



## Models of Child Health Appraised

(A Study of Primary Healthcare in 30 European countries)

# Work Package 1: Report on Patient Experiences of Primary Care in 5 DIPEx countries

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# **Report on Patient experiences of primary care in 5 DIPEx countries**

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## Introduction

Children in Europe are recipients of various models of primary care, the merits of which have not been scientifically studied until now. This means that many children may be receiving preventive and health care services which are based on models that are not optimal. The overall aim of MOCHA is to appraise existing models of primary health care for children with the ultimate objective of improving overall child health as a whole in Europe. To achieve this, a mixed methods approach is used. This report presents the results of a qualitative study of children's experiences of primary care using the tried and tested methodology developed by the Health Experiences Research Group (formerly DIPEx), University of Oxford (<http://www.healthtalk.org/research/research-methods>). Qualitative researchers from five different countries that are part of the DIPEx International network worked collaboratively to explore patients' experiences in their respective countries across Europe: Czech Republic, Germany, The Netherlands, Spain and United Kingdom. This study sits within the wider work of Work Package 1 (Identification of models of children's primary health care) and Work Package 2 (Interface with secondary, social and complex care). The specific objective of this task is to provide insights into the experiences of children and parents in terms of primary health care for children and the primary/secondary care interface. Including the views of children, young people and their parents is an essential component in the appraisal of health systems. A system may well work efficiently but, if it has no relevance to its users, it cannot be considered a successful determinant of good health. Qualitative inquiry into children's and parent's experiences of primary health care for children will provide valuable triangulation and identification of areas of concern to children, young people and their families.

## Structure of the report

**Chapter 1** aims to provide contextual information. This includes background information on: the different health systems in the five countries; studying patient experiences and DIPEx International; and an overview of existing literature on patients' experiences of primary care services for children. **Chapter 2** describes the methodology used to collect children's experiences and those of parents. The chapter describes how participants were recruited and gives an overview of all participants included in the study. The chapter also describes how data were analysed. The findings are described in **Chapter 3 - 12**. Patients' experiences of the following themes are presented in this chapter: Reasons for using primary care services; Accessing primary care services; The surgery environment; Relationships with primary care professionals; Continuity of care; Medical records; Independence and autonomy; Health information; The role of schools; and Financial issues. Within each chapter several subthemes are described. Each subtheme starts with a description of the experiences of "healthy" children and their parents which is followed by two paragraphs describing the experiences of children with mental and physical health conditions and their parents. Each chapter is closed with a paragraph including suggestions for improving services. **Chapter 13** provides an overview of the main conclusions which will be discussed in the context of existing literature. The strengths and limitations of the study are also discussed.

## Chapter 1 - Background

### 1.1 Introduction

This chapter aims to provide an overview of a number of key concepts and themes that are the backdrop to the task of examining patient experiences. This includes a description of the health care systems in the five different countries, an introduction to patient experiences, and an overview of the existing literature on patients' experiences of primary health care for children. The aims and objectives of the task are also described.

### 1.2 Primary care

Primary health care is defined broadly as the first port of call for any individual in need of preventive or curative health advice and action. It is an important determinant of health and takes many forms (Davy et al., 2015; WHO 2008). The core principles of primary care are that it is:

- Generalist in nature: primary care focuses on the person who needs advice or treatment, rather than on a specific disease or area of the body (Kringos, 2015);
- Person centred: the provision of care has to be tailored to patients' needs (Saltman, 2006);
- Provides first contact with health services;
- Provides a referral point to other forms of care: primary care has a gatekeeping role in some countries;
- Coordinates care: primary care is a key factor in coordinating care that extends over different specialities and specialists (Kringos, 2010; WHO, 2012)
- Provides continuity of care over the life course and with chronic disease: a primary care physician and team of other health professionals may care for the child throughout his or her childhood, and continue to care for the family throughout a large part of their lives (Kringos 2015; WHO 2016);
- Involves teamwork and collaboration: primary care is comprised of a number of health professionals working alongside each other, and in many cases in collaboration with the patients, or in the case of younger children, with their carers/families (Kringos, 2015);
- Features preventive care throughout the child's life course: preventive care concentrates on the growth and development of the child, to prevent the child from severe health problems (Wieske et al., 2012);
- Home-centred care (Blair et al., 2017: page 19).

### **1.2.1 Primary care for children**

Primary care for children fits within this generic picture, but has to accommodate the very different physiological and intellectual developments of the child compared with adults; the range of specific childhood conditions and illnesses; the high dependence at least in the early years on parents or guardians who are not the 'patient' but vital to the child's wellbeing and their access to health care; and the complex interaction with society including in particular the education sector (Van Dijk, 2008; Blair et al., 2017). In terms of health service users, it is estimated that children in England make up 25% of a typical primary care practice population, but are associated with 40% of the workload (Wolfe, 2013). Thus they are an important group who have a great deal of contact with primary care services (Del Torso et al., 2013).

