care is available within reasonable reach of parents and children, with ample opening hours, good appointment systems and other aspects of service organization and delivery that allow children to obtain the services when they need them" [definition adapted from Evans et al., 2013(4)]

In the framework by Kringos et al. (2010), accessible care is defined in seven subcategories, namely Availability, Geographic accessibility, Affordability, Acceptability, Utilization, Accommodation of accessibility and Equality in access. (5)

Affordability and Acceptability are separate domains in the MOCHA working model. Equality in access seems closely related to "equable" as defined in the MOCHA working model. Utilization, defined as "actual consumption of primary care services" is a consequence of parents with children accessing the system that is difficult to judge by public stakeholders. Thus, this leaves the availability, geographic accessibility and the accommodation of accessibility as important parts of accessible care as defined by Kringos.

This operationalization of accessible care is in line with the definition of accessible care by Evans et al. (2013), who defined it as "the availability of good health services within reasonable reach of those who need them and of opening hours, appointment systems and other aspects of service organization and delivery that allow people to obtain the services when they need them".(4) Factors that play a role in accessible care are waiting times, consultation times and opening times (1, 14-18), as well as the availability of the healthcare provider by phone (16) and geographical accessibility. Geographical accessibility includes the distance to a location, as well as the travel time and travel distance (1, 7, 14, 15, 19-22).

An alternative definition and operationalization of accessible care was found in the study of Levesque et al., (2013).(1) In 2013, they published a study that aimed to conceptualize patient-centred access to care. In their article, they give an overview of the different definitions of access or accessibility in literature and its dimensions (table 2.3). Levesque et al. (2013) define access as "the opportunity to identify healthcare needs, to seek healthcare services, to reach, to obtain or use health care services, and to actually have a need for services fulfilled".(1) Levesque et al. conceptualized five dimensions of accessibility of health care, namely 1) approachability, 2) acceptability, 3) availability and accommodation, 4) affordability and 5) appropriateness (table 2.3). However, this is a broader definition of access than the one employed by Kringos, and like the Kringos definition, some of the dimensions of access are covered in other aspects of the MOCHA working model.

We therefore propose to adopt the definition of Evans et al., (2013), and use the distinction provided by Kringos in *availability*, *geographic accessibility* and the *accommodation of accessibility*, to enable operationalization in attributes (1).

Table 2.3. Dimensions of accessibility of care according to Levesque et al., (2013).(1)

DIMENSION	description
Approachability	people facing health needs can actually identify that some form of services exists, can be reached, and have an impact on the health of the individual
Acceptability	cultural and social factors determining the possibility for people to accept the aspects of the service (e.g. the sex or social group of providers, the beliefs associated to systems of medicine) and the judged appropriateness for the persons to seek care.
Availability and accommodation	health services (either the physical space or those working in health care roles) can be reached both physically and in a timely manner.
Affordability	the economic capacity for people to spend resources and time to use appropriate services.
Appropriateness	the fit between services and clients need, its timeliness, the amount of care spent in assessing health problems and determining the correct treatment and the technical and interpersonal quality of the services provided

2.3.3 Acceptable

In the Kringos Framework, acceptable care is defined as "patient satisfaction with the organisation of primary care". In contrast, acceptability of care is defined by Evans et al. (2013) as "people's willingness to seek services, based on their judgement of effectiveness of the service and whether or not they are treated with dignity and respect" (4). Acceptability is low when patients perceive services to be ineffective or when social and cultural factors such as language or the age, sex, ethnicity or religion of the health provider discourage them from seeking services. Social and cultural accessibility can be enhanced by ensuring that health workers and the health system more generally treat all patients and their families with dignity and respect. It seems that Kringos' definition of acceptable care (i.e. patients' satisfaction) is the result of the acceptability of care as defined by Evans et al. (2013)(4). However, people willingness to seek services is still the action that results from the evaluation of other dimensions of the health care service, including but not limited to effectiveness and being treated with dignity and respect. The latter two aspects are operationalized within other aspects of the model, and therefore acceptability of care is not measured independently in this study.

2.3.4 Appropriate

Appropriate primary care is effective in meeting the child's needs, timely and of high technical quality [definition adapted from Levesque, 2013(1)]

Appropriate care as a term is not used in the Kringos Framework and alternative definitions were sought. According to Levesque (2013), who defines appropriate care as an aspect of accessible care, appropriate care is "the fit between services and clients' need, its timeliness, the amount of care spent in assessing health problems and determining the correct treatment and the technical and interpersonal quality of the services provided".(1) Thus, appropriateness of care might be a result of aspects of the quality, efficiency and comprehensiveness of care as defined in the Primary Care Monitor.

In contrast, Lavis et al. (1996) distinguish two types of appropriateness: appropriateness of a service and appropriateness of the setting in which care is provided.(23) Appropriateness of service is defined as "a service that is expected to do more good than harm for a patient with a given indication or set of indications". An inappropriate service is one that is not expected to benefit the patient or, in the more extreme case, may harm the patient, and appropriate service might also be viewed as effective care. Thus, it will affect the quality indicators of care as defined in the Primary Care monitor. Appropriateness of setting is determined by "whether the patient's clinical characteristics, and the services required for his or her care, match the setting in which the care is provided". Appropriate care can be given in an inappropriate setting. That way, it will impact the efficiency of health care. In some countries, it can also result in additional out-of-pocket costs through penalties.

2.3.5 Continuous

Continuous primary care is the experience of a continuous caring relationship with the individual and groups of health care professionals by a single child and its parents over time, that is responsive to the child's changing needs. [definition developed in the project]

In the article by Kringos et al. (2010), continuity in care has three subdomains, which are the longitudinal continuity of care, the informational continuity of care and the relational continuity of care.(5) Definitions as used by Kringos are provided in table 2.2. Alternatively, according to an article by Gulliford et al. (2006), there are two important perspectives on the continuity of care, which influence the quality of care over time.(24) From the patient perspective, it is the patient's experience of a 'continuous caring relationship' with an identified health care professional, which has components of both the longitudinal and the relational continuity of care as defined by Kringos. From the provider perspective, continuity of care is the delivery of a 'seamless service' through integration, coordination and the sharing of information between different providers. This definition combines the informational continuity of care, but also incorporates some aspects of coordinated care. Moreover, Haggerty and Reid (2003) systematically reviewed continuity across disciplines and they defined continuity of care as: the perceived coordination of care for a single patient over time.(25) Continuity includes how the discrete care events interrelate and how they are effectively communicated and managed

amongst all members of the care team. Their model consists of three types of continuity: Informational continuity, defined as the use of information on past events and personal circumstances to make current care appropriate for each individual, Management continuity, defined as a consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs and relational continuity—An ongoing therapeutic relationship between a patient and one or more providers. This model is again extended by Price et al., (2013) by adding features of the circle of care that influence and enable continuity, such as provider connectedness, a set of ten communication patterns that are used to support continuity across the circle of care and environmental factors outside the circle that can indirectly influence continuity.(26)

From these varying classifications and definitions of continuity of care we propose to use the two (longitudinal and relational continuity of care) of the three subdomains as proposed by Kringos, and to add the management continuity as proposed by Haggerty and Reid (2003) and the provider connectedness as proposed by Price et al. because these all describe different attributes of care that concern the actual relationship between the child, the parent and the provider.(5, 25, 26) We have decided to capture the organisational aspects of continuity (such as informational continuity of care) of care under coordination of care (Table 2.4).

Table 2.4. The four subdomains of continuity in care, based on Kringos et al. (2010)(5), Haggerty and Reid (2003)(25), and Price et al. (2013)(26).

Longitudinal continuity of care	Having a long-term relationship between primary care providers and their patients in their practice beyond specific episodes of illness or disease
Relational continuity of care	The quality of the longitudinal relationship between primary care providers and patients, in terms of accommodation of patient's needs and preferences, such as communication and respect for patients
Provider connectedness	The sense of knowing and trust between providers who share care of a patient, which facilitates (informal) sharing of information and sharing of duties
Management continuity	A consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs

Coordinated primary care is deliberately organizing child care activities and sharing of information among all of the participants concerned with a child's care with the aim to achieve safer and more effective care [definition adapted from McDonald et al. 2007 (3)]

2.3.6 Coordinated

Coordinated care is defined by Kringos et al. (2010) as "the ability of primary care providers to coordinate <u>use</u> of other levels of health care".(5) This is reflected by the presence of a gatekeeping system, the structure of the primary care practice, skill-mix of primary care providers and integration between primary and secondary care and between primary care and public health services.

Table 2.5. Subdomains of coordination of care based on Kringos et al. (2010)(5) and McDonald et al. (2007)(27)

POCHA end report

Gatekeeping system	The level of direct access for patients to health care providers without a referral from a primary care provider
Primary care practice and team structure	The extent to which practices are shared, team size and tenure
Skill-mix of primary care providers	The extent to which there is diversification and substitution of primary care providers
Integration of primary care-secondary care	The extent to which there are specialist outreach models and clinical protocols facilitating shared care
Integration of primary care and public health	The extent to which primary care providers collaborate with practitioners from the public health sector to provide services that influence health
Informational continuity of care	The organized collection of each patient's medical information readily available to any health care provider caring for the patient

McDonald et al., 2007, describe care coordination as "the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services".(27) Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities.(27) Another aspect of the definition of care coordination by McDonald et al. (2007) is "the exchange of information among participants responsible for different aspects of care", but this latter aspect of coordinated care overlaps with the informational continuity of care as defined by Kringos (2010).(5) See Table 2.5.

2.3.7 Equable

Equable primary care is the absence of systematic and potentially remediable differences in access to primary care and health status across population groups [definition adapted from Kringos et al., 2010(5)]

Where the Kringos model identifies equity in health, the MOCHA model refers to equable primary care. Equity in Health is defined by Kringos et al. (2010), as "the absence of systematic and potentially remediable differences in health status across population groups".(5) Equity in Health is partly influenced by equality in access (defined as "the extent to which access to primary care services is provided on the basis of health needs, without systematic differences on the basis of individual or social characteristics"), and by the affordability of primary care.

2.3.8 Empowering

Empowerment in primary care is a process through which children (and parents) gain greater control over decisions and actions affecting a child's health; WHO definition (2)

Empowerment is not in outputs of care as defined in the Donabedian model(13), and it is also not in the Kringos Framework.(7) In 2009, empowerment was defined by the WHO as "a process in which patients understand their role, are given the knowledge and skills by their health-care provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation".(2) In an article of Loukanova et al. (2007), three different definitions of patient empowerment are given.(28) The one that most aligns with the WHO definition from 2009 is the one by Gibson: "a social process of recognizing, promoting and enhancing people's abilities to meet their own personal needs, solve their own problems and mobilize the necessary resources to feel in control of their own lives".(29) Empowerment involves information sharing, doctor-patient communication, shared decision making and patient-self-care or self-management(28). Higher patient empowerment will impact the quality of primary care.

2.3.9 Transparent

Transparent primary care is the degree to which a healthcare service or provider is open to children and parents about their quality, cost structure, services and work method; definition of Levesque et al. (1)

An additional factor that has an influence on the perception of quality of primary healthcare is the degree of transparency of healthcare providers. Transparency refers to the degree to which a healthcare service or provider is open about their quality, cost structure, services and work method (1, 14, 19, 20, 30, 31). Although transparency is not in the Primary Care monitor by Kringos, numerous studies have shown that healthcare transparency can influence the perception patients have on the general quality of healthcare (14, 19, 30, 32, 33). A study by Levesque, Harris (1) shows that healthcare transparency plays a key role when patients realise that they require healthcare and start researching the possibilities for available healthcare. Furthermore, a report from NZa (14) shows that patients often look for information regarding the reputation and quality of a healthcare institution and its specialists. Additionally, a study by Wiegers, Hopman (34) shows that transparency regarding healthcare providers and their performances is lacking. The importance of transparency is increased when patients have choices with regard to what health care provider they choose, and the need for objective information in doing so (1, 19).

2.3.10 Confidential

Confidentiality in primary care is the right of a child to have personal, identifiable medical information kept private if they choose to, from medical professionals as well as parents [developed in the project]

The definition of patient confidentiality is that personal information of a patient is only shared with one's own physician and a short list of necessary collaborators(35). The confidentiality of health data ensures that personal information is only disclosed to authorized persons for authorized purposes at authorized times(36). It is known that many patients are unaware of or misunderstand their legal or ethical right to medical confidentiality, which leads them to both over- and underestimate confidentiality protections(37). Confidentiality and privacy are issues when health professionals are expected to keep shared records, which might be a major requirement for integrated care(38). There is always a trade-off in determining the extent to which information is shared. To provide informed treatment, those delivering care must be briefed on the prior and current clinical problems and on how these are being handled. However, patients might have limits to how much information is shared between health professionals, especially when it does not directly relate to the medical problem at hand, or is related to sensitive issues like sexuality or psychological problems (38). Moreover, specifically directed at children, a child of a certain age might want to keep some information private from the parents.

3. Research Questions

Following the aim of this project to elicit formative values from the general public in five different countries and to determine public priorities in the assessment of the quality of a child-oriented primary care system, the next main research question and sub-questions were formulated.

What are the priorities of European citizens in assessing the quality of primary care for children in Europe?

- 1. What are the experiences and/or perceptions of European citizens of the quality of currently provided primary care for children?
- 2. What are the preferences of European citizens with respect to the quality attributes of primary care for children?

Based on the diversity of the primary care systems with respect to the type of lead practitioner (general-practitioner-led, pediatrician-led or mixed), the United Kingdom, the Netherlands, Germany, Spain and Poland were chosen for studying these research questions.

The United Kingdom and The Netherlands both have a general-practitioner-led system, with the general practitioner being the gatekeeper to other health care services. In the Netherlands, the preventive care services are separated from primary care, in the United Kingdom these services are partly integrated and partly separated.

Germany and Spain both have a primary-care-pediatrician-led system, with respectively completely and partial open access to secondary care. In both countries, preventive services are partly integrated in primary care and partly separated from it.

In Poland, primary care for children may be provided by both the general practitioner and the pediatrician (mixed system). There is open access to secondary care and preventive care is integrated in primary care.

4. Methods

4.1 Design

In a descriptive, cross-sectional, quantitative design, a questionnaire was used to elicit preferences of a representative sample of the general public with respect to children's primary care and to measure experiences of the quality of currently provided care.

4.2 From Output Definitions to Operationalization of Attribute-items of Quality of Children's Primary Care

Based on the review of literature, the child and carer centred outputs of each of the dimensions of the primary care system were defined. Through an iterative process within the MOCHA project team, the outputs were operationalized in 40 attribute-items. Attribute-items were operationalized in plain language and technical jargon was avoided as much as possible. Between one and nine attribute-items were operationalized for each of the nine outputs of a child-oriented health care system (Table 4.1; Appendix 1).

Table 4.1. Attributes with output definitions, and attribute-items of a high quality primary care system, with attribute-item numbers. The list with attribute-items can be found in Appendix 1.