Initial analyses of models of primary care for children have focused on the type of lead practitioner – defined in the MOCHA project as the individual who takes clinical responsibility for the child. The models organised by lead practitioners have typically been organised into three broad categories: those that are led by a primary care paediatrician; those that are led by a general practitioner (GP); and those that have a mixed model, with both health professionals available for consultation. Several forms and models of primary care exist for children and young people in Europe and these include (Blair et al., 2017: page 19):

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

The following section describes the forms and models of primary child health care in the five countries involved in this study: Czech Republic, Germany, Netherlands, Spain and United Kingdom.

### **1.2.2 Primary child health care in the five countries**

A short description of every system will be provided, after which the similarities and differences between the five countries will be elucidated.

#### **1.2.2.1 Primary care in Czech Republic**

The first person a child or family speaks to about a medical issue of concern is the paediatrician, who is also the lead practitioner. The Czech Republic has a specialty which is a general practitioner for children and adolescents who, when selected by parents, becomes

the “registering paediatrician” for the child. It is usually necessary to be registered with the paediatrician in order to be able to receive care. Primary health care for children in the Czech Republic includes preventive care (preventive examinations and vaccinations), diagnostic care, therapeutic care, assessments, and coordination of care provided by other health care professionals. Primary care paediatricians collaborate with the Regional Public Health Offices in epidemiological surveillance by reporting cases of selected communicable diseases. Preventive examinations for children are conducted by the registering GP, a paediatrician in primary care. The first examination must be completed during the first two weeks of a child’s life. In total, there are 9 preventive examinations in the first year of life. After that, there is a preventive examination at 18 months of age and, after the child is 3 years old, there are preventive examinations every two years (Samková & Velemínský, 2012). In total, there are 9 preventive check-ups from 3 years to adulthood plus there is one exit examination when the individual is 18 years before transitioning to adult care. All examinations are covered through public health insurance. Access to secondary care is open, but at the same time a referral system is functional. As such, primary care paediatricians do not play a true gatekeeping role. Out-of-hours primary care is provided by emergency departments of hospitals and serves to handle urgent medical issues. Ninety percent of the population have health insurance via public health insurance companies, so-called sickness funds. For people who are not employed – including children – this fund receives monthly payments from the state. Usually, primary health care professionals are sole practitioners who often employ a nurse who has administrative duties and conducts home visits. Each paediatrician has a maximum of 1023 children on list (Alexa et al., 2015). Czech Republic has a statist social health system in which the state holds the regulatory power but grants privileges for the financing and provision of health services to social actors (e.g., sickness funds with their own health facilities) (Böhm et al., 2013).

#### **1.2.2.2 Primary care in Germany**

The first person a child or family speaks to about a medical issue is the paediatrician, who is also the lead practitioner. Ninety percent of the paediatricians also work as a GP (Busse et al., 2014). The German health care system has traditionally no gatekeeping system; there is open access to secondary care. Out-of-hours services are organized in the same way everywhere in Germany. When no GP is available (late evenings, weekends, holidays) there is a specific location in every city where patients can go and see a GP if it is an emergency. There is also a centralized number that patients can call to find out about the location of out-of-hours services. In many cases the surgery is inside a hospital or one of the usual GP surgeries. Every GP is required to take part and be at this location a couple of days per month. There are 9 preventive child health examinations in total in Germany between birth and age 6. Health insurance is mandatory under the “Gesetzliche Krankenversicherung” and is based on a social health insurance system in which societal actors have competencies to regulate and finance the health system but where most service providers perform for profit (Böhm et al., 2013). As a consequence, children and parents can select any family physician, or register voluntarily with a family physician who is enrolled in the “family physician care model” of a sickness fund. Health professionals organise care independently, without strong regulation from the state or insurance funding. Patient and professional freedom is

emphasized in Germany; as a consequence patients have had free choice of physicians since 1999.

#### **1.2.2.3 Primary care in The Netherlands**

The first person a child or family will speak to about a medical issue is a GP, who treats almost all uncomplicated health problems and is the cornerstone of Dutch primary care. Everyone is required to register with a GP. Currently, 30% of GPs work solo, 30% in multidisciplinary health centres, and 40% in group practices. Out-of-hours primary care is provided by general practitioner cooperatives and is available daily from 5 p.m. to 8 a.m. on weekdays and throughout the weekend. It is intended for urgent complaints that cannot wait until the next day (Giessen et al., 2011). Practice assistants and practice nurses play an important role in the surgery. Practice assistants perform routine diagnostic and therapeutic interventions and serve as patients' point of contact for health education and the booking of practice visits. Practice nurses, who usually have a professional nursing background, are often involved in disease prevention, chronic care management, mental health services, frail elderly assessments, and care of families with young children. Dutch paediatricians, who are based in secondary care, see few common child health problems. The GP predominantly focuses on curative health care (Boode & Pijpers, 2014). Preventive care in children has a separate lead: the preventive child physician who is part of the Dutch Youth Care System, which is regulated by the Ministry of Health, Welfare and Sports as well as local governments. These preventive services are usually delivered in schools and may include health promotion programmes, screening for specific physical abnormalities, wellness visits and (freely accessible) consultation hours. The more individually oriented tasks are carried out by youth health care physicians (who must refer onwards if a prescription is required), with others conducted by nurses and medical assistants. In total, children have 22-24 contact moments with preventive child health services (NCJ, 2015). Some of those are combined with getting a vaccination. A patient must obtain a GP referral prior to visiting other health services, with the exception of acute conditions such as trauma. The Dutch health care system is socialized: health care is accessible to everyone. Health insurance is compulsory; the basic insurance package is almost comprehensive and includes all primary care services (Giessen et al., 2011).

#### **1.2.2.4 Primary care in Spain**

In Spain, primary care for children is organized in parallel with the adults' primary care system. Primary Health Care Centres have separate areas for children and adults, and children are normally cared for by a paediatrician (or exceptionally a GP when there is a shortage of specialists in paediatrics). A paediatrician is the first person a child or family speaks to about a medical issue. The primary care paediatrician is also the lead practitioner, who is the person who assumes clinical responsibility for the child patient. When a child is 14, he or she is transferred directly to the adult family physician of his or her parents. Primary paediatric care is provided by employed paediatricians in the primary care centres' public network. Primary health care professionals are gatekeepers to other health care services and health care levels. In Spain there is a standard "Healthy Children" programme that must be followed by every child, since birth. Before hospital discharge a blood sample

for the screening of metabolic diseases is taken, as well as a thorough physical examination including hearing capabilities by using evoked potentials. After hospital discharge each child is entitled to 11 visits in total until the child is 6 years old, with two more optional visits. During these visits the compulsory vaccination programme is enforced. If the child does not attend the scheduled visits, the parents are given a reminder when the child goes to the doctor's surgery for a consultation. Health screenings are structured and children need to be able to accomplish predetermined development goals at given ages. If not, the child is referred to specialized care by a physiotherapist or a speech therapist, for example, or specialist paediatric care. In the case of emergencies children are referred to Hospital Emergency units where a paediatric team is on board 24h/day. Primary care services in Spain are run by the state rather than by health professionals. Health care facilities provide voluntary coverage, and are governed by decentralised authorities or regions. Each area has their own health care programme for children, however, these programs are quite similar. Primary care in Spain is funded through general taxation/National Health Service, in which the state has a dominant role (Böhm et al., 2013). In addition to a public network of health centres, there are also private medical offices which are more common in rural areas (Garcia et al., 2010).

#### **1.2.2.5 Primary care in United Kingdom**

Primary care for children in the UK is primarily the responsibility of GPs (general practitioners, sometimes also known as family practitioners). All adults and children are expected to be registered with a GP, who is the first point of contact for most health queries, unless it is an emergency. Most surgeries also employ practice nurses who may provide some of the care for children with long term conditions. All GP practices are linked to an out-of-hours service, the details of which are available on the surgery answer phone outside normal working hours. The out-of-hours service usually runs from 6.30 pm to 8am on weekdays, and all day at weekends and bank holidays, but this will vary if the practice runs some evening or Saturday morning surgeries. Patients can also visit NHS 'walk-in centres', which are usually managed by nurses and available to everyone. Some also offer access to doctors and no appointment is needed. Most centres are open every day and outside office hours. They can be used when a patient's usual GP surgery is closed; when a patient cannot get an appointment when they need one; or when they need to see a GP or nurse but have not registered with a surgery. Walk-in centres can be used when the health problem is not an emergency and are not designed for treating long-term conditions or immediately life-threatening problems. If a patient has an injury that is not serious, they can also visit a minor injuries unit (MIU) or urgent care centre (UCC). Minor Injury Units are nurse-led services that treat injuries such as strains, sprains, and broken bones. No appointment is needed. If necessary, some patients might be referred to specialist services or to a GP. School nurses provide a variety of services such as health and sex education within schools, carrying out developmental screening, undertaking health interviews and administering immunisation programmes. School nurses can be employed by the local health authority, community NHS providers or by a school directly. The UK also has a network of health visitors, nurses who provide support to families with new babies and children under the age of 5. They provide public health and health promotion support. Children are immunized

either in primary care or in school. Routine vaccinations are offered free of charge on the NHS to all babies and children. Primary health care is gatekeeper to health care services and health care levels. GPs are generally self-employed and reimbursed by the National Health Service; GPs usually work in a partnership with other GPs. Some GPs are also employed on a salaried basis by GP partners in a practice. In the UK, there is a tax-based national health system.