ATTRIBUTES	DEFINITION	ATTRIBUTE-ITEMS
ACCESSIBLE	Accessible primary care is available within reasonable reach of parents and children, with ample opening hours, good appointment systems and other aspects of service organization and delivery that allow children to obtain the services when they need them" [adapted from Evans et al., 2013](4)	1, 2, 3, 4, 5, 6, 7, 8, 9
AFFORDABLE	Affordable primary care can be accessed without inordinate financial barriers, such as high copayments or cost-sharing arrangements [adapted from Kringos et al., 2010](5)	10, 11
APPROPRIATE	Appropriate primary care is effective in meeting the child's needs, timely and of high technical quality [adapted from Levesque, 2013](1)	12, 13, 14, 15, 16, 17
CONFIDENTIAL	Confidentiality in primary care is the right of a child to have personal, identifiable medical information kept private if they choose to, from medical professionals as well as parents [developed in the project]	18, 19, 20
CONTINUOUS	Continuous primary care is the experience of a continuous caring relationship with the health care professional(s) by a single child and its parents over time, that is responsive of the child's changing needs [based on Kringos et al. 2010,(5) Haggerty and Reid (2003)(25), and Price et al. (2013)(26)]	21, 22, 23, 24, 25, 26
COORDINATED	Coordinated primary care is deliberately organizing child care activities and sharing of information among all of the participants concerned with a child's care with the aim to	27, 28, 29, 30, 31

	achieve safer and more effective care [Mold, 2014(3)]	
EMPOWERING	Empowerment in primary care is a process through which children and parents gain greater control over decisions and actions affecting a child's health [WHO definition(2)]	32, 33, 34, 35, 36, 37
EQUABLE	Equable primary care is the absence of systematic and potentially remediable differences in access to primary care and health status across population groups" [adapted from Kringos et al., 2010(5)]	38, 39
TRANSPARENT	Transparent primary care is the degree to which a healthcare service or provider is open to children and parents about their quality, cost structure, services and work method [Levesque et al., 2013(1)]	40

4.3 The questionnaire

In the project, a questionnaire was developed, the Preferences fOr Child Health Care Assessed (POCHA) Instrument. The POCHA consisted of five parts (Appendix 2):

- 1. background characteristics
- 2. the health status of the child(ren) and current health care consumption of any child(ren) below the age of 18
- 3. child independence, i.e. the age at which a child could be or should be able to make decisions independent from its parents
- 4. the quality of the primary care system
- 5. the prioritization of the 40 attribute-items of a child-oriented primary care system

4.3.1 Background Characteristics

The following background characteristics of respondents were measured:

- age: 19 years or younger, between 20 and 24, between 25 and 29,, between 65 and 69, 70 years or older;
- gender: female, male;
- country: United Kingdom, Netherlands, Germany, Spain, Poland; and the countries' region;
- number of children: 1, 2, 3, other;
- number of children < 18: yes/no;
- highest level of completed education: with the following categories for the UK: Entry level, GCSE (grades D-G), GCSE (grades A*-C), A-Level, Higher National Certificate/National Diploma, Bachelor Degree, Master Degree, Doctoral Degree; comparable categories for the other four countries;
- size of the city, where the respondent lives: < 100, 100 1000, 1000 10000, 10000 20000, 20000 100000, 100000 200000, 20000 1000000, > 1000000.

4.3.2 Health Status and Health Care Consumption

Health status was measured by asking: "In the past 12 months, has (one of) your child(ren) had a medical condition that lasted longer than 6 weeks?". "What condition was this/were these? Please indicate all conditions that apply for any child(ren) below the age of 18." Conditions to choose were: Eczema, Asthma, Hay fever, Allergy, Stomach ache, Headache, Back problems, Fatigue, Sleep problems, Depressive complaints, Hyperactivity and ADHD, Constipation, Overweight and obesity, Other: ...

Following the question on health status, health care consumption for children < 18 with long-term disease (> 6 weeks) in the previous 12 months was measured with the frequency of contact with primary and secondary health care providers (general practitioner, physiotherapist, social worker, district nurse, paediatrician, hospital specialist, other namely....).

4.3.3 Quality of the Primary Care System

In order to measure experiences and/or perceptions of primary care for children, the attribute-items were presented as statements and respondents were asked to rate the extent to which they agreed with each statement, on a 5-point rating scale (strongly disagree to strongly agree). To limit the length of the questionnaire, ten randomly selected statements were presented to each respondent, out of the complete set of 40 attribute-items (Appendix 1). If the respondent had no direct experience with primary care for children, he was asked to react on the statement based on his perceptions of primary care for children in his country. These perceptions could be based on media coverage and/or on stories from friends and family.

For each respondent on the questionnaire, the ten statements were randomly selected out of 40 statements on the quality of the primary care system for children.

4.3.4 Prioritization of Attribute-items of a Child Oriented Primary Care System

To determine what people find the most important characteristics (= attribute-items) of the quality of a primary care system, we aimed to ask respondents to rank the 40 items in terms of importance. However, it is unfeasible for a respondent to rank 40 items.

Thus, instead of a full ranking, the partial ranking technique of best-worst scaling (BWS) was used. In BWS, respondents are presented with smaller sets of attribute-items, and are asked to select the most and least important attribute-item (Figure 4.1.). In this project, we chose to present four attribute-items in each question, and limit the number of questions to 20. Thus, each attribute-item could be presented twice to each respondent ((4 items per question*20 questions)/ total of 40 attribute-items). An experimental design was generated in R-software to vary the combinations of attribute-items over the questions to ensure there was no overlap (attribute-item combinations shown multiple times). Eight different versions of ten BWS questions were generated, each containing the 40 attribute-items in different combination from each other (Appendix 3).

Two random sets of ten questions were presented to each respondent.

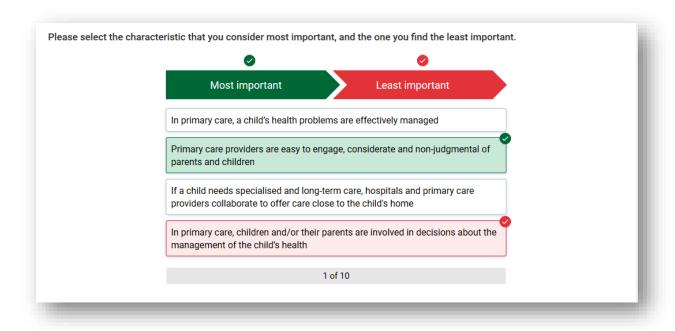


Figure 4.1. Example of a prioritization question from the English Survey.

4.3.5 Translations

The English questionnaire was translated in Dutch, German, Spanish, and Polish, by certified translators. Translated questionnaires were checked by native speakers who were familiar with the country's primary care system.

4.4 Sampling Methodology

An online survey was used to collect data. Recruitment of participants took place by Research Now SSI, through the dynamic sampling platform Dynamix™. This platform makes use of online communities, social networks and websites of all types. When building online panels, a broad, multi-sourced approach is employed. Participants are recruited via partnerships with trusted loyalty programs as well as via banner ads, pop ups and messages on websites, TV advertising and offline. A reward strategy is used to achieve maximum representation within online sample. In addition, a suite of controls is used to ensure duplicates are not present in any online sample and to ensure the quality of survey data.

4.5 Respondent Sample

The target sample size of respondents, being citizens (men/women) 18-65 years of age, per country was calculated at 500. A broad, diverse, and representative sample of respondents in the five countries was recruited by Research Now SSI. Table 4.2 shows the quota for background characteristics (age, gender) used for sampling, and the distribution of the educational level of the general population, aged 18-65 years, for the five European countries. For the quota used for location per country, see Appendix 4. For the education categories and distribution in low-middle-high for each of the five countries, see Appendix 5.

Table 4.2 Quota for background characteristics (gender, age) used for sampling, and the distribution of the educational level of the general population, aged 18-65 years, for the five European countries (N=2403).

	UK	NL	DE	ES	PL
	N=496	N=469	N=469	N=491	N=478
	%	%	%	%	%
Gender					
- Female	50.4	49.7	49.8	49.8	50.5
- Male	49.7	50.3	50.2	50.2	49.5
Age plus gender					
- 18-24 female	7.4	6.6	6.2	5.2	7.3
- 18-24 male	7.5	6.8	6.4	5.4	7.6
- 25-35 female	10.8	9.3	9.3	9.6	12.0
- 25-35 male	10.5	9.4	9.4	9.7	12.3
- 35-44 female	11.1	11.5	11.0	12.8	9.8
- 35-44 male	10.9	11.7	11.2	13.3	9.6
- 45-54 female	11.0	11.4	11.7	12.0	10.4
- 45-54 male	10.8	11.6	11.8	11.9	10.1
- 55-64 female	9.9	10.8	11.5	10.3	11.2
- 55-64 male	10.2	10.9	11.7	9.9	9.7
Educational level					
- Low	37.0	34.3	17.0	56.0	53.1
- Middle	36.0	42.1	60.0	18.0	34.4
- High	27.0	23.6	23.0	26.0	12.5

4.6 Ethics

According to the criteria of the Dutch Medical Research Involving Human Subjects Act, this study did not need to be submitted for ethical approval by a Medical Ethical Committee. The study was reviewed and approved by the ethical committee of the Faculty of Behavioural, Management and Social Sciences of the University of Twente under file number BCE17583, on September 19, 2017.

4.7 Data Analysis

Background characteristics of respondents in the five countries were analysed using descriptive statistics. Perceptions on quality of care were analysed using descriptive analysis for each country. Chi-square tests were performed to test whether there are significant differences in background characteristics and perceived quality of care between respondents from the different countries.

Priorities for attribute-items of quality of care were calculated using counts analysis on an individual and a group level. First, as each attribute-item was shown twice to each respondent, the number of times an attribute-item of quality could be selected as most and least important was two. The number of times each attribute-item was selected as best and worst was counted at individual level. Then, best-worst scores were calculated by subtracting the number of times each attribute-item was selected as least important from the number of times it was selected as most important. Individual best worst counts ranged from -2 (not important) to +2 (important).

Group priorities of attribute-items are calculated by summing the best-worst scores of the individuals in the group for each attribute-item. Best-worst scores were normalized over groups

POCHA end report

by dividing the best-worst count by the number of times each attribute-item was presented to the group (2*number of respondents in the group) and multiplying this ratio with 100, resulting in a priority score ranging from +100 to -100. Group best worst scores were calculated for respondents in each country, male and female respondents and respondents with and without children below the age of 18. Priority scores were compared between countries with ANOVA (F-test).

5. Results

5.1 Background Characteristics

In total, 2403 respondents filled out the questionnaire, of which 496 were respondents from the United Kingdom, 469 from the Netherlands, 469 from Germany, 491 from Spain, and 478 from Poland. Due to the sampling methodology used in this study, a response rate could not be calculated. The background characteristics of respondents on the questionnaire survey are presented in table 5.1.

Table 5.1. Background characteristics of the respondents

Background Characteristics	U	ľΚ	٨	IL	D	ÞΕ	E	:S	P	^{p}L	F	0
	n	(%)										
Age											1.5	0.190
19 years or younger	16	(3)	17	(4)	12	(3)	7	(1)	9	(2)		
between 20 and 29	97	(20)	75	(16)	82	(17)	88	(18)	108	(23)		
between 30 and 39	110	(22)	87	(19)	95	(20)	115	(23)	102	(21)		
between 40 and 49	112	(23)	112	(24)	101	(22)	129	(26)	95	(20)		
between 50 and 59	103	(21)	112	(24)	125	(27)	116	(24)	106	(22)		
between 60 and 69	58	(12)	66	(14)	54	(12)	36	(7)	58	(12)		
Gender											1.8	0.121
Female	266	(54)	219	(47)	247	(53)	259	(53)	261	(55)		
Male	230	(46)	250	(53)	222	(47)	232	(47)	217	(45)		
Children											30.8	0.000
No Children	214	(43)	195	(42)	222	(47)	179	(36)	162	(34)		
Children < 18	173	(35)	148	(32)	143	(30)	235	(48)	173	(36)		
Children > 18	109	(22)	126	(27)	104	(22)	77	(16)	143	(30)		
City size											16.1	0.000
1 - 20.000	839	(35)	186	(38)	169	(36)	189	(40)	116	(24)		
20.000 - 100.000	595	(25)	122	(25)	147	(31)	111	(24)	112	(23)		
100.000 - 200.000	281	(12)	54	(11)	76	(16)	37	(8)	65	(13)		
200.000 - 1.000.000	429	(18)	65	(13)	59	(13)	91	(19)	107	(22)		
> 1.000.000	259	(11)	69	(14)	18	(4)	41	(9)	91	(19)		
Educational level												
- Low	140	(28)	87	(19)	143	(31)	54	(11)	12	(3)		
- Middle	180	(36)	198	(42)	216	(46)	168	(34)	239	(50)		
- High	176	(36)	184	(39)	110	(23)	269	(55)	227	(48)		

5.1.1 Representativeness of the Samples of the five Countries

Comparison of background characteristics of the samples per country shows perfect representativeness for the background variables age and gender, as per requested to the marketing agency that was asked to recruit participants. The samples of the UK and The Netherlands showed an underrepresentation of low-educated respondents and an overrepresentation of high-educated respondents. The sample of Germany showed an underrepresentation of middle-educated respondents and an overrepresentation of low-educated respondents. Both the Spain and Poland samples showed an underrepresentation of low-educated respondents and an over-representation of middle- and high-educated respondents (Table 4.2 and Appendix 5).

5.1.2 Comparison of the Samples of the Countries

The age and gender distribution of the public samples of the five participating countries were comparable. The family composition of the respondents in the samples differed significantly between countries; the percentage of respondents with children below 18 years of age ranged from 30% (Germany) to 48% (Spain). The distribution of the size of the city, where the respondents live, also differed significantly between the samples of the five countries. The distribution of the educational level of the respondents was not compared, because of the difference in educational system and categorisation between countries.

The average number of children per respondent in each country varied from 2.1 in the UK to 1.6 in Spain (table 5.2).

Table 5.2	Number of children	n rospondonts with children	< 18 in the different countries.
Tuble 3.2.	Number of children	n respondents with thildren	10 ili tile dijjerent codniciles.

Children (n)	UK	NL	DE	ES	PL
1	37.6%	33.1%	47.6%	46.0%	41.0%
2	39.3%	48.6%	35.0%	46.0%	41.6%
3	16.2%	13.5%	14.0%	7.2%	16.2%
4	2.9%	4.7%	1.4%	0.4%	0.6%
5	2.3%	0.0%	2.1%	0.4%	0.6%
6	1.7%	0.0%	0.0%	0.0%	0.0%
average	2.13	1.99	1.82	1.65	1.80

5.1.3 Health Care Consumption

The health care use of respondents with children below 18 years of age in the past 12 months is presented in Table 5.3. Figure 5.1 shows for respondents of each country the number of different health care professionals contacted in the last year, the frequency of contact with the general practitioner (GP) in the past year as well as the frequency of contact with a paediatrician. Although the average number of contacts of respondents with health care professionals did not differ much between countries (from 2.9 in the Netherlands, to 3.4 in Poland and Spain), differences in the contact per type of health care professional were observed between countries. There were statistically significant differences in the percentage of respondents who had contact with the GP (range 84-93%), the district nurse (range 8-29%), and the paediatrician (range 29-78%).

Most recognizable, there seems to be a difference in pattern of health care use between the Netherlands & the UK, and Germany, Spain & Poland. In the UK and the Netherlands, the majority of respondents indicated that they did not have contact with a paediatrician (as expected, based on the countries' categorisation with respect to the primary lead practitioner), while the majority of the respondents in Germany, Spain and Poland did. Also, in these three latter countries, respondents had more frequent contact with the general practitioner (Table 5.3 and Figure 5.1).

The percentage of respondents who had contact with other care providers did not differ between countries; mean percentages were 85% for contacts with the dentist (range 77-93%), 23% for contacts with the physiotherapist (range 20-25%), 13% for contacts with the social worker (9-17%), and 36% for contacts with another hospital specialist (range 31-39%).

Table 5.3. Percentage of respondents with children under 18 years of age who had contact with care providers in the past 12 months, for each of the five countries.