#### **1.2.2.6 Comparison of the primary care health systems**

The MOCHA project has attempted to map the different countries in terms of children's primary care services using the traditional method of mapping systems by lead practitioner (Blair et al., 2017). This has shown that in the Czech Republic, Germany and Spain, the primary child health care services are led by a paediatrician. In The Netherlands and United Kingdom, the child health care services are general practitioner-led services. As a consequence, the first person a child or family will speak to about a medical issue is the paediatrician in the Czech Republic, Germany and Spain, and the GP in The Netherlands and United Kingdom. In the Czech Republic, Germany and Spain, preventive examinations are done by the primary health care physician. In The Netherlands there are special preventive services. In the UK immunisations take place at the GP surgery or in schools. In the Czech Republic and Germany, there is open access to other health services. In contrast, in The Netherlands, Spain and UK, primary child health care professionals act as gatekeepers (Blair et al., 2017). The financial organisation of primary health services is based on an etatist social health insurance in the Czech Republic and The Netherlands. This means that in these countries, the state holds the regulatory power but grant privileges for the financing and provision of health services to societal actors. In Germany, there is a social health insurance system in which societal actors have competencies to regulate and finance the health system but where most service providers perform for profit. In Spain and the UK there is a National Health Service in which the state has a dominant role (Blair et al., 2017).

### **1.3 Patients' experiences**

A fundamentally important aspect of primary care services is that they are person-centred (EXPH, 2014). There is increasing evidence that just focusing on 'outcomes' is insufficient to judge a primary care system (or a health care system as a whole) (Papanicolas et al., 2013). It is vital to also assess the patient's experience of the health care service, which in turn provides important evidence about the best way to run and provide services. Without the input of children, young people and their families it is difficult to ensure the suitability of primary care systems to meet the needs of children and young people. Careful observation, measurement, recording, interpretation and analysis of patients' subjective experiences are essential to appreciating what is working well in primary child health care, what needs to be changed, and how to go about making improvements (Coulter, 2014).

People's experiences can be studied in a wide range of ways, encompassing both narrative studies and surveys (Ziebland et al., 2013). There is no perfect method for gathering experience data and it is important to be aware of the strengths and limitations of different approaches (Coulter, 2009). Surveys generally use probability samples that aim to obtain

representative results. Narrative methods, such as in-depth interviews or focus groups , can produce richer, more detailed data than surveys with fixed response options. They are used to obtain accounts of people's experiences and the way they explain or interpret these (Coulter, 2014). In this study, we will use qualitative research methods developed by the Health Experiences Research Group (HERG) of the Oxford University for identifying patients' experiences. In the following, we will use the term "DIPEX methodology" to refer to this methodology. The following sections describe the idea behind the DIPEX methodology and provide background information about DIPEX International.

### **1.3.1 DIPEX and Healthtalk**

In 1999, Drs Ann McPherson and Andrew Herxheimer had the idea to develop a website that would provide reliable information about ordinary people's experiences of health and illness. In 2001, the website Healthtalk.org was launched. The Health Experiences Research Group at Oxford University Nuffield Department of Primary Care Health Services was set up to collect and analyse health experiences using rigorous qualitative research methods to ensure that the information provided at the Healthtalk website is balanced and accurate. The primary aim of Healthtalk is to describe the widest practical range of individual experiences from the patients' point of view and to provide a rich information resource for patients affected by the diseases and those who look after them (Herxheimer & Ziebland, 2003). In Healthtalk projects, interviews are collected with approximately 40-50 people chosen to represent a broad range of experiences. The inclusion of a broad sample is vital to represent the many different ways that health issues affect people's lives. Interviews typically start by asking the participant a general question intended to elicit the story in the person's own words (Ziebland et al., 2008). After a thematic analysis, 20-30 detailed summaries are presented on the website ([www.healthtalk.org](http://www.healthtalk.org)). Video and audio clips are selected from the interviews to illustrate the different experiences people described. This 'experiential' information is linked to other evidence based information (Herxheimer et al., 2000). It is intended to represent what it is like to have a condition so that users can find information that resonates with their own, and to deliver new information in a palatable format. The DIPEX methodology has been taught to international partners. This has resulted in counterparts' websites in the Czech Republic, Germany, the Netherlands and Spain amongst others as part of the DIPEX International initiative.

### **1.3.2 DIPEX International**

DIPEX International was founded to promote the spread worldwide of well researched data on people's experiences of health and illness (DIPEX International, 2017). Members of DIPEX International use the DIPEX methodology developed at the University of Oxford in the UK. DIPEX International aims: 1) to promote excellence of qualitative research into people's experiences of health and illness; 2) to advance the use and application of the results of this research to inform and improve health and health care; 3) to support cross-cultural comparisons of people's experiences of health and health care, and encourage appropriate action of the findings. In this study, five European members of DIPEX International are collaborating: the Czech Republic, Germany, the Netherlands, Spain and United Kingdom.

## 1.4 Overview of literature

Children's and parent's views are often excluded in research on primary care services for children, much of which is entirely adult focused. Research that has examined patients' experience of primary care in adulthood identifies a range of issues as important. These include accessibility and availability of health services (Cheraghi-Shoi et al., 2008; Gerard et al., 2008; Rubin et al., 2006), continuity of care (Baker et al., 2006; Guthrie & Wyke, 2006; Salisbury et al., 2009), and interpersonal aspects of care (Coulter 2005; Wensing et al., 2002). In a systematic review of patient perceptions of health care quality in different settings, Mohammed et al (2016) identified 10 dimensions of care that are relevant to patients: communication, health care access, shared decision making, clinical quality/provider knowledge and skills, physical environment, patient education, electronic medical record, pain control, discharge process, and preventive services. Several of these dimensions came to the fore in a review study by Davey et al (2013). They found five aspects of primary care provision that emerged as being important to young adults (18-25 years) in the UK: the accessibility and availability of services, the confidentiality of health-related information, issues relating to communication with healthcare professionals, continuity of care, and behaviours and attitudes expressed towards young adults by health care professionals. Hargreaves and Viner (2011) showed in their review of 38 NHS surveys undertaken in the UK that, although the majority of young people (16-24 years) are satisfied with health care, they consistently report poorer experience of care than older adults. They found that children and young people were significantly less likely than adults to feel confidence and trust in their doctors or that they were treated with respect. These results show that it is important to get a more detailed insight into the experiences of children and their parents when it comes to primary health care services for children.

Although it is widely recognized that children are willing, capable and legally entitled to be active participants in their health care (Van Staa et al., 2011), parents are generally invited to evaluate paediatric care and services rather than children themselves (Ammentorp, 2007; Smith, 2011). This is problematic because previous research has shown the importance of asking young people themselves as their perceptions differ from those of their parents (Byczkowski, 2010; Frank & Gallery, 2004; Knopf et al., 2008; Lindeke et al., 2009; Mitchel & Sloper, 2002). As stated above, there is a dearth of literature on children's and parent's views of primary health care for children. As a consequence, we know little about their experiences of health care. In the following, we provide an overview of the existing literature on children's and parent's experiences of primary health care for children and other health services in Europe. Most of those studies were conducted in the UK.

Curtis et al. (2004), focussing on children's and young people's experiences of local health services in the UK, highlighted that they were articulate in relating examples of good relationships with health professionals, good provision for younger children in waiting areas and good general practice. They also identified the importance of improved planning and resourcing. The pivotal role of communication and relationships was emphasized both in terms of what young people felt was good and what they said needs improving. Schalkers et al. (2014) conducted a qualitative study incorporating different participatory

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data collection methods to investigate children's experiences with and perspectives on the quality of hospital care and services in the Netherlands. They identified five themes that were relevant to children: attitudes of health care professionals, communication with staff, contact with peers and family, treatment procedures and hospital environment. This study showed that, using a number of participatory research methods, children were very eager to share their experiences. Furthermore, Ahuja and Williams (2010) conducted a qualitative study in which they explored the experiences of children and their families of specialist mental health care in the UK (CAMHS). Themes emerged that include difficulties in gaining access to appropriate services because of lack of clarity in referral routes, poor communication among different agencies, and the impact of diagnoses on the young people and their families. Families that are known to health professionals were satisfied with the information and support provided about the services. Most identified particular staff that they had found helpful in their journey. The themes emerging from these studies are similar to those found in the review studies of Davey et al. (2013) and Mohammed et al. (2016) focusing on (young) adult perceptions of (primary) health care: the accessibility and availability of services, physical environment, communication with healthcare professionals, attitudes of healthcare professionals, provider knowledge and skills, and continuity of care.

Many more studies focused on children's and parents' views of health care professionals. In their study of adolescents, Schaeuble et al. (2010) demonstrated that provider interactions are very important in their appraisal of primary healthcare quality. This was also shown in a study by Jager et al. (2014), who found that adolescents with psychosocial problems and their parents attribute high importance to communication, especially affective communication. Freake et al. (2007) reviewed 54 studies asking adolescents about their views of the professionals that help them. She found that adolescents think it is important that what they tell professionals is confidential; that health care professionals explain things, give information and advice; listen to them; are kind, caring, sympathetic, understanding; are competent, experienced and qualified; don't patronize or treat them like a child; are non-judgemental. In addition, adolescents noted that it is important that they can trust health care professionals; that they feel comfortable; that they see the same person each time; and that they are treated as an individual and not just part of their job. Furthermore, she found that girls prefer to see a female doctor for many issues. In addition, Robinson (2010) found in her review of 31 studies reporting on children and young people's views of health professionals in the UK that health professionals should be familiar, accessible and available; be informed and competent; provide accessible information; be a good communicator; participate in care; ensure privacy and confidentiality, and demonstrate acceptance and empathy.

Eliciting the views of children, young people and their parents is essential in the appraisal of health systems. Qualitative inquiry into children's experience of primary health care will provide valuable triangulation and identification of areas of concern to children, young people and their families. This triangulation is essential for the MOCHA project: without the

input of young people it is difficult to ensure the suitability of primary care systems to meet the needs of children and young people.