Health care use		l	JK	1	VL	1	DE .	1	ES	1	PL	ANOVA	
		n	(%)	F	Sig.								
General	No	27	(16)	24	(16)	15	(10)	17	(7)	18	(10)	13.6	0.000
Practitioner	Yes	146	(84)	124	(84)	128	(90)	218	(93)	155	(90)		
Dentist	No	21	(12)	18	(12)	10	(7)	42	(18)	40	(23)	1.6	0.162
	Yes	152	(88)	130	(88)	133	(93)	193	(82)	133	(77)		
Physiothera-	No	130	(75)	113	(76)	107	(75)	188	(80)	133	(77)	1.6	0.182
pist	Yes	43	(25)	35	(24)	36	(25)	47	(20)	40	(23)		
Social	No	144	(83)	126	(85)	127	(89)	206	(88)	157	(91)	1.8	0.119
Worker	Yes	29	(17)	22	(15)	16	(11)	29	(12)	16	(9)		
District	No	126	(73)	132	(89)	132	(92)	199	(85)	123	(71)	8.3	0.000
Nurse	Yes	47	(27)	16	(11)	11	(8)	36	(15)	50	(29)		
Peadiatrician	No	122	(71)	98	(66)	41	(29)	52	(22)	43	(25)	47.3	0.000
	Yes	51	(29)	50	(34)	102	(71)	183	(78)	130	(75)		
Hospital	No	110	(64)	92	(62)	99	(69)	143	(61)	116	(67)	0.57	0.685
Specialist	Yes	63	(36)	56	(38)	44	(31)	92	(39)	57	(33)		

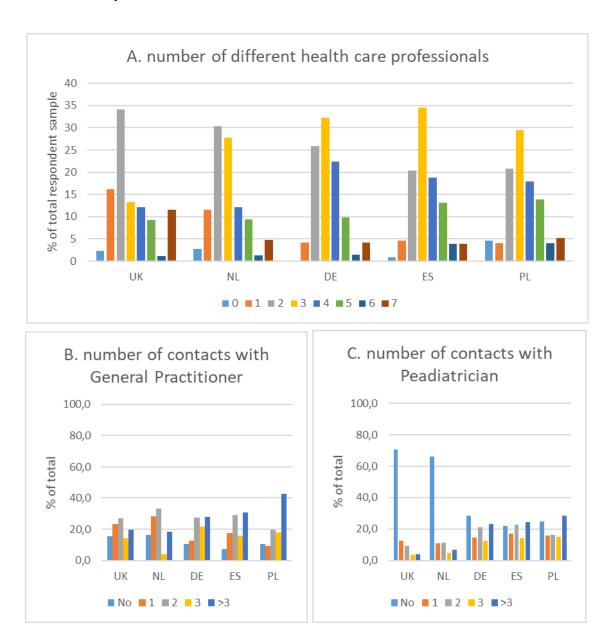
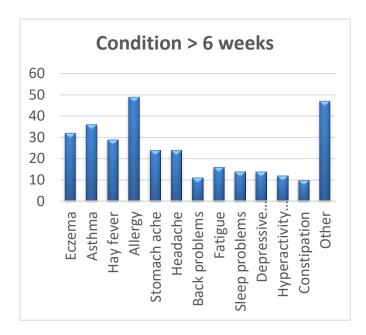


Figure 5.1. Health care consumption. A. number of different health care professionals contacted in the last year. B. frequency of contact with the general practitioner (GP) in the past year. C. frequency of contact with a paediatrician in the past year.

5.1.4 Health Status

Of the respondents with (at least) one child below the age of 18, about 25% (n=196) indicated that at least one child had a condition that lasted more than 6 weeks in the past year. This number varied from 27% in the UK to 17% in Germany (24% in NL; 20% in ES; 24% in Poland). The frequency different conditions (lasting longer than 6 weeks) were reported, is presented in figure 5.2 for all respondents and in table 5.4 for each country separately.

The conditions that were reported most frequently were allergies, asthma, eczema and hay fever (Figure 5.2). The majority of respondents (\sim 66%) reported one condition in their child(ren), around 14% reported two and another 10% reported three conditions in their child(ren).



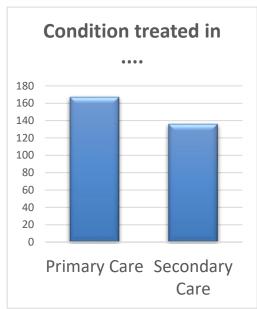


Figure 5.2. Frequency of different conditions in respondents with children < 18 and contact with primary and secondary care professionals as a result.

Table 5.4 shows some differences in the reported prevalence of the conditions in the five countries. These differences between countries should be interpreted with cautiousness, as reported rates are the result of reports of lay-people respondents, different names and definitions may be used, and cultural differences may exist in the perception of when something is a medical condition. Also, rates have not been adjusted for differences in background characteristics between the respondents of the five countries. Concluding, based on these reported prevalence rates it is not possible to draw conclusions with regard to the health status of children in these countries.

Of the 196 respondents, 167 had contact with a primary care physician to get the child treated and 136 had contact with a secondary care health professional.

Table 5.4. Reported frequency of conditions lasting longer than 6 weeks for each country.

Conditions	UK	NL	DE	ES	PL
Eczema	23.4%	25.0%	0.0%	21.7%	4.8%
Asthma	29.8%	13.9%	12.0%	17.4%	14.3%
Hay fever	17.0%	11.1%	12.0%	13.0%	19.0%
Allergy	17.0%	13.9%	32.0%	32.6%	31.0%
Stomach ache	10.6%	16.7%	12.0%	8.7%	14.3%
Headache	8.5%	8.3%	20.0%	10.9%	16.7%
Back problems	6.4%	5.6%	4.0%	2.2%	9.5%
Fatigue	2.1%	13.9%	8.0%	8.7%	9.5%
Sleep problems	12.8%	8.3%	4.0%	2.2%	7.1%
Depressive complaints	19.1%	13.9%	0.0%	2.2%	0.0%
Hyperactivity and ADHD	2.1%	19.4%	4.0%	2.2%	4.8%
Constipation	0.0%	0.0%	8.0%	13.0%	4.8%

Overweight and obesity	0.0%	2.8%	0.0%	2.2%	7.1%
Other	19.1%	38.9%	32.0%	15.2%	21.4%

5.2 The Quality of Primary Care for Children

5.2.1 Overall Satisfaction Score

Based on their experiences or perceptions of primary care, respondents indicated to what extent they were satisfied with the quality of primary care for children in their country. Answers were give on a scale of 1 (very dissatisfied) to 10 (perfectly satisfied). In Table 5.5 scores for overall satisfaction with child-oriented primary care are presented, and in figure 5.3 the distribution of scores is visualized.

Mean satisfaction scores differ significantly between countries (F 75.9; p=0.000). Respondents from Spain were most satisfied with the quality of primary care in their country while respondents from Poland were least satisfied.

Table 5.5. Satisfaction with Child-Oriented Primary Care: average score and standard deviation (SD) on a scale from 1 (very dissatisfied) to 10 (very satisfied).

	Satisfaction					
Country	Average	SD				
UK	7.0	1.7				
NL	6.9	1.3				
DE	6.9	1.7				
ES	7.2	1.6				
PL	5.5	2.2				

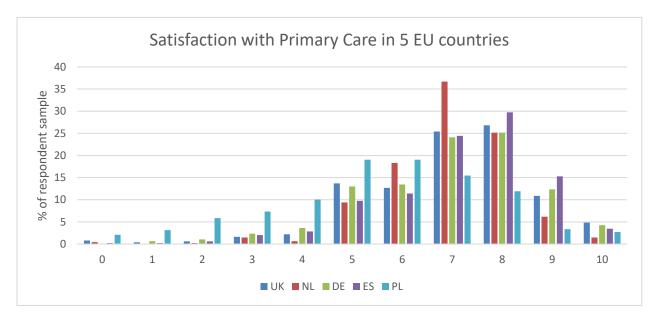


Figure 5.3. Satisfaction rating per country (scale 0 (very dissatisfied)-10 (very satisfied)).

5.2.2 Quality of Primary Care for Children

Each respondent rated the quality of the health care system on ten out of 40 attribute-items. Based on the average agreement over all 40 attribute-items, perceived quality of the health care system was highest in the Netherlands (70%), followed by the United Kingdom (68%). Perceived quality was lower in Germany (64%) and Spain (62%), while lowest perceived quality was found in Poland (56%).

In figure 5.4 the perceived quality of the primary care system for children is presented per country per attribute-item. The list of attribute-items, themes and descriptions can be found in Appendix 1. It can be seen that agreement with attribute-items ranges from 12% (Poland, CONF; protect privacy from parents [item 19]) to 86% (Netherlands, CONT; health care professionals show dignity and respect [item 25]). For some attribute-items, the perceived quality of care is very comparable in all countries, for instance with regard to item 3 (ACC; primary care has ample opening hours), item 15 (APP; care is provided in primary care) and item 28 (COOR; replacement is quickly available). For other attribute-items of high quality care, the perceived quality is very different between countries, for instance for items 40, 18 and 36 (TRANS; transparency about the quality of care [item 40], CONF; the right of the child to a confidential consultation [item 18], EMP; the extent to which the opinions of the child are taken into account [item 36]).

Clearly divergent from the other attribute-items in all countries is the extent to which in primary care a child can limit his parents' access to the child's medical records in order to protect his privacy (CONF; privacy from parents [item 19]), for which agreement ranges from 12 to 36%.

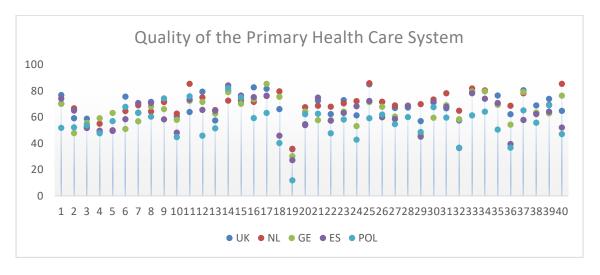


Figure 5.4. The quality of the primary care system for children in five EU countries. Normalized sum of respondents that either agreed or strongly agreed with the statement (1-40) on the high quality of care with respect to that attribute-item. For attribute-item description, see Appendix 1.

5.2.3 Differences in Quality of the Primary Care System between five EU Countries

From figure 5.4 it can be seen that for some attribute-items there are large differences in perceived quality of that attribute-item between countries. Significant differences between countries were with regard to the perceived quality of care for 27 out of 40 items of quality of primary care for children (Table 5.5).

Highly significant were the differences in the right to a confidential consultation [item 18]; the extent to which primary care professionals are open about the quality of the health services available to children [item 40]; the extent to which in primary care the facilities and equipment are available to deliver the services that are needed for children [item 12]; and the extent to which primary care providers take into account the child's opinion on their management of the child's health [item 36]. Perceived quality of the health care system on these items were consistently lower for Poland and Spain.

Table 5.5. Comparison of the percentage of agreement (summed percentage of respondents that agree and strongly agree) with the statements on each of the 40 attribute-items of quality of the primary care system, indicated by the respondents of the 5 countries.

	% Agreement with statement							
	UK	NL	GE	ES	POL	ALL	Chi ²	Sign.
ACC; timely [item 1]	77	70	70	74	52	69	22.2	0.000
ACC; appointment system [item 2]	59	67	48	65	52	58	17.7	0.001
ACC; opening hours [item 3]	59	52	55	52	54	54	5.7	0.227
ACC; referral primary care [item 4]	49	55	59	50	48	52	10.2	0.037
ACC; referral secondary care [item 5]	50	50	63	50	57	54	7.0	0.134
ACC; range of services [item 6]	76	65	51	58	68	63	16.4	0.003
ACC; distance [item 7]	63	69	57	71	63	65	6.0	0.196
ACC; building [item 8]	72	64	68	71	60	67	12.6	0.014
ACC; medical record [item 9]	72	71	66	58	74	68	5.9	0.204
AFF; feasible system [item 10]	60	63	58	48	45	55	15.0	0.005
AFF; free point of delivery [item 11]	64	85	72	73	76	74	7.1	0.130
APP; facilities [item 12]	79	75	72	65	46	67	52.0	0.000
APP; time [item 13]	57	65	63	65	51	60	9.3	0.054
APP; clean [item 14]	80	73	79	84	82	80	8.8	0.067
APP; primary care [item 15]	72	74	70	76	75	73	2.4	0.660
APP; effective [item 16]	83	72	74	75	59	72	21.1	0.000
APP; expertise [item 17]	82	76	85	76	63	76	30.0	0.000
CONF; consultation [item 18]	66	80	75	46	40	61	74.3	0.000
CONF; privacy from parents [item 19]	35	36	30	27	12	28	45.6	0.000
CONF; authorization MR [item 20]	55	68	64	54	62	60	7.2	0.126
CONT; medical record [item 21]	73	69	58	75	63	67	15.5	0.004
CONT; relationship [item 22]	62	68	58	57	48	59	18.7	0.001
CONT; consistency [item 23]	73	71	64	63	58	66	8.9	0.064
CONT; familiarity [item 24]	61	72	53	68	43	60	29.5	0.000
CONT; dignity and respect [item 25]	85	86	71	72	59	75	22.9	0.000
CONT; easy to engage [item 26]	72	72	68	60	62	67	7.8	0.097
COOR; primary and secondary [item 27]	67	69	60	59	55	62	17.1	0.002
COOR; replacement [item 28]	67	69	69	68	60	67	10.3	0.036

COOR; specialized care [item 29]	57	70	47	45	49	53	24.1	0.000
COOR; other health professionals [item 30]	71	73	60	71	68	69	5.3	0.259
COOR; timely [item 31]	67	78	69	68	60	68	14.5	0.006
EMP; child independent [item 32]	57	65	58	36	37	51	45.3	0.000
EMP; well informed [item 33]	80	82	79	78	61	76	18.6	0.001
EMP; understanding [item 34]	80	80	80	74	64	76	16.9	0.002
EMP; self-management [item 35]	76	70	69	71	50	67	28.2	0.000
EMP; opinions child [item 36]	62	69	54	39	37	52	40.3	0.000
EMP; decision making [item 37]	80	78	79	58	65	72	24.5	0.000
EQA; child health [item 38]	69	63	63	62	56	63	5.3	0.253
EQA; child access [item 39]	74	69	63	64	69	68	1.7	0.784
TRANS; quality [item 40]	65	85	76	52	47	65	60.4	0.000

If we focus on the items with a lower perceived quality (lower agreement) over all countries, and the items on which the countries are most different, two items stand out.

The first attribute-item which was in the bottom ten items with regard to overall quality and in the top ten list with highest differences in perceived quality within countries was "the ability of the child to express his opinions about his health management independently from his parents" (EMP; child independent [item 32]). More than 65% of respondents from the Netherlands agreed with this statement, compared to less than 40% of respondents from Poland and Spain.

The second attribute-item was the extent to which primary care providers take into account the child's opinion on their management of the child's health (EMP; opinions child [item 36]). Almost 70% of respondents from the Netherlands agreed with this statement, compared to less than 40% of respondents from Poland and Spain.

In table 5.6, the ten attribute-items in which the largest difference existed between countries are presented in column 1, while the ten attribute-items which were lowest in the list of overall agreement are presented in column 2.

Table 5.6. Attribute-item with largest differences between countries (largest difference, column 1). Lowest ten ranked attribute-items of the health care system based on perceived quality (low performance, column 2) over countries. Bold items are in both columns.

Largest Difference between Countries	Low Performance over all Countries
CONF; consultation [item 18]	CONF; privacy from parents [item 19]
TRANS; quality [item 40]	EMP; child independent [item 32]
APP; facilities [item 12]	ACC; referral primary care [item 4]
EMP; opinions child [item 36]	EMP; opinions child [item 36]
CONT; familiarity [item 24]	COOR; specialized care [item 29]
EMP; child independent [item 32]	ACC; referral secondary care [item 5]
CONT; dignity and respect [item 25]	ACC; opening hours [item 3]
EMP; self-management [item 35]	AFF; feasible system [item 10]
ACC; timely [item 1]	ACC; appointment system [item 2]
COOR; specialized care [item 29]	CONT; relationship [item 22]

5.3 Public Priorities for Assessment of Quality of a Child Oriented Primary Care System

5.3.1 Agreement in Priorities between five EU countries

The three most important attribute-items of a high quality primary care system for children, with average priority scores over all respondents between 28% and 26% were:

- 1. Primary care providers provide care within a reasonable amount of time, given the severity of the health issue (ACC; timely [item 1])
- 2. Primary care providers have the skills and competences to provide the care a child needs (APP; expertise [item 17])
- 3. In primary care, a child's health problems are effectively managed (APP; effective [item 16])

These three attribute-items were in the top 10 of prioritized attribute-items in all of the five individual countries (table 5.7). Highest agreement between countries was found with regard to whether primary care providers have the skills and competences to provide the care a child needs [item 17], which was ranked in the top three for four out of five of the countries, and ranked 6^{th} in Spain. The two attribute items which were in the top five for at least four countries were the extent to which primary care providers provide care within a reasonable amount of time, given the severity of the health issue [item 1], and the extent to which a child's health problems are effectively managed in primary care [item 16].

Another attribute-item which was in the top 10 in all countries was item 27, whether if a child needs specialised and long-term care, hospitals and primary care providers collaborate to offer care close to the child's home (ranked 10th in the UK, 9th in NL, and 8th in Germany, Spain and Poland).

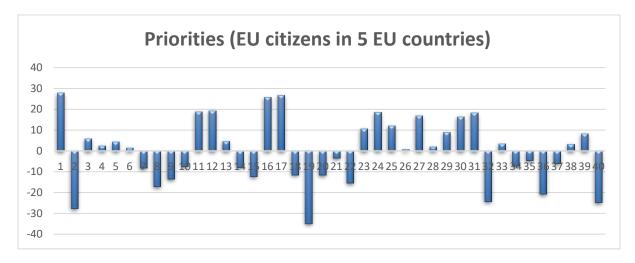


Figure 5.5. Priorities for attributes of quality of primary care for children according to respondents in five EU countries.

5.3.2 Differences in Priorities between five EU countries

Table 5.7 shows the overall priority scores and the rank order for the 40 attribute-items of primary child care per country. For priority scores per country, see also Appendix 6.

Priority scores for all individual items are significantly different between countries. Examples of attribute-items which have a positive priority score overall, but which have a difference of more than 30% in priority score between countries are:

- ACC; opening hours [item 3]. Primary care services for children have ample opening hours, the after-hour care arrangements are good enough, and home-visits are planned if needed (relatively important in Poland and Spain, not so important in the Netherlands) (F=26.0; p<0.000).
- ACC; referral secondary care [item 5]. Children and/or their parents can make an appointment with secondary or other health care providers without a referral from a primary care provider (very important in Poland, not so important in the Netherlands and UK) (F=87.5; p<0.000).
- EQA; child health [item 38]. A child's health is not influenced by the parents' social status, economic situation, racial or ethnic background and/or geographic location (very important in Germany and Spain. less important in the other countries) (F=25.5; p<0.000).
- ACC; referral primary care [item 4]. Children and/or their parents can make an appointment with other primary care providers without a referral from the main primary care provider (very important in Poland, not so important in the other countries) (F=41.2; p< 0.000).

Visually, the range of priority scores per item is presented in figure 5.6.

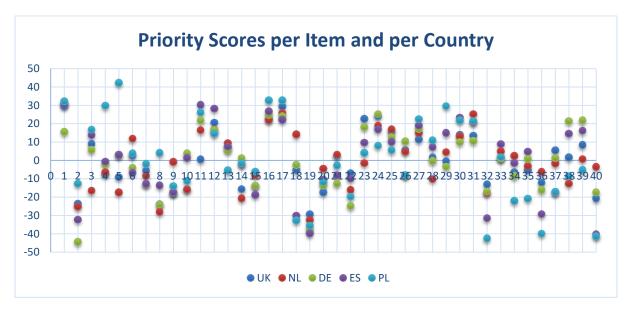


Figure 5.6. Range in priority score in the five EU countries for all items

Table 5.7. Average priority score and relative rank for the 40 attribute-items of primary care for children for the respondents in the five countries. Priority scores can range from -100 to 100. Ranking of items within a country ranges from 1 (most important) to 40 (least important).

ITEM	UF	ζ	NI		D_{i}	Е	E.	S	Pl		F	Sign
1	30	(1)	31	(1)	15	(10)	31	(1)	32	(4)	8.9	0.000
2	-24	(38)	-25	(38)	-44	(40)	-32	(38)	-13	(30)	21.2	0.000
3	9	(11)	-17	(34)	6	(15)	14	(13)	17	(11)	26.0	0.000
4	-8	(28)	-7	(27)	-2	(24)	-1	(22)	30	(5)	41.2	0.000
5	-9	(29)	-17	(35)	3	(18)	3	(20)	42	(1)	87.5	0.000
6	3	(16)	12	(12)	-4	(27)	-7	(25)	4	(18)	9.5	0.000
7	-6	(25)	-8	(29)	-13	(30)	-13	(30)	-2	(21)	2.8	0.024
8	-24	(39)	-28	(39)	-24	(37)	-14	(31)	4	(17)	23.8	0.000
9	-18	(36)	-1	(20)	-17	(35)	-17	(32)	-14	(31)	8.8	0.000
10	-16	(33)	-16	(32)	4	(17)	1	(21)	-11	(28)	17.0	0.000
11	1	(21)	16	(8)	22	(4)	30	(2)	26	(7)	20.7	0.000
12	21	(6)	17	(7)	16	(9)	28	(3)	15	(12)	5.9	0.000
13	7	(13)	9	(13)	5	(16)	7	(17)	-5	(24)	7.2	0.000
14	-16	(33)	-21	(37)	1	(20)	-2	(24)	-2	(20)	17.3	0.000
15	-14	(32)	-8	(28)	-14	(32)	-19	(34)	-6	(25)	4.1	0.002
16	23	(5)	22	(4)	25	(2)	27	(4)	33	(3)	3.6	0.006
17	29	(2)	26	(2)	24	(3)	22	(6)	33	(2)	3.3	0.010
18	-5	(23)	14	(10)	-2	(25)	-30	(36)	-33	(36)	63.6	0.000
19	-29	(40)	-33	(40)	-38	(39)	-40	(39)	-36	(37)	2.8	0.023
20	-17	(35)	-4	(25)	-14	(31)	-10	(29)	-12	(29)	4.5	0.001
21	3	(17	3	(17)	-13	(29)	-8	(27)	-3	(22)	8.9	0.000
22	-7	(27	-16	(33)	-25	(38)	-10	(28)	-20	(33)	9.4	0.000
23	23	(4	-1	(21)	18	(7)	10	(15)	4	(16)	16.5	0.000
24	24	(3	19	(5)	25	(1)	17	(9)	8	(14)	8.2	0.000
25	16	(7	17	(6)	13	(11)	10	(14)	6	(15)	4.2	0.002
26	6	(14	5	(15)	10	(13)	-8	(26)	-8	(26)	12.8	0.000
27	11	(10	15	(9)	17	(8)	19	(8)	22	(8)	2.8	0.024
28	2	(18	-10	(30)	0	(23)	7	(18)	11	(13)	10.6	0.000
29	0	(22	4	(16)	-3	(26)	15	(11)	30	(6)	24.9	0.000
30	14	(8	13	(11)	10	(14)	23	(5)	22	(9)	5.6	0.000
31	14	(9	25	(3)	11	(12)	21	(7)	21	(10)	6.2	0.000
32	-13	(31	-18	(36)	-17	(34)	-31	(37)	-42	(40)	27.6	0.000
33	1	(20	5	(14)	1	(21)	9	(16)	2	(19)	2.4	0.046
34	-7	(26	2	(18)	-9	(28)	-1	(23)	-22	(35)	17.9	0.000
35	-5	(24	-3	(23)	1	(22)	5	(19)	-21	(34)	18.0	0.000
36	-12	(30	-6	(26)	-16	(33)	-29	(35)	-40	(38)	34.9	0.000
37	5	(15	-2	(22)	1	(19)	-17	(33)	-17	(32)	22.6	0.000
38	2	(19	-13	(31)	21	(6)	15	(12)	-9	(27)	25.5	0.000
39	8	(12	1	(19)	22	(5)	16	(10)	-5	(23)	15.3	0.000
40	-21	(37	-4	(24)	-17	(36)	-40	(40)	-41	(39)	57.7	0.000

5.4 Priorities for Improvement of the current Quality of Care in five EU countries

For each country, we combined priority scores with perceived quality to identify the attributeitems with the highest potential for improvement, which are also most important according the respondents from that country (Figures 5.7-5.11).

5.4.1 Priorities for Improvement of the current Quality of Care in the UK

The potential for improvement of the quality of the health care system for children in the UK is the highest for (figure 5.7):

- CONT; familiarity [item 24]. All health care providers involved in the care of a child know about each other's involvement, trust each other and work well together.
- ACC; opening hours [item 3]. Primary care services for children have ample opening hours, the after-hour care arrangements are good enough, and home-visits are planned if needed
- APP; time [item 13]. Primary care providers are able to dedicate enough time to working with a child.

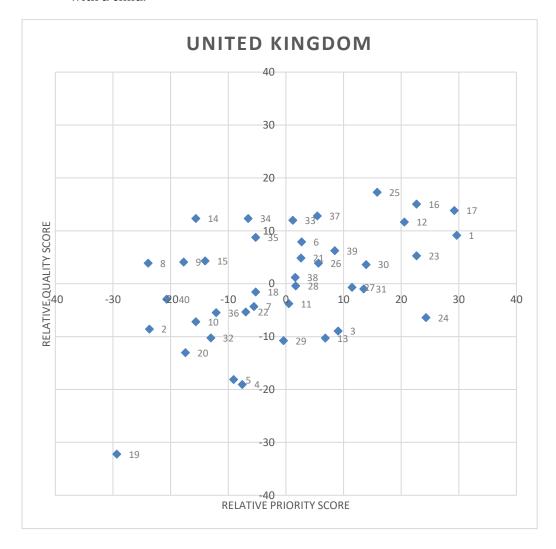


Figure 5.7. Potential for improvement of primary care for children in the United Kingdom.

5.4.2 Priorities for Improvement of the current Quality of Care in the Netherlands

The potential for improvement of the quality of the health care system for children in the Netherlands is the highest for (figure 5.8):

- APP; time [item 13]. Primary care providers are able to dedicate enough time to working with a child.
- ACC; range of services [item 6]. Children and/or their parents know about the range of services available in primary care and how they can access them.

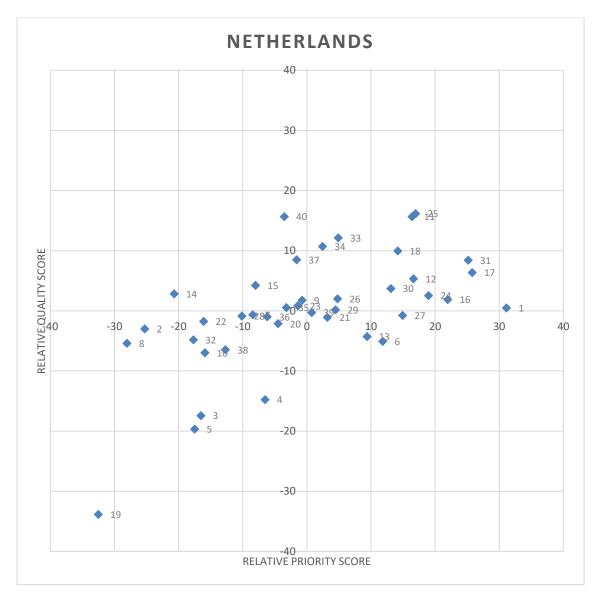


Figure 5.8. Potential for improvement of primary care for children in the Netherlands.

5.4.3 Priorities for Improvement of the current Quality of Care in Germany

The potential for improvement in Germany is highest with regard to (figure 5.9):

- CONT; familiarity [item 24]. All health care providers involved in the care of a child know about each other's involvement, trust each other and work well together.
- ACC; opening hours [item 3]. Primary care services for children have ample opening hours, the after-hour care arrangements are good enough, and home-visits are planned if needed.
- COOR; other health professionals [item 30]. If the main primary care provider of a child is not able to meet the needs of that child, that care can be given by other health professionals within the primary care practice.
- COOR; primary and secondary [item 27]. If a child needs specialised and long-term care, hospitals and primary care providers collaborate to offer care close to the child's home.
- AFF; feasible system [item 10]. The effort needed to get coverage and/or repayment for any out-of-pocket cost of primary care for a child is reasonable and feasible.

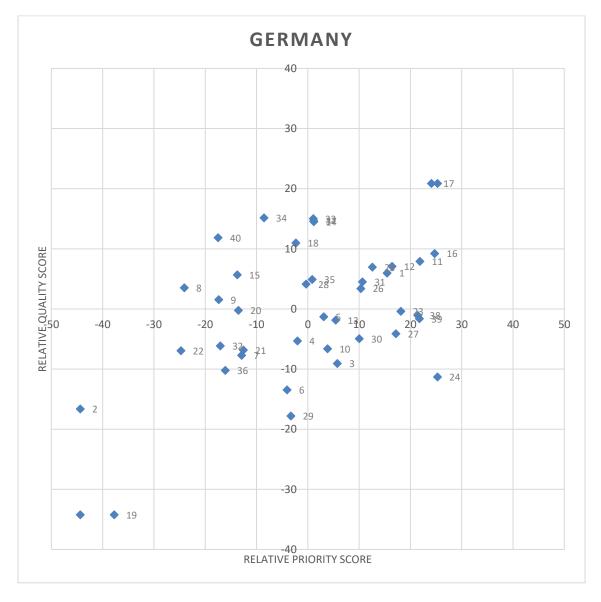


Figure 5.9. Potential for improvement of primary care for children in Germany.

5.4.4 Priorities for Improvement of the current Quality of Care in Spain

The potential for improvement in Spain is highest with regard to (figure 5.10):

- ACC; opening hours [item 3]. Primary care services for children have ample opening hours, the after-hour care arrangements are good enough, and home-visits are planned if needed.
- COOR; specialized care [item 29]. Specialised care (e.g. physiotherapy, dental healthcare, psychological care, specialised chronic care nurses) is available to a child within the primary care provider's practice.

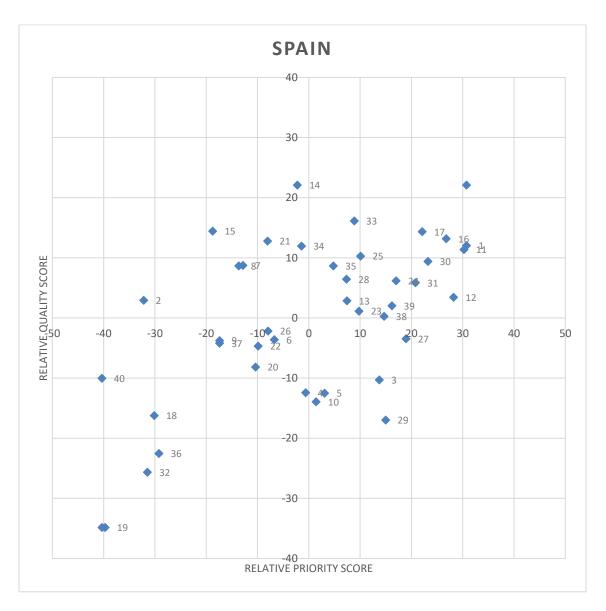


Figure 5.9. Potential for improvement of primary care for children in Spain.

5.4.5 Priorities for Improvement of the current Quality of Care in Poland

The potential for improvement in Poland is highest with regard to (figure 5.11):

- CONT; familiarity [item 24]. All health care providers involved in the care of a child know about each other's involvement. trust each other and work well together.
- APP; facilities [item 12]. In primary care, the facilities and equipment are available to deliver the services that are needed for children.
- ACC; referral primary care [item 4]. Children and/or their parents can make an appointment with other primary care providers without a referral from the main primary care provider.
- COOR; specialized care [item 29]. Specialised care (e.g. physiotherapy, dental healthcare, psychological care, specialised chronic care nurses) is available to a child within the primary care provider's practice.
- ACC; timely [item 1]. Primary care providers provide care within a reasonable amount of time, given the severity of the health issue.