### **1.5 Aims and objectives**

The main aim of this study is to explore and understand children's and parents' experiences of primary health care for children in Europe. The research objectives are as follows:

- To explore experiences of primary health care for children in the Czech Republic, Germany, The Netherlands, Spain and United Kingdom from the perspective of "healthy" children and young people;
- To explore experiences of primary health care for children in the Czech Republic, Germany, The Netherlands, Spain and United Kingdom from the perspective of parents of "healthy" children;
- To explore experiences of primary health care for children in the Czech Republic, Germany, The Netherlands, Spain and United Kingdom from the perspective of children and young people with complex mental health care needs;
- To explore experiences of primary health care for children in the Czech Republic, Germany, The Netherlands, Spain and United Kingdom from the perspective of parents of children with complex mental health care needs;
- To explore experiences of primary health care for children in the Czech Republic, Germany, The Netherlands, Spain and United Kingdom from the perspective of children and young people with complex physical health care needs;
- To explore experiences of primary health care for children in the Czech Republic, Germany, The Netherlands, Spain and United Kingdom from the perspective of parents of children with complex physical health care needs.

The next chapter of this report outlines the methodological approach used by the research team to address these research objectives.

## Chapter 2 - Methodology

In this study, we used the qualitative research methodology developed by the Health Experiences Research Group (HERG) University of Oxford, which includes illness narratives and semi-structured interviews (Ziebland & Herxheimer, 2008). The relatively unstructured, open-ended nature of the interview method helps to identify participants' own concerns, meanings and priorities rather than being led by a highly focused research interest.

### 2.1 Participants

We focused on the experiences of children as well as parents. Children were eligible for inclusion if they were aged 10-18. Parents were eligible for inclusion if they had at least one child under 18. Participants were recruited using maximum variation sampling, which involves including a broad range of experiences and demographic characteristics (Coyne, 1997; Marshall, 1996). We aimed to identify and include the widest range of experiences of children and parents in terms of primary care services for children, rather than to identity the numerical distribution that exists in the wider population. Participants were recruited through a number of different sources including GPs, hospitals, mental and social health care organisations, newspaper adverts, charities, patient associations, rehabilitation centres, schools, snowballing, social media and word of mouth. Table 2.1 gives an overview of the different recruitment strategies used in each of the five countries.

#### 2.1.1 Children and young people

In this study, we focussed on the experiences of "healthy" children, children with (complex) mental health conditions, and children with (complex) physical health conditions and their parents. A "healthy" child refers to the well-child, i.e., children with no or only occasional minor conditions and without any (complex) physical or mental health condition. We also included children with complex health conditions and their parents as their experiences of primary care services may differ from those of "healthy" children and their parents. Bearing in mind the complex health conditions relevant to Work Package 2 of the MOCHA project, we included children with ADHD, Traumatic Brain Injury (TBI), and epilepsy.

In total, 84 children participated in the study, of which 35 were considered "healthy". Twenty-nine children had ADHD as well as, sometimes, other conditions such as depression and/or autism and 20 had TBI or epilepsy. Table 2.2 gives an overview of all children who participated in the study. The majority of participants were boys (58%). Among children with ADHD the percentage of boys was relatively high compared to the children in the "healthy" children group and children with TBI or epilepsy (69% vs 57% and 45%, respectively). Children varied in age between 10 and 18 years. The mean age of all children participating in the study was 14.8 years ( $SD=2.0$ ). The children participating in the Netherlands were somewhat younger compared to the children participating in the other countries (12.4 years vs 14.1 – 15.7 years). All children with a mental health condition had an ADHD diagnosis. Of the children with a complex physical health condition, 25% had a

**Table 2.1 Overview of recruitment strategies used in each country**

Czech Republic	Germany	Netherlands	Spain	UK
"Healthy" children: - researcher's personal network - schools - snowball method - social media - word of mouth	"Healthy" children: - GPs - Hospitals - newspaper adverts - researcher's personal network - social media	"Healthy" children: - researcher's personal network - schools - snowball method - social media	"Healthy" children: - GPs - researcher's personal network - snowball method - social media - word of mouth	"Healthy" children: - charities - national organisations - schools - snowballing - social media
Children with complex mental health conditions: - GPs - mental and social health care organisations - patient associations - researcher's personal network - schools for children with mental health conditions - snowball method - social media - word of mouth	Children with complex mental health conditions: - GPs - hospitals - newspaper adverts - patient associations - rehabilitation centres - schools for children with special needs - social media	Children with complex mental health conditions: - GPs - mental and social health care organisations - patient associations - researcher's personal network - school for children with mental health conditions - snowball method - word of mouth	Children with complex mental health conditions: - child psychiatry specialist - GPs - researcher's personal network - social media	Children with complex mental health conditions: - charities and support groups (national and local) - social media - specialist schools