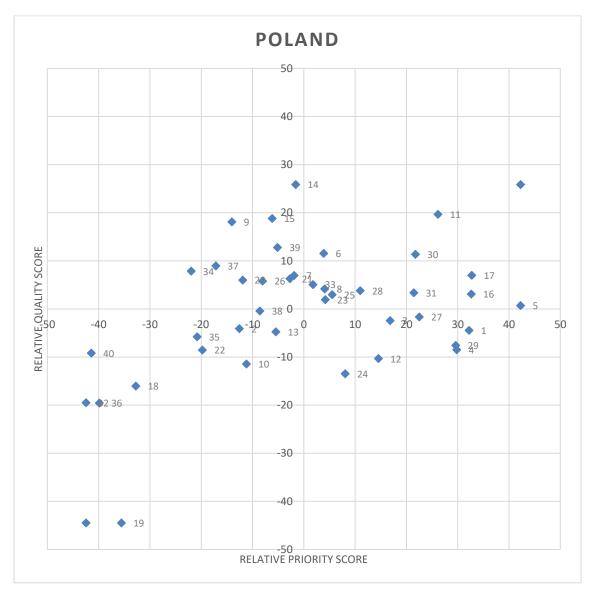


Figure 5.11. Potential for improvement of primary care for children in Poland.

6. Conclusions

6.1 Main Findings

The goal of the task, described in this report, was to elicit formative values from the general public in five European countries and to determine public priorities in the assessment of the quality of a child-oriented primary care system. We have achieved this goal through the following steps.

In the first step, we identified and defined the nine relevant outputs of a child-oriented health care system from a child, youth and carer centred perspective, as adopted in the MOCHA working model. The relevant outputs were: affordability, accessibility, appropriateness, continuity, coordination, equability, empowerment, transparency, and confidentiality. In the second step, through an iterative process within the MOCHA project team the outputs were operationalized. This resulted in 40 attribute-items in total: between one and nine items per output in order to cover the full description of each output. In the third step, perceptions of the quality of currently provided primary care for children and priorities with regard to quality assessment were elicited in a representative sample (N=2403) of the general public in the UK, the Netherlands, Germany, Spain and Poland.

6.1.1. Perceived Quality of Primary Care for Children in the EU

With regard to the satisfaction with primary care for children, the results of this study indicate that there is a significant difference in satisfaction with primary care for children between countries. Respondents from Spain were most satisfied, while respondents from Poland were least satisfied.

The aspect of a primary care system that was judged lowest was whether the child has the possibility to limit his parents' access to his medical records [item 19]. Less than half of respondents in the UK and the Netherlands to only a very small minority of respondents in Poland agreed with this statement. Other items, for which there is low agreement (bottom 10) in at least four out of five countries is the extent to which a child is able to express his opinions about his health management independently from his parents [item 32]; whether children and/or parents have the possibility to make an appointment with other primary care providers [item 4] and whether primary care services for children have ample opening hours, the afterhour care arrangements are good enough, and home-visits are planned if needed [item 3].

Large differences between countries were found for respondents' agreement on the statement whether the child has the right to a confidential consultation with a primary care provider [item 18]; whether primary care professionals are open about the quality of the health services [item 40]; the availability of primary care facilities and equipment [item 12]; and whether the opinion of the child is taken into account [item 36]. Agreement scores for these items were consistently lower in Poland and Spain.

6.1.2. Public Priorities for assessment of quality of Primary Care

Universal priorities for primary care for children according to the citizens from the five EU countries included in this study are: timeliness related to severity, efficacy, practitioner child specific skills (communication), ability to arrange all appropriate services [respectively items 1,

16, 17, 27]. Items which were consistently prioritized low in all countries were: whether primary care services for children have a convenient appointment system [item 2]; whether a child can limit their parents' access to the child's medical records in order to protect his privacy [item 19] and whether a child can express his opinions about his health management independently from his parents [item 32].

Although there are some aspects of care which seem to be universally prioritized (or not), each country also has its very specific priorities. For instance, very important to respondents in Poland was the extent to which children and/or their parents can make an appointment with other primary or secondary health care providers without a referral from a primary care provider [items 5 and 6]. This was prioritized much lower in other countries. In the top ten priorities in the Netherlands was whether a child has the right to a confidential consultation with the primary care provider [item 18; rank 10]. This item was prioritized much lower in the other countries. Finally, whether a child's health is not influenced by the parents' social status, economic situation, racial or ethnic background and/or geographic location [item 38, rank 6] is very important to respondents from Germany, but less important in other countries.

6.1.3. Quality vs. Priority

There are attribute-items of primary care which are universally judged low with regard to quality, but are not a priority to the country citizens in all countries. An example of such an item is whether a child can express his opinions about his health management independently from his parents [item 32]. If these findings were replicated in all countries, it could be that this attribute-item is not a determinant of a high quality primary care system. Besides, the answers depend to large degree on who is asked. If we would be able to ask children, they might probably express different priorities.

However, for the large majority of items, the results of this study indicate that strengths and weaknesses of the current primary care system and the public's priorities differ per country. This means that the potential for improvement is different in each country. A major strength of this study is that by combining priority scores with an evaluation of the perceived quality for each of the five countries, it became possible to identify the most important areas of potential improvement in each country.

A next step could be to analyse whether strengths in one country can be transferred to another country. An interesting attribute-item with respect to transferral is item 24: All health care providers involved in the care of a child know about each other's involvement, trust each other and work well together. This item is most important to respondents from Germany (a country with a paediatrician-led system and open access), and the quality of the current system in Germany is judged low on this item. The performance of the Spanish (also paediatrician-led, partial open access) and Dutch (GP-led, no open access) primary care systems are judged relatively good. It would be interesting to study how the Dutch, Spanish and German systems promote coordination between health care providers, and whether aspects of the Dutch or Spanish system with respect to this item could be transferred to Germany.

6.2 Strengths and Limitations

A limitation of this study is that, for practical reasons, it was not possible to extend this research to all 30 EU/EEA countries. In order to include respondents of countries with a diversity of

primary care systems, the criterion of 'lead-practitioner' was chosen. Of course, the design of our study does nog allow to relate differences in perceptions of or priorities for the current system to the criterion 'lead practitioner'. Moreover, although some "universal" priorities were found within the five countries included in the study, the diversity in priorities between countries does not allow generalization of these priorities to all EU countries.

Another limitation is that, although the samples of the five countries showed perfect representativeness for the background variables age and gender, four of them (UK, The Netherlands, Spain and Poland) showed an overrepresentation of middle and/or high-educated respondents. Only Germany showed an overrepresentation of low-educated respondents. Whether or not (and how) this has influenced the results of the study is not known. The difference between educational systems of countries does not permit to repeat the analyses for the high, middle, and low educational groups in the whole sample. In addition, the sample size per country does not allow sub-analyses according to educational level (or other background characteristics) per country.

A strength of this study is that the best-worst scaling methodology was used to prioritize attribute-items based on importance for a high quality primary care system for children. Best-worst scaling forces respondents to prioritize, in contrast to more traditional verbal or numerical rating scales per item. Even with the high number of attribute-items to prioritize, and thus the relatively low number of times each item was shown to keep the survey burden acceptable, this method proved to be successful in eliciting the general public's preferences and allowed for discrimination of priorities between the five countries.

6.3 Recommendations

This study shows that the POCHA questionnaire can be used to elicit the priorities of citizens in the EU for the assessment of the quality of the primary care system for children. Preferably, the questionnaire should first be further refined, shortened and validated, before it is enrolled in further countries. In addition, it would be interesting to develop a child-specific variant of the POCHA survey with children and young people, as this may uncover other priorities for primary care.

If prioritization by citizens is combined with performance evaluation of the current system, the results of such an exercise could help direct efforts for improvement of the health care system. Thereby, policy makers of countries that plan health care reform, can use the results of a survey such as the POCHA in their own country in their decision process.

References

- 1. Levesque J-F, Harris MF, Russell G. Patient-centred access to health care: conceptualising access at the interface of health systems and populations. Int J Equity Health. 2013;12(1):18.
- 2. WHO. Guidelines on Hand Hygiene in Health Care: First Global Patient Safety Challenge Clean Care Is Safer Care. Geneva: World Health Organization; 2009 [2:[
- 3. AHRQ UPDATES ON PRIMARY CARE RESEARCH: CARE COORDINATION MEASURES ATLAS AND DATABASE. Annals of family medicine. 2014;12(5):484-.
- 4. Evans DB, Hsu J, Boerma T. Universal health coverage and universal access. Bulletin of the World Health Organization. 2013;91(8):546-a.
- 5. Kringos DS, Boerma WG, Bourgueil Y, Cartier T, Hasvold T, Hutchinson A, et al. The European primary care monitor: structure, process and outcome indicators. BMC Fam Pract. 2010;11:81.
- 6. Declaration of Alma-Ata 1978 [Available from: http://www.euro.who.int/en/health-topics/Health-systems/primary-health-care/main-terminology.
- 7. Kringos DS, Boerma WG, Hutchinson A, van der Zee J, Groenewegen PP. The breadth of primary care: a systematic literature review of its core dimensions. BMC Health Serv Res. 2010;10:65.
- 8. Thomas S. ['European primary care': a visionary report of the Dutch Health Council on primary health care in the European Union]. Nederlands tijdschrift voor geneeskunde. 2005;149(20):1086-8.
- 9. Boerma W, Dubois C. Mapping primary care accross Europe. Saltman RB, Rico A, Boerma W, editors: Open University Press; 2007. 22-49 p.
- 10. Blair M, Rigby M. Final Report on Current Models of Primary Care for Children. . London; 2017.
- 11. Bronfenbrenner U. The Ecology of Human Development: Experiments by Nature And Design1979.
- 12. Donabedian A. The quality of care. How can it be assessed? Jama. 1988;260(12):1743-8.
- 13. Donabedian A. Explorations in quality assessment and monitoring. Volume 1, Volume 11980.
- 14. NZa. Visiedocument richting geven aan keuzes. 2007.
- 15. RIVM. De prestaties van de Nederlandse zorg. 2010.
- 16. Groenewegen PP, Kerssens JJ, Sixma HJ, van der Eijk I, Boerma WG. What is important in evaluating health care quality? An international comparison of user views. BMC Health Services Research. 2005;5(1):16.
- 17. Grol R, Wensing M, Mainz J, Ferreira P, Hearnshaw H, Hjortdahl P, et al. Patients' priorities with respect to general practice care: an international comparison. Family practice. 1999;16(1):4-11.
- 18. Sixma HJ, Kerssens JJ, Campen Cv, Peters L. Quality of care from the patients' perspective: from theoretical concept to a new measuring instrument. Health expectations. 1998;1(2):82-95.
- 19. Schäfer W, Kroneman M, Boerma W, Berg M, Westert G, Devillé W, et al. The Netherlands: health system review. Health systems in transition. 2010;12(1):xxvii, 1-228.
- 20. Schafer WL, Boerma WG, Kringos DS, De Maeseneer J, Gress S, Heinemann S, et al. QUALICOPC, a multi-country study evaluating quality, costs and equity in primary care. BMC Fam Pract. 2011;12:115.
- 21. Kringos DS, Boerma WG, Hutchinson A, Saltman RB. Building primary care in a changing Europe: World Health Organization, European Observatory on Health Systems and Policies; 2015.
- 22. Gené-Badia J, Ascaso C, Escaramis-Babiano G, Sampietro-Colom L, Catalán-Ramos A, Sans-Corrales M, et al. Personalised care, access, quality and team coordination are the main dimensions of family medicine output. Family practice. 2007;24(1):41-7.

- 23. Lavis JN, Anderson GM. Appropriateness in health care delivery: definitions, measurement and policy implications. CMAJ: Canadian Medical Association Journal. 1996;154(3):321-8.
- 24. Gulliford M, Naithani S, Morgan M. What is 'continuity of care'? Journal of health services research & policy. 2006;11(4):248-50.
- 25. Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. Continuity of care: a multidisciplinary review. BMJ (Clinical research ed). 2003;327(7425):1219-21.
- 26. Price M, Lau FY. Provider connectedness and communication patterns: extending continuity of care in the context of the circle of care. BMC Health Serv Res. 2013;13:309.
- 27. McDonald KM, Sundaram V, Bravata DM, Lewis R, Lin N, Kraft SA, et al. AHRQ Technical Reviews. Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies (Vol 7: Care Coordination). Rockville (MD): Agency for Healthcare Research and Quality (US); 2007.
- 28. Loukanova S, Molnar R, Bridges JF. Promoting patient empowerment in the healthcare system: highlighting the need for patient-centered drug policy. Expert review of pharmacoeconomics & outcomes research. 2007;7(3):281-9.
- 29. Gibson CH. A concept analysis of empowerment. Journal of advanced nursing. 1991;16(3):354-61.
- 30. Hanson K, Yip WC, Hsiao W. The impact of quality on the demand for outpatient services in Cyprus. Health economics. 2004;13(12):1167-80.
- 31. Brabers A, van Reitsma-Rooijen M. Patiënten over telefonische bereikbaarheid. Huisarts en wetenschap. 2011;54(5):265-.
- 32. Klink A. Visie op de eerstelijnszorg:" Dynamische eerstelijnszorg '. Den Haag: VWS. 2008.
- 33. Zorgbalans R. De prestaties van de Nederlandse gezondheidszorg'. 2014.
- 34. Wiegers T, Hopman P, Kringos D, Bakker Dd. NIVEL Overzichtstudies: de eerste lijn. 2011.
- 35. Anesi GL. The "decrepit concept" of confidentiality, 30 years later. The virtual mentor: VM. 2012;14(9):708-11.
- 36. Gostin LO, Turek-Brezina J, Powers M, Kozloff R, Faden R, Steinauer DD. Privacy and security of personal information in a new health care system. JAMA. 1993;270(20):2487-93.
- 37. Sankar P, Mora S, Merz JF, Jones NL. Patient Perspectives of Medical Confidentiality: A Review of the Literature. Journal of General Internal Medicine. 2003;18(8):659-69.
- 38. Rigby M, Roberts R, Williams J, Clark J, Savill A, Lervy B, et al. Integrated record keeping as an essential aspect of a primary care led health service. BMJ: British Medical Journal. 1998;317(7158):579-82.

Appendices

Appendix 1. List of attribute-items, themes and descriptions.