**Table 2.1 continued Overview of recruitment strategies used in each country**

Czech Republic	Germany	Netherlands	Spain	UK
<p>Children with physical complex health conditions:</p> <ul style="list-style-type: none"> <li>- hospitals</li> <li>- patient associations</li> <li>- personal networks of staff at the research unit</li> <li>- researcher's personal network</li> <li>- rehabilitation centres</li> <li>- snowball method</li> <li>- social media</li> <li>- word of mouth</li> </ul>	<p>Children with physical complex health conditions:</p> <ul style="list-style-type: none"> <li>- GPs</li> <li>- hospitals</li> <li>- newspaper adverts</li> <li>- patient associations</li> <li>- rehabilitation centres</li> <li>- schools for children with special needs</li> <li>- social media</li> </ul>	<p>Children with physical complex health conditions:</p> <ul style="list-style-type: none"> <li>- hospitals</li> <li>- patient associations</li> <li>- personal networks of staff at research unit</li> <li>- rehabilitation centres</li> <li>- researcher's personal network</li> <li>- schools for children with special needs</li> <li>- snowball method</li> <li>- social media</li> </ul>	<p>Children with physical complex health conditions:</p> <ul style="list-style-type: none"> <li>- GPs</li> <li>- hospitals</li> <li>- rehabilitation centres</li> <li>- researcher's personal network</li> <li>- social media</li> </ul>	<p>Children with physical complex health conditions:</p> <ul style="list-style-type: none"> <li>- charities and support groups (national and local)</li> <li>- health professionals</li> <li>- social media</li> <li>- snowballing</li> </ul>

brain injury (traumatic or acquired) and 75% had epilepsy. Table 2.3 presents descriptive characteristics of all children in total and per country.

### **2.1.2 Parents**

We included 88 parents in the study. Thirty-four had a “healthy” child, 30 had a child with ADHD or another mental health condition, and 24 had a child with either a brain injury or epilepsy or another physical health condition. Table 2.4 presents an overview of all parents included in the study. The youngest parent that participated in our study was 22 years and from Germany; the oldest one was 55 years and from Spain. The mean age of all parents was 41.3 years ( $SD=7.0$ ). Predominantly, mothers participated in the study, and 82% of participants were female. Only in the group of parents with a “healthy” child in Germany did more fathers participate than mothers (75% were male). We also included some parents who had a child with autism, anxiety disorder, or a rare disease. Table 2.5 shows the descriptive characteristics of the parents, in total and per country.

## **2.2 Data collection**

Data collection consisted of in-depth interviews with children and parents, focus groups with children and parents, and a secondary analysis of interviews conducted in earlier studies in one of the five countries. In total, 80 in-depth interviews were conducted and 9 focus groups with a total of 52 participants. Furthermore, 40 interviews were used in a secondary analysis. Table 2.6 gives an overview of the number of in-depth interviews and focus groups conducted in each country, and the number of interviews used for secondary analysis in each country.

### **2.2.1 In-depth interviews**

Children and parents were interviewed separately in their own homes, or elsewhere if they preferred, between February 2015 and April 2017. Interviews with 34 children in the UK (aged 14-25) were conducted in 2015-6 by SP for an earlier study funded by the National Institute for Health Research (NIHR) Oxford Biomedical Research Centre. Interviews with 11 “healthy” children from that study were re-analysed for this MOCHA study. In the Czech Republic and Germany, participants were interviewed by the main researchers (LKK and AP respectively). In The Netherlands and Spain, interviews were conducted by a research assistant (GAB and CRP respectively).

All interviews were in-depth narratives, conducted with a view to eliciting experiences of primary care services for children. The first part of the interview consisted of a narrative, which allowed participants to talk about their experiences, perspectives and concerns in their own way, unprompted (Riessman, 2008). In the second part of the interview, a semi-structured interviewing approach was adopted to explore some topics that had not been discussed and other topics in more detail. An interview guide, based on the one used for the UK interviews in 2015-6, was developed by the research team and included key topics.

These were identified from earlier interviews, from literature reviews, and discussions with health professionals, and with MOCHA researchers involved in Work Package 1 and Work

Package 2 (See Appendix 1). Participants were only interviewed once. All interviews were audio- or video-recorded with participants' consent. When interviewing children, alternative methods were sometimes used to elicit data in addition to "normal" conversation. This was particularly the case if a child seemed to have little to say or remembered very little about their experiences. For example, pictures showing fairly typical health care scenes were shown to a child in order to start a conversation with the child, or a child was asked about their views on several statements about primary health care services (see Appendices 2 and 3 for the pictures and the statements respectively). Occasionally children were asked to write a letter to their GP or health minister about what they liked and disliked about their appointment with the GP or the surgery (see Appendix 4). In The Netherlands, one interview with a girl with an acquired brain injury was conducted via Skype chat as she had difficulties with speaking. She felt more at ease using a chat programme rather than participating in a typical face-to-face research interview. In the Czech Republic, two interviews were conducted via Skype because it was the preferred way of contact for the participants – one "healthy" girl without complex needs and one girl with epilepsy. These interviews were oral and text chat was not used. Some interviews were conjoint interviews in which two participants were interviewed at the same time. In the Czech Republic, for example, a child with TBI and his mother were interviewed together because the child had some communication issues and preferred being interviewed with his mother present.