ITEM NR	ІТЕМ ТНЕМЕ	ITEM DESCRIPTION
1	ACC; timely [item 1]	Primary care providers provide care within a reasonable amount of time, given the severity of the health issue
2	ACC; appointment system [item 2]	Primary care services for children have a convenient appointment system
3	ACC; opening hours [item 3]	Primary care services for children have ample opening hours, the after-hour care arrangements are good enough, and home-visits are planned if needed
4	ACC; referral primary care [item 4]	Children and/or their parents can make an appointment with other primary care providers without a referral from the main primary care provider
5	ACC; referral secondary care [item 5]	Children and/or their parents can make an appointment with secondary or other health care providers without a referral from a primary care provider
6	ACC; range of services [item 6]	Children and/or their parents know about the range of services available in primary care and how they can access them
7	ACC; distance [item 7]	Primary care services for children are nearby, and are easily reached on foot or by bike, car and/or public transport
8	ACC; building [item 8]	Primary care services for children can be easily accessed with buggies, wheelchairs, or other assistive devices
9	ACC; medical record [item 9]	A child and/or his parents have access to a child's medical records
10	AFF; feasible system [item 10]	The effort needed to get coverage and/or repayment for any out-of-pocket cost of primary care for a child is reasonable and feasible
11	AFF; free point of delivery [item 11]	Primary care services for a child are free at the point of delivery, or out-of-pocket costs are fully covered or repaid by insurance
12	APP; facilities [item 12]	In primary care, the facilities and equipment are available to deliver the services that are needed for children
13	APP; time [item 13]	Primary care providers are able to dedicate enough time to working with a child
14	APP; clean [item 14]	Primary care services for children are provided in a clean and appealing setting
15	APP; primary care [item 15]	Health care for children is provided in the primary care setting whenever possible
16	APP; effective [item 16]	In primary care, a child's health problems are effectively managed
17	APP; expertise [item 17]	Primary care providers have the skills and competences to provide the care a child needs
18	CONF; consultation [item 18]	A child has the right to a confidential consultation with the primary care provider
19	CONF; privacy from parents [item 19]	In primary care, a child can limit their parents' access to the child's medical records in order to protect his privacy
20	CONF; authorization MR [item 20]	In primary care, the child and/or the parents have to authorise other health care providers accessing the child's medical records
21	CONT; medical record [item 21]	Any primary care provider caring for a child has access to a full overview of that child's medical records

22	CONT; relationship [item 22]	A child and his parents have a long-term relationship with primary care providers, beyond specific episodes of illness or disease
23	CONT; consistency [item 23]	Primary care providers offer a consistent and coherent approach to the management of a child's health, which is adjusted when the needs of that child change
24	CONT; familiarity [item 24]	All health care providers involved in the care of a child know about each other's involvement, trust each other and work well together
25	CONT; dignity and respect [item 25]	Primary care providers treat children and their parents with dignity and respect
26	CONT; easy to engage [item 26]	Primary care providers are easy to engage, considerate and non-judgmental of parents and children
27	COOR; primary and secondary [item 27]	If a child needs specialised and long-term care, hospitals and primary care providers collaborate to offer care close to the child's home
28	COOR; replacement [item 28]	If a child's main primary care provider is sick or on leave, a replacement is available quickly
29	COOR; specialized care [item 29]	Specialised care (e.g. physiotherapy, dental health, psychological care, specialised chronic care nurses) is available to a child within the primary care provider's practice
30	COOR; other health professionals [item 30]	If the main primary care provider of a child is not able to meet the needs of that child, that care can be given by other health professionals within the primary care practice
31	COOR; timely [item 31]	In primary care, a child is referred to other health care providers swiftly if this is needed
32	EMP; child independent [item 32]	In primary care, a child can express his opinions about his health management independently from his parents
33	EMP; well informed [item 33]	In primary care, children and their parents are well informed about (the management of) the child's health
34	EMP; understanding [item 34]	Primary care providers make reasonable efforts to ensure that a child and his parents understand the information they provide
35	EMP; self-management [item 35]	Children and/or their parents are assisted by primary care providers in acquiring the skills to promote and manage the child's health
36	EMP; opinions child [item 36]	Primary health care providers take into account the child's opinion on their management of the child's health
37	EMP; decision making [item 37]	In primary care, children and/or their parents are involved in decisions about the management of the child's health
38	EQA; child health [item 38]	A child's health is not influenced by the parents' social status, economic situation, racial or ethnic background and/or geographic location
39	EQA; child access [item 39]	A child's access to primary care and the quality of care he receives are not influenced by the parents' social status, economic situation, racial or ethnic background and/or geographic location
40	TRANS; quality [item 40]	Primary care providers are open about the quality of the health services available to children

Appendix 2. The POCHA questionnaire.



Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

Welcome,

On the next pages you will find a questionnaire about the quality of primary care for children in Europe.

This questionnaire was developed as part of the MOCHA project. The MOCHA project is a European project that aims to improve the quality of primary care for children in European countries. More information about MOCHA can be found on the website: http://www.childhealthservicemodels.eu/

We feel it is important to include the opinions of European citizens when assessing the quality of primary care for children in Europe. This is why we are asking for your opinions. You can help us by filling in this questionnaire. It is a chance to share your views on what is important in children's primary care in your country and how well you think that's being done at the minute. Filling in the questionnaire will take between 15 and 20 minutes.

Filling in this survey is open to all adult citizens in the countries we're studying, including those adults who do not have children (yet). You're not committed to anything and you can stop filling it in at any point.

Thank you very much for your help,

On behalf of the MOCHA team, Janine van Til and Magda Boere-Boonekamp

In this questionnaire we use the following definitions:

Primary care: Primary care refers to the work of health professionals who act as a first point of consultation for all patients within the health care system. This would usually be someone like a GP or your GP nurse. In some countries this also includes a pediatrician.

Secondary care: Secondary care refers to services provided by medical specialists who generally do not have the first contact with a patient. Secondary care is sometimes used to mean the same as hospital care.

Child: Every person under 18 years.

Background Information

This sections asks for a few details about you and your personal circumstances. We'll use this information to direct you to specific parts of the questionnaire.

Question 1. What is your age?

I am	19 years or younger	0	between 20 and 24
O	between 25 and 29	0	between 30 and 34
C	between 35 and 39	0	between 40 and 44
C	between 44 and 49	0	between 50 and 54
C	between 55 and 59	0	between 60 and 64
O	between 65 and 69	0	70 years or older

Question 2. What is your gender?

I am ... o Female o Male

Question 3. In which region of the UK do you live?

- o London
- o Yorkshire & Humberside
- East Midlands
- o East Anglia
- o South East
- South West
- West Midlands
- o North West
- $\circ \quad Scotland \\$
- o Wales
- o Northern Ireland
- o North East

Question 4. Are you a parent?

- o Yes
- No -> go to question 12

Question 5. How many children do you have?

- 0 1
- 0 2
- 0 3
- o Other, namely

Question 6. Are one or more of your children under the age of 18?

- o Yes
- o No -> go to question 12

Contact with healthcare providers

Question 7. How often have you had contact with the following care providers for your child(ren) in the past 12 months?

For programmer: In the current survey, 1 "other namely" needs to be filled in before the respondent can proceed! A respondent should be able to proceed without selecting "other".

Not at all	1	2	3	More than 3 times
0	0	0	0	0
0	0	0	0	0
0	0	0	0	0
0	0	0	0	0
0	0	0	0	0
0	0	0	0	0
0	0	0	0	0
0	0	0	0	0
0	0	0	0	0
	0 0 0 0 0 0 0			

Question 8. In the past 12 months, has (one of) your child(ren) had a medical condition that lasted longer than 6 weeks?

- o Yes
- o No -> go to question 12

Question 9. What condition was this/were these? Please indicate all conditions that apply for any child(ren) below the age of 18.

- o Eczema
- o Asthma
- o Hay fever
- Allergy
- Stomach ache
- o Headache
- o Back problems
- o Fatigue
- Sleep problems
- o Depressive complaints
- o Hyperactivity and ADHD

- Constipation
- o Overweight and obesity
- o Other:

Question 10. Was this condition treated in primary care, for example by your GP, a physiotherapist, social worker, etc.?

- Yes
- \circ No

Question 11. Was this condition treated in secondary care, for example, by a specialist in the hospital, in a rehabilitation centre, etc.?

- Yes
- \circ No

Child Autonomy

Question 12. Depending on their age, a child can operate independently from his or her parents. Later in this questionnaire, we will show you statements about the interaction between "the child and/or their parents" and primary care services.

To help us interpret your answers to those statements, can you tell us at what age you think a child should be able to do the following things. Where you read "his" in the descriptions below, you can also read "her".

The child	At ag	ge							
	<12	12	13	14	15	16	17	18	>18
knows about the range of services available in health care and how he can access them	0	0	0	0	0	0	0	0	0
can make an appointment with primary care providers without parental involvement	0	0	0	0	0	0	0	0	0
can make an appointment with secondary care providers without parental involvement	0	0	0	0	0	0	0	0	0
can express his opinions about his health management independently from those of the parents	0	0	0	0	0	0	0	0	0
can have a confidential consultation with the health care provider	0	0	0	0	0	0	0	0	0
can have access to his medical records	0	0	0	0	0	0	0	0	0
can authorise other health care providers to have access to his medical records	0	0	0	0	0	0	0	0	0
can limit access to his medical records from his parents, in order to protect his privacy	0	0	0	0	0	0	0	0	0
is responsible for promotion and management of his own health	0	0	0	0	0	0	0	0	0
is involved in decisions about the management of his own health	0	0	0	0	0	0	0	0	0

The Quality of Primary Care

To determine the quality of a health care system, we want to identify what people find important. In this part of the questionnaire we want you to tell us what you think is important in the assessment of primary care for children.

For this, we use a type of question which might be unfamiliar to you. This is an example of such a question:

For programmer: Adapt example to format used in SSI survey.

	most important	least important
Primary care providers treat children and their parents with dignity and respect	0	0
Primary care providers are easy to engage, considerate and non- judgmental of parents and children	0	0
If a child needs specialised long-term care, hospitals and primary care providers collaborate to offer care close to the child's home	0	0
If a child's main primary care provider is sick or on leave, a replacement is available quickly	0	0

In the question, you see a list of four potential characteristics of primary care. Read these carefully. First, choose which you find <u>most</u> important in primary care for children. Next, decide which of these characteristics you find <u>least</u> important in primary care for children.

→ Remove second example

Please note:

- You might feel all characteristics are important, but choose the answer based on what you feel should have the highest (and lowest) priority when a child visits primary care.
- It is not possible to select the same characteristic as most and least important.
- Where you read "his" in the descriptions of characteristics, you can also read "her".

Do you understand this type of question? Then please go to the next page of this questionnaire.

First, choose which you find <u>most</u> important in primary care for children. Next, decide which of these characteristics you find <u>least</u> important in primary care for children. Do this for every question. There are ten questions of this type.

Question 13.	most important	least important
Children and/or their parents can make an appointment with secondary or other health care providers without a referral from a primary care provider	0	0
Children and/or their parents know about the range of services available in primary care and how they can access them	0	0
Primary care services for children are nearby, and are easily reached on foot or by bike, car and/or public transport	0	0
Primary care services for children can be easily accessed with buggies, wheelchairs, or other assistive devices	0	0

Question 14.	most important	least important
A child and/or his parents have access to the child's medical records	0	0
The effort needed to get insurance coverage and/or repayment for the out-of-pocket cost of primary care for a child is reasonable and feasible	0	0
Primary care services for children are free at point of delivery, or covered or repaid by insurance	0	0
In primary care, the facilities and equipment are available to deliver the services that are needed for children	0	0

Question 15.	most important	least important
Primary care providers are able to dedicate enough time to working with a child	0	0
Primary care services for children are provided in a clean and appealing setting	0	0
Health care for children is provided in the primary care setting whenever possible	0	0
In primary care, a child's health problems are effectively managed	0	0

Question 16.	most important	least important
Primary care providers have the skills and competences to provide the care a child needs	0	0
A child has the right to a confidential consultation with his primary care provider	0	0
In primary care, a child can limit his parents' access to the child's medical records in order to protect his privacy	0	0
In primary care, the child and/or the parents have to authorise other health care providers accessing the child's medical records	0	0

Question 17.	most important	least important
Any primary care provider caring for a child has access to a full overview of that child's medical records	0	0
A child and his parents have a long-term relationship with primary care providers, beyond specific episodes of illness or disease	0	0
Primary care providers offer a consistent and coherent approach to the management of a child's health, which is adjusted when the needs of that child change	0	0
All health care providers involved in the care of a child know about each other's involvement, trust each other and work well together	0	0

Question 18.	most important	least important
Primary care providers treat children and their parents with dignity and respect	0	0
Primary care providers are easy to engage, considerate and non- judgmental of parents and children	0	0
If a child needs specialised and long -term care, hospitals and primary care providers collaborate to offer care close to the child's home	0	0
If a child's main primary care provider is sick or on leave, a replacement is available quickly	0	0

Question 19.	most important	least important
Specialised care (e.g. physiotherapy, dental healthcare, psychological care, specialised chronic care nurses) is available to a child within the primary care provider's practice	0	0
If the main primary care provider of a child is not able to meet the needs of that child, that care can be given by other health professionals within the primary care practice	0	0
In primary care, a child is referred to other health care providers swiftly if this is needed	0	0
In primary care, a child can express his opinions about his health management independently from his parents	0	0

Question 20.	most important	least important
In primary care, children and their parents are well informed about (the management of) the child's health	0	0
Primary care providers make reasonable efforts to ensure that a child and his parents understand the information they provide	0	0
Children and/or their parents are assisted by primary care providers in acquiring the skills to promote and manage the child's health	0	0
Primary health care providers take into account the child's opinion on their management of the child's health	0	0

Question 21.	most important	least important
In primary care, children and/or their parents are involved in decisions about the management of the child's health	0	0
A child's health is not influenced by the parents' social status, economic situation, racial or ethnic background and/or geographic location	0	0
A child's access to primary care and the quality of care he receives are not influenced by the parents' social status, economic situation, racial or ethnic background and/or geographic location	0	0
Primary care providers are open about the quality of the health services available to children	0	0

Question 22.	most important	least important
Primary care providers offer care within a reasonable amount of time, given the severity of the health issue	0	0
Primary care services for children have a convenient appointment system	0	0
Primary care services for children have ample opening hours, the after- hours care arrangements are good enough, and home-visits are planned if needed	0	0
Children and/or their parents can make an appointment with other primary care providers without a referral from the main primary care provider	0	0

Experiences of Primary Care

In the next part of the questionnaire we ask you about the experiences you have had with primary care for children in your country. If you have no direct experience of primary care for children, please answer based on your perceptions of primary care for children in your country. You can base your perceptions on media coverage and/or on stories from friends and family.

In the next ten questions we present statements about the potential quality of primary care for children. You can indicate to what extent you agree with each statement, on a scale of strongly disagree to strongly agree. Remember, you are indicating to what extent you feel that the proposition is true for the primary care system in place for children in your country.

	Strongly disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not Applicable
Primary care providers provide care within a reasonable amount of time, given the severity of the health issue	0	0	0	0	0	0
Primary care services for children have a convenient appointment system	0	0	0	0	0	0
Primary care services for children have ample opening hours, the after-hours care arrangements are good enough, and home-visits are planned if needed	0	0	0	0	0	0
Children and/or their parents can make an appointment with other primary care providers without a referral from the main primary care provider	0	0	0	0	0	0
Children and/or their parents can make an appointment with secondary or other health care providers without a referral from a primary care provider	0	0	0	0	0	0

Are you ready to continue with the questionnaire? Then go to the next page. Experiences with primary care

To what extent do you agree with the following statements? [rand 10] Q 22-32 [see programming notes, 10 out of 40 items at random, for each individual]

	Strongly disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Not Applicable
Primary care providers provide care within a reasonable amount of time, given the severity of the health issue	0	0	0	0	0	0
Primary care services for children have a convenient appointment system	0	0	0	0	0	0
Primary care services for children have ample opening hours, the after-hour care arrangements are good enough, and home-visits are planned if needed	0	0	0	0	0	0
Children and/or their parents can make an appointment with other primary care providers without a referral from the main primary care provider	0	0	0	0	0	0
Children and/or their parents can make an appointment with secondary or other health care providers without a referral from a primary care provider	0	0	0	0	0	0
Children and/or their parents know about the range of services available in primary care and how they can access them	0	0	0	0	0	0
Primary care services for children are nearby, and are easily reached on foot or by bike, car and/or public transport	0	0	0	0	0	0
Primary care services for children can be easily accessed with buggies, wheelchairs, or other assistive devices	0	0	0	0	0	0

A child and/or his parents have access to a child's medical records	0	0	0	0	0	0
The effort needed to get coverage and/or repayment for any out-of-pocket cost of primary care for a child is reasonable and feasible Primary care services for a	0	0	0	0	0	0
child are free at the point of delivery, or out-of-pocket costs are fully covered or repaid by insurance	0	0	0	0	0	0
In primary care, the facilities and equipment are available to deliver the services that are needed for children	0	0	0	0	0	0
Primary care providers are able to dedicate enough time to working with a child	0	0	0	0	0	0
Primary care services for children are provided in a clean and appealing setting	0	0	0	0	0	0
Health care for children is provided in the primary care setting whenever possible	0	0	0	0	0	0
In primary care, a child's health problems are effectively managed	0	0	0	0	0	0
Primary care providers have the skills and competences to provide the care a child needs	0	0	0	0	0	0
A child has the right to a confidential consultation with the primary care provider	0	0	0	0	0	0
In primary care, a child can limit his parents' access to the child's medical records in order to protect his privacy	0	0	0	0	0	0

In primary care, the child and/or the parents have to authorise other health care providers accessing the child's medical records	0	0	0	0	0	0
Any primary care provider caring for a child has access to a full overview of that child's medical records	0	0	0	0	0	0
A child and his parents have a long-term relationship with primary care providers, beyond specific episodes of illness or disease	0	0	0	0	0	0
Primary care providers offer a consistent and coherent approach to the management of a child's health, which is adjusted when the needs of that child change	0	0	0	0	0	0
All health care providers involved in the care of a child know about each other's involvement, trust each other and work well together	0	0	0	0	0	0
Primary care providers treat children and their parents with dignity and respect	0	0	0	0	0	0
Primary care providers are easy to engage, considerate and non-judgmental of parents and children	0	0	0	0	0	0
If a child needs specialised and long- term care, hospitals and primary care providers collaborate to offer care close to the child's home	0	0	0	0	0	0
If a child's main primary care provider is sick or on leave, a replacement is available quickly	0	0	0	0	0	0
Specialised care (e.g. physiotherapy, dental	0	0	0	0	0	0

healthcare, psychological care, specialised chronic care nurses) is available to a child within the primary care provider's practice						
If the main primary care provider of a child is not able to meet the needs of that child, that care can be given by other health professionals within the primary care practice	0	0	0	0	0	0
In primary care, a child is referred to other health care providers swiftly if this is needed	0	0	0	0	0	0
In primary care, a child can express his opinions about his health management independently from his parents	0	0	0	0	0	0
In primary care, children and their parents are well informed about (the management of) the child's health	0	0	0	0	0	0
Primary care providers make reasonable efforts to ensure that a child and his parents understand the information they provide	0	0	0	0	0	0
Children and/or their parents are assisted by primary care providers in acquiring the skills to promote and manage the child's health	0	0	0	0	0	0
Primary health care providers take into account the child's opinion on their management of the child's health	0	0	0	0	0	0
In primary care, children and/or their parents are involved in decisions about the management of the child's health	0	0	0	0	0	0

A child's health is not influenced by the parents' social status, economic situation, racial or ethnic background and/or geographic location	0	0	0	0	0	0
A child's access to primary care and the quality of care he receives are not influenced by the parents' social status, economic situation, racial or ethnic background and/or geographic location	0	0	0	0	0	0
Primary care providers are open about the quality of the health services available to children	0	0	0	0	0	0
Question 33. To what exten your country? Give your an	-			-		

Quality of Primary Care

In the last part of this questionnaire, we will ask another ten questions similar to the one's you answered before. First, choose which you find <u>most</u> important in primary care for children. Next, decide which of these characteristics you find <u>least</u> important in primary care for children. Do this for every question. There are ten questions of this type.

Again, where you read "his" in the characteristics below, you can also read "her".

Question 34.	most important	least important
Children and/or their parents can make an appointment with secondary or other health care providers without a referral from a primary care provider	0	0
Children and/or their parents know about the range of services available in primary care and how they can access them	0	0
Primary care services for children have ample opening hours, the after-hours care arrangements are good enough, and home-visits are planned if needed	0	0

Children and/or their parents can make an appointment with other		
primary care providers without a referral from the main primary	0	0
care provider		

Question 35.	most important	least important
A child and/or his parents have access to the child's medical records	0	0
The effort needed to get insurance coverage and/or repayment for the cost of primary care for a child is reasonable and feasible	0	0
Health care for children is provided in the primary care setting whenever possible	0	0
In primary care, a child's health problems are effectively managed	0	0

Question 36.	most important	least important
Primary care providers are able to dedicate enough time to working with a child	0	0
Primary care services for children are provided in a clean and appealing setting	0	0
Primary care services for a child are covered or repaid by insurance, and/or have acceptable out-of-pocket costs	0	0
In primary care, the facilities and equipment are available to deliver the services that are needed for children	0	0

Question 37.	most important	least important
Primary care providers have the skills and competences to provide the care a child needs	0	0
A child has the right to a confidential consultation with the primary care provider	0	0
Primary care providers offer a consistent and coherent approach to the management of a child's health, which is adjusted when the needs of that child change	0	0
All health care providers involved in the care of a child know about each other's involvement, trust each other and work well together	0	0

Question 38.	most important	least important
Any primary care provider caring for a child has access to a full overview of that child's medical records	0	0
A child and his parents have a long-term relationship with primary care providers, beyond specific episodes of illness or disease	0	0
In primary care, a child can limit his parents' access to the child's medical records in order to protect his privacy	0	0
In primary care, the child and/or the parents have to authorise other health care providers accessing the child's medical records	0	0

Question 39.	most important	least important
Primary care providers treat children and their parents with dignity and respect	0	0
Primary care providers are easy to engage, considerate and non- judgmental of parents and children	0	0
In primary care, a child is referred to other health care providers swiftly if this is needed	0	0
In primary care, a child can express his opinions about his health management independently from his parents	0	0

Question 40.	most important	least important
Specialised care (e.g. physiotherapy, dental healthcare, psychological care, specialised chronic care nurses) is available to a child within the primary care provider's practice	0	0
If the main primary care provider of a child is not able to meet the needs of that child, that care can be given by other health professionals within the primary care practice	0	0
If a child needs specialised and long-term care, hospitals and primary care providers collaborate to offer care close to the child's home	0	0
If a child's main primary care provider is sick or on leave, a replacement is available quickly	0	0

Question 41.	most important	least important
In primary care, children and their parents are well informed about (the management of) the child's health	0	0
Primary care providers make reasonable efforts to ensure that a child and his parents understand the information they provide	0	0
A child's access to primary care and the quality of care he receives are not influenced by the parents' social status, economic situation, racial or ethnic background and/or geographic location	0	0
Primary care providers are open about the quality of the health services available to children	0	0

Question 42.	most important	least important
In primary care, children and/or their parents are involved in decisions about the management of the child's health	0	0
A child's health is not influenced by the parents' social status, economic situation, racial or ethnic background and/or geographic location	0	0
Children and/or their parents are assisted by primary care providers in acquiring the skills to promote and manage the child's health	0	0
Primary care providers take into account the child's opinion on their management of the child's health	0	0

Question 43.	most important	least important
Primary care providers provide care within a reasonable amount of time, given the severity of the health issue	0	0
Primary care services for children have a convenient appointment system	0	0
Primary care services for children are nearby, and are easily reached on foot or by bike, car and/or public transport	0	0
Primary care services for children can be easily accessed with buggies, wheelchairs, or other assistive devices	0	0

Finally, we want to collect some background information about you as a person. This information will allow us to check whether the group of people completing the questionnaire is a good representation of the people living in your country.

Question 44. What is your highest level of completed education?

I have completed ... o Entry level

GCSE (grades D-G)GCSE (grades A*-C)

o A-Level

o Higher National Certificate/National Diploma

Bachelor DegreeMaster DegreeDoctoral Degree

Question 45. What is the size of the city you live in?

I live in a city with a \circ < 100

population of ... o 100 – 1.000

1.000 - 10.00010.000 - 20.000

0 20.000 - 100.000

100.000 - 200.000200.000 - 1.000.000

> 1.000.000

Thank you for your participation in completing the questionnaire. Your answers will be used to determine priorities in improving the quality of the primary care system for children.

Appendix 3. Combinations of attribute-items used in the experimental design.

version 1					version 2				
question	item 1	item 2	item 3	item 4	question	item 1	item 2	item 3	item 4
13	16	20	27	32	13	16	26	27	37
14	6	10	19	35	14	4	6	7	39
15	5	12	22	28	15	8	20	23	30
16	13	17	29	38	16	7	18	25	38
17	17	31	33	35	17	3	5	24	27
18	9	22	27	33	18	9	12	15	33
19	3	15	21	38	19	6	17	34	37
20	7	26	30	34	20	1	11	21	40
21	5	8	14	18	21	3	23	29	31
22	19	21	24	40	22	8	14	26	28
34	4	7	13	16	34	10	13	17	22
35	6	14	25	34	35	5	10	21	32
36	1	18	23	29	36	4	9	14	32
37	11	30	31	37	37	15	22	31	35
38	4	28	39	40	38	1	19	20	34
39	1	2	37	39	39	2	12	16	36
40	12	15	26	36	40	29	36	39	40
41	8	11	24	32	41	2	13	30	38
42	10	20	23	36	42	11	25	28	35
43	2	3	9	25	43	18	19	24	33

version 3						version 4				
question		item 1	item 2	item 3	item 4	question	item 1	item 2	item 3	item 4
	13	12	21	35	39	13	7	19	20	31
	14	3	18	22	23	14	3	12	23	33
	15	13	24	27	29	15	2	14	26	30
	16	4	8	16	31	16	24	28	36	40
	17	14	28	30	40	17	15	27	34	38
	18	2	14	25	38	18	5	14	20	36
	19	6	11	17	39	19	1	3	4	6
	20	9	24	35	36	20	2	17	21	32
	21	1	3	27	40	21	10	16	29	39
	22	16	19	30	32	22	19	22	25	35
	34	10	19	36	37	34	1	5	13	34
	35	15	20	26	29	35	18	29	38	40
	36	7	31	33	34	36	11	22	23	28
	37	5	15	37	38	37	4	7	9	10
	38	6	18	26	32	38	16	30	33	37
	39	1	7	10	11	39	8	9	24	32
	40	2	9	23	33	40	11	13	21	39
	41	8	13	17	25	41	6	18	26	35
	42	20	21	28	34	42	8	25	27	37
	43	4	5	12	22	43	12	15	17	31

Appendix 4. Location quota used for sampling per location in each country.

Region of UK	Percentage
East Anglia	9.075
East Midlands	7.142
London	13.791
North East	4.125
North West	11.13
Northern Ireland	2.834
Scotland	8.516
South East	13.463
South West	8.145
Wales	4.756
West Midlands	8.685
Yorkshire & Humberside	8.337

Region of The Netherlands	Percentage
Drenthe	2.841
Flevoland	2.372
Friesland	3.791
Gelderland	11.881
Groningen	3.569
Limburg	6.773
Noord-Brabant	14.724
Noord-Holland	16.412
Overijssel	6.666
Utrecht	7.447
Zeeland	2.206
Zuid-Holland	0.21318

Region of Germany	Percentage
Baden-Württemberg	13.04
Bayern	15.557
Berlin	4.27
Brandenburg	3.101
Bremen	0.818
Hamburg	2.197
Hessen	7.488
Mecklenburg-Vorpommern	2.059
Niedersachsen	9.51
Nordrhein-Westfalen	21.753
Rheinland-Pfalz	4.974
Saarland	1.249
Sachsen	4.968
Sachsen-Anhalt	2.858
Schleswig-Holstein	3.396

POCHA end report

Thüringen	2.762

Region of Spain	Percentage
Andalucía	18.275
Aragón	2.79
Asturias (Principado de)	2.233
Balears (Illes)	2.547
Canarias	4.883
Cantabria	1.261
Castilla -La Mancha	4.398
Castilla y León	5.144
Cataluña	15.762
Ceuta and Melilla	0.361
Comunidad Valenciana	10.608
Extremadura	2.329
Galicia	5.724
Madrid (Com. De)	13.958
Murcia (Región de)	3.172
Navarra (C. Foral de)	1.343
País Vasco	4.552
Rioja (La)	0.66

Region of Poland	Percentage
Dolnoslaskie	7.69
Kujawsko-Pomorskie	5.437
Lódzkie	6.632
Lubelskie	5.527
Lubuskie	2.695
Malopolskie	8.532
Mazowieckie	13.566
Opolskie	2.735
Podkarpackie	5.44
Podlaskie	3.051
Pomorskie	5.846
Slaskie	12.275
Swietokrzyskie	3.277
Warminsko-Mazurskie	3.754
Wielkopolskie	9.021
Zachodnio-Pomorskie	4.521

Appendix 5. Categories and distribution of educational level for each of the five countries.

NL

Netherlands	1	LO (lagere school, LAVO, VGLO)		
	2	LBO (LBO, LTS, ITO, LEAO, Huishoudschool, LLO)	Low	34.3%
	3	MAO (MAVO, IVO, MULO, ULO, 3jr HBS, 3jr VWO, 3jr VHMO)		
	4	MBO (MTS, UTS, MEAO)	Middle	42.1%
	5	HAO (HAVO, VWO, Atheneum, Gymnasium, NMS, HBS, Lyceum)	ivildale	42.170
	6	HBO (HTS, HEAO, Wetensch. kand., Univers. onderwijs kand.)	High	23.6%
	7	WO (Universitair onderwijs, Doctoraalopleiding, TH)	nign	23.0%

UK

	1 Combined Junior and Infant School / Infant School		
UK	2 Junior School	Low	37.0%
	3 Comprehensive School		
	4 Comprehensive School (GCSE)/ Secondary Modern (GCSE)/ Grammar School (GSCE)/ City Technology College (CGSE)/ Sixth Form	Middle	36.0%
	5 College and Institution of Higher education		
	6 Open College -College of Technology - Institute/ Teacher Training College	High	27.0%
	7 University/ Open University		

DE

Germany	1	Grundschule Hauptschule	Low	17.0%
	3	Realschule	LOW	17.0%
	4	Gymnasium/ Berufliches Gymnasium/ Fachgymnasium, Gesamtschule	Middle	60.0%
	5	Fachoberschule, Fachschule, Berufsschule, Berufsfachschule	Wilddle	00.076
	6	Technische Hochschule, Pädagogische Hochschule, Kunsthochschule/ Musikhochschule		
	7	Fachhochschule	High	23.0%
	8	Universität, Technische Universität		

PL

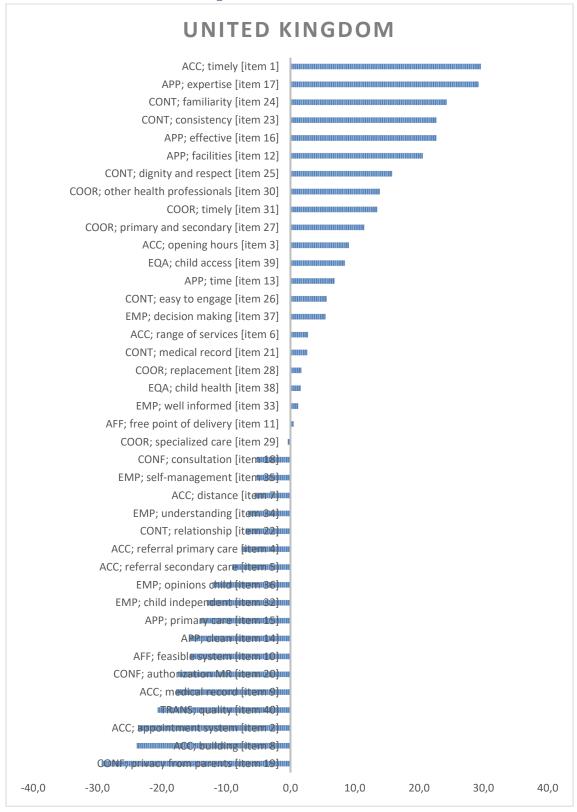
	1	Szkola podstawowa / Gimnazjum	Low	53.1%
Poland	2	Technikum / Liceum Ogólnoksztalcace / Szkola Zasadnicza / Liceum Profilowane	Middle	34.4%
	3	Panstwowe Wyzsze Szkoly Zawodowe- Niepanstwowe Szkoly Wyzsze - Wyzsze Szkoly Zawodowe		
	4	Szkoly Morskie - Wojskowe / Wyzsza Szkola Policji - Pedagogiczne		
	5	Akademie Muzyczne, Sztuk Pieknych, Teatralne I Filmowe Teologiczne - Wychowania Fizycznego - Medyczne -Rolnicze – Ekonomiczne	High	12.5%
	6	Politechniki		
	7	Uniwersytety		1

ES

	1	Educación Primaria	Low	56.0%	
Spain	2	Educación Secundaria Obligatoria (ESO)/BUP	LOW	30.070	
	3	Bachillerato/Curso de Orientación Universitaria (COU)	Middle	18.0%	
	4	Formación Profesional	Wilddle	16.076	
	5	Ciclo formativo de Grado Superior			1
	6	Licenciatura/Diplomatura/Ingeniería	High	26.0%	
	7	Tercer Ciclo/Doctorado		i	1

Appendix 6. Priorities per country.

Public Priorities in the United Kingdom

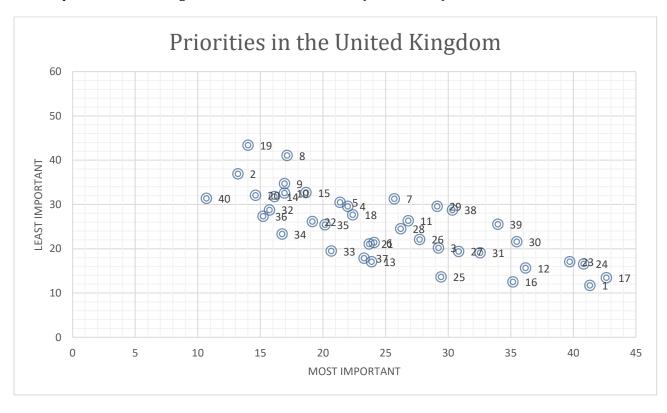


Most important in the UK are:

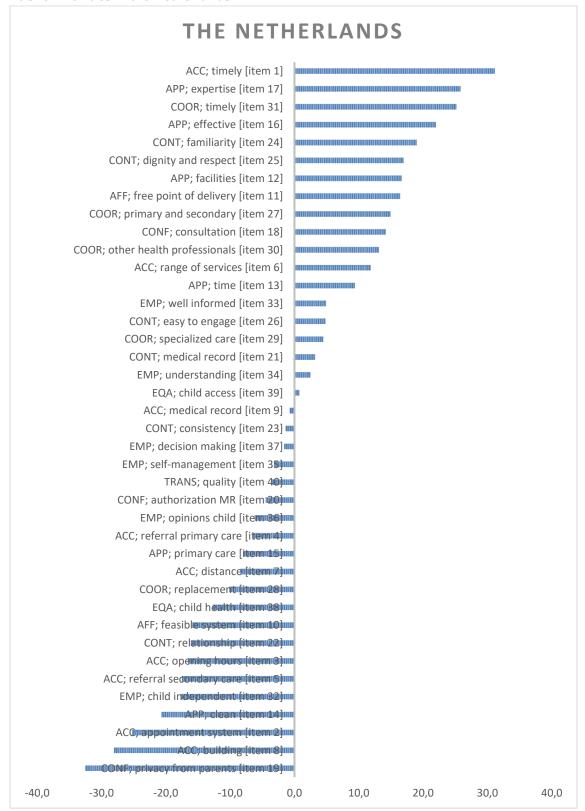
- 1. Primary care providers provide care within a reasonable amount of time, given the severity of the health issue (attribute 1)
- 2. Primary care providers have the skills and competences to provide the care a child needs (attribute 17)
- 3. All health care providers involved in the care of a child know about each other's involvement, trust each other and work (attribute 24)
- 4. Primary care providers offer a consistent and coherent approach to the management of a child's health, which is adjusted (attribute 23)
- 5. In primary care, a child's health problems are effectively managed (attribute 16)

Least important in the UK are:

- 1. In primary care, a child can limit parental access to the child's medical records in order to protect his privacy (attribute 19)
- 2. Primary care services for children can be easily accessed with buggies, wheelchairs, or other assistive devices (attribute 8)
- 3. Primary care services for children have a convenient appointment system (attribute 2)
- 4. Primary care providers are open about the quality of the health services available to children (attribute 40)
- 5. A child and/or his parents have access to a child's medical records (attribute 9)
- 6. In primary care, the child and/or the parents have to authorise other health care providers accessing the child's medical records (attribute 20)



Public Priorities in the Netherlands

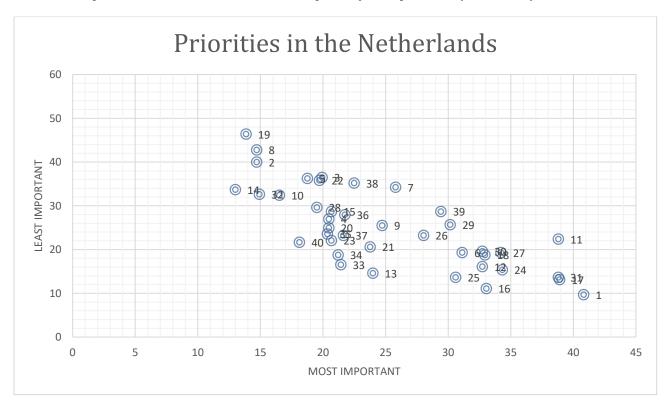


Most important in the Netherlands are:

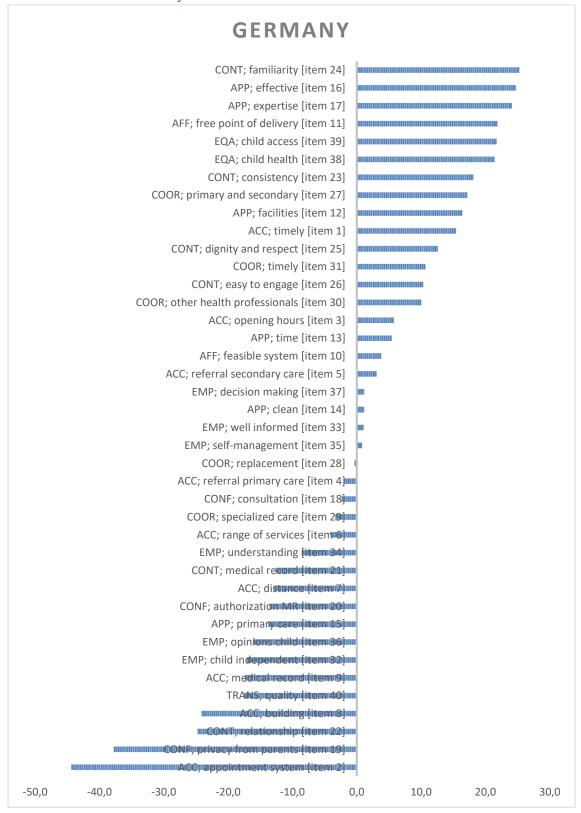
- 1. Primary care providers provide care within a reasonable amount of time, given the severity of the health issue (attribute 1)
- 2. Primary care providers have the skills and competences to provide the care a child needs (attribute 17)
- 3. In primary care, a child is referred to other health care providers swiftly if this is needed (attribute 31)
- 4. In primary care, a child's health problems are effectively managed (attribute 16)
- 5. All health care providers involved in the care of a child know about each other's involvement, trust each other and work (attribute 24)

Least important in the Netherlands are:

- 1. In primary care, a child can limit parental access to the child's medical records in order to protect his privacy (attribute 19)
- 2. Primary care services for children can be easily accessed with buggies, wheelchairs, or other assistive devices (attribute 8)
- 3. Primary care services for children have a convenient appointment system (attribute 2)
- 4. Primary care services for children are provided in a clean and appealing setting (attribute 14)
- 5. In primary care, a child can express his opinions about his health management independently from his parents (attribute 32)
- 6. Children and/or their parents can make an appointment with secondary or other health care providers without a referral from a primary care provider (attribute 5)



Public Priorities in Germany

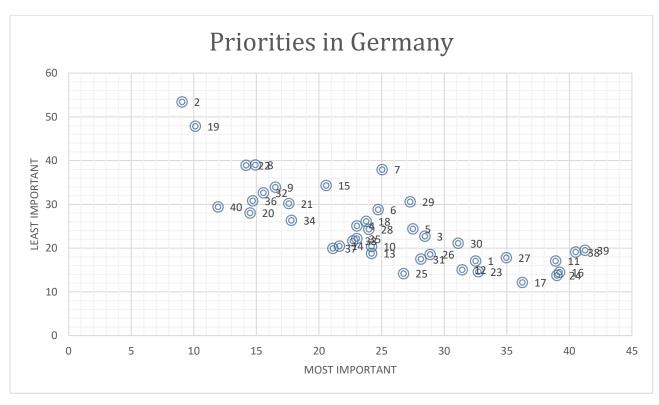


Most important in Germany are:

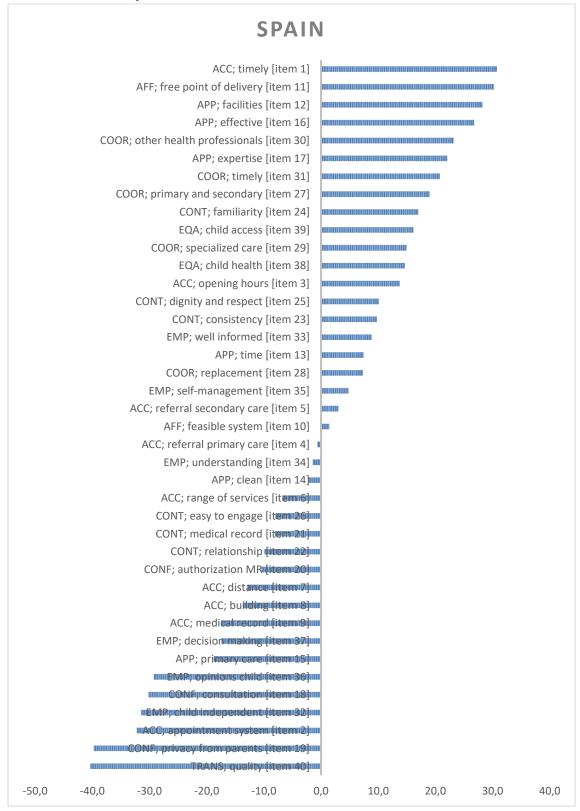
- 1. All health care providers involved in the care of a child know about each other's involvement, trust each other and work (attribute 24)
- 2. In primary care, a child's health problems are effectively managed (attribute 16)
- 3. Primary care providers have the skills and competences to provide the care a child needs (attribute 17)
- 4. Primary care services for a child are free at the point of delivery, or out-of-pocket costs are fully covered or repaid (attribute 11)
- 5. A child's access to primary care and the quality of care he receives are not influenced by the parents' social status, economic situation, racial or ethnic background and/or geographic location (attribute 39)

Least important in Germany are:

- 1. Primary care services for children have a convenient appointment system (attribute 2)
- 2. In primary care, a child can limit parental access to the child's medical records in order to protect his privacy (attribute 19)
- 3. A child and his parents have a long-term relationship with primary care providers, beyond specific episodes of illness or disease (attribute 22)
- 4. Primary care services for children can be easily accessed with buggies, wheelchairs, or other assistive devices (attribute 8)
- 5. Primary care providers are open about the quality of the health services available to children (attribute 40)
- 6. A child and/or his parents have access to a child's medical records (attribute 9)
- 7. In primary care, a child can express his opinions about his health management independently from his parents (attribute 32)



Public Priorities in Spain

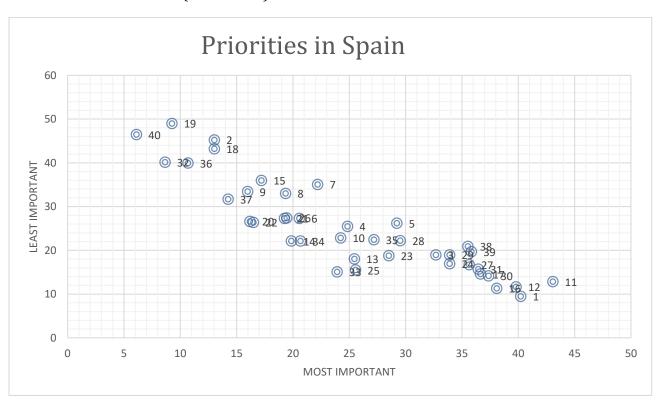


Most important in Spain are:

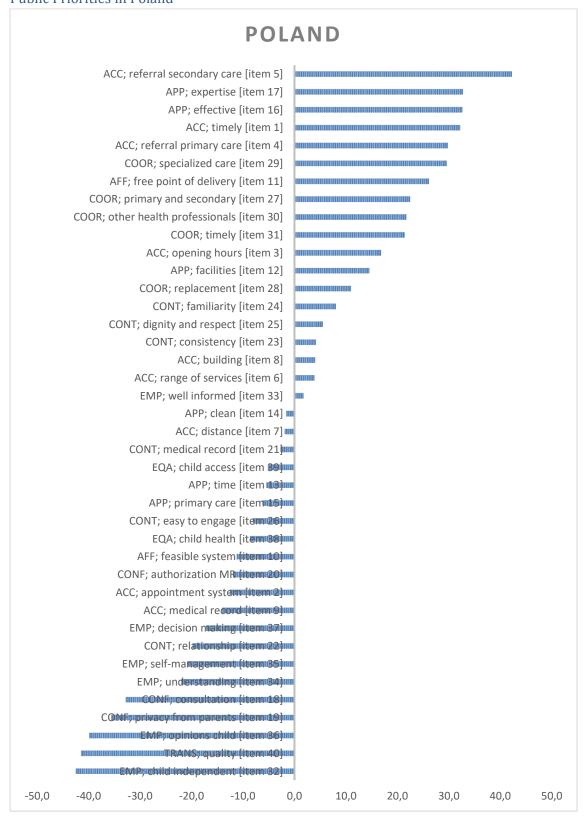
- 1. Primary care providers provide care within a reasonable amount of time, given the severity of the health issue (attribute 1)
- 2. Primary care services for a child are free at the point of delivery, or out-of-pocket costs are fully covered or repaid (attribute 11)
- 3. In primary care, the facilities and equipment are available to deliver the services that are needed for children (attribute 12)
- 4. In primary care, a child's health problems are effectively managed (attribute 16)
- 5. If the main primary care provider of a child is not able to meet the needs of that child, that care can be given by other health professionals within the primary care practice (attribute 30)

Least important in Spain are:

- 1. Primary care providers are open about the quality of the health services available to children (attribute 40)
- 2. In primary care, a child can limit parental access to the child's medical records in order to protect his privacy (attribute 19)
- 3. Primary care services for children have a convenient appointment system (attribute 2)
- 4. In primary care, a child can express his opinions about his health management independently from his parents (attribute 32)
- 5. A child has the right to a confidential consultation with the primary care provider (attribute 18)
- 6. Primary health care providers take into account the child's opinion in their management of the child's health (attribute 36)



Public Priorities in Poland



Most important in Poland are:

- 1. Primary care providers provide care within a reasonable amount of time, given the severity of the health issue (attribute 5)
- 2. Primary care providers have the skills and competences to provide the care a child needs (attribute 17)
- 3. In primary care, a child's health problems are effectively managed (attribute 16)
- 4. Primary care providers provide care within a reasonable amount of time, given the severity of the health issue (attribute 1)
- 5. Children and/or their parents can make an appointment with other primary care providers without a referral from the main primary care provider (attribute 4)

Least important in Poland are:

- 1. In primary care, a child can express his opinions about his health management independently from his parents (attribute 32)
- 2. Primary care providers are open about the quality of the health services available to children (attribute 40)
- 3. Primary health care providers take into account the child's opinion on their management of the child's health (attribute 36)
- 4. In primary care, a child can limit parental access to the child's medical records in order to protect his privacy (attribute 19)
- 5. A child has the right to a confidential consultation with the primary care provider (attribute 18)
- 6. Primary care providers make reasonable efforts to ensure that a child and his parents understand the information they provide (attribute 34)
- 7. Children and/or their parents are assisted by primary care providers in acquiring the skills to promote and manage the child's health (attribute 35)