### **2.2.2 Focus groups**

Focus groups are a form of group interview that capitalises on communication between research participants in order to generate data (Kitzinger, 1995). The group process can help people explore and clarify their views in a way that would be less easily accessible in a one-to-one interview. In total, 9 focus groups were conducted, 5 with children and 4 with parents. A total of 26 children and 26 parents participated in these group discussions. Each focus group consisted of two to nine participants. The focus groups covered a list of topics, formulated using a semi-structured interview guide which was developed by the research team (see Appendix 4). Most focus groups were facilitated by two researchers, one leading the discussion while the other took notes (Czech Republic: LK and ES.; Germany: AP and JK; Spain: VM and CRP, with support from two undergraduate and one postgraduate students). In the UK, an experienced senior researcher (SP) conducted 2 focus groups alone, one group with 5 parents whose children had ADHD, and the other in a specialist school with 2 children who had ADHD. At the same time as this second focus group, two other HERG researchers (AMB and AM) also conducted a small focus group with 2 children with ADHD. This was on the advice of the teacher who felt that the children were more likely to take part in the discussion if there were 2 small groups of 2 participants rather than one of 4 participants. All focus group interviews lasted 60 to 100 minutes and were audio-recorded.

### **2.2.3 Secondary analysis**

In addition to the in-depth interviews and focus groups with children and parents, a secondary analysis of pre-existing narrative interviews was conducted. The following interview collections were used for secondary analysis:

- Germany: DIPEx Germany collected interviews with people living with ADHD for the development of a Healthtalk module on experiences of children and adolescents with AD(H)D for the German DIPEx Project “Krankheitserfahrungen.de”. These interviews were conducted between January 2015 and November 2016. Fourteen interviews with children and adolescents with AD(H)D and 9 interviews with their parents were included in this study for secondary analysis.
- The Netherlands: Within a larger project on ‘Early diagnosis of rare disease’, 11 parents of children with a rare disease were interviewed about their experiences of the diagnostic period. These interviews were conducted between May 2016 and February 2017. All 11 interviews were used for this study.
- UK: A secondary analysis was conducted of interviews with young people living with epilepsy. These interviews were conducted in 2007-8 and collected for the development of a Healthtalk module on young people’s experiences of epilepsy. Six of these interviews, with children aged 14-18, were included in the secondary analysis for this study.

### **2.3 Ethical considerations**

The purpose and process of the study was explained to all participants prior to the in-depth or focus group interview. Participants were able to withdraw at any time. Before the in-depth or focus group interview, written informed consent was obtained. Where a participant was younger than a certain age (i.e., Germany 14 years; Czech Republic 15 years; Netherlands, Spain, UK: 16 years), written informed consent was also obtained from the legal representative (usually a parent). Ethics committee approval was obtained from the Olomouc University Social Health Institute (Czech Republic), University Medical Center Göttingen (Germany), the University Medical Center Groningen (The Netherlands), University Hospital of Nuestra Señora de la Candelaria (Spain) and University of Oxford (UK).

### **2.4 Analysis**

All interviews were fully transcribed verbatim, and each transcript was returned to the participant to read and check for accuracy. When analysing the interviews, a qualitative interpretative approach was taken, combining thematic analysis with constant comparison (Glaser and Strauss, 1967; Green and Thorogood, 2014; Pope et al., 2000). The research team (i.e., the authors), all of whom communicated in English and had a high level of spoken and written English, held monthly Skype meetings throughout the recruitment, data collection and analysis phases. Four face-to-face workshops were also held (in October 2015, November 2016, March 2017 and July 2017). Interviews and focus group discussions were analysed for themes that structured participants’ experiences using a thematic analysis combined with constant comparison. These themes were developed from the earlier UK study with young people and discussed in a face-to-face workshop in London in March 2017. All five researchers agreed on the coding frame, based on topics covered in the interview guide and emergent themes, and conducted a separate thematic analysis of their own data. The results of these analyses were compared and checked for

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differences and similarities and discussed during a face-to-face workshop in Amsterdam in July 2017. Extracts from the interviews, translated by each country researcher, are used to illustrate the results. AtlasTI (Germany, Netherlands, Spain), NUD\*IST®, QSR (QSR International Pty, 2002) (UK) and QSR NVivo10 (Czech Republic) were used to facilitate data retrieval and coding, analysis of themes and systematic comparison.

**Table 2.2: Overview of all children participating in the study**

ID	Country <sup>1</sup>	Type of interview <sup>2</sup>	Gender <sup>3</sup>	Age	Health conditions	Age at diagnosis
<u>"Healthy children"</u>						
1	CZ	F	M	13	-	-
2	CZ	F	F	15	-	-
3	CZ	F	M	14	-	-
4	CZ	F	M	12	-	-
5	CZ	F	M	14	-	-
6	CZ	I	F	15	-	-
7	CZ	I	M	10	-	-
8	CZ	I	M	13	-	-
9	CZ	I	M	16	-	-
10	CZ	I	F	18	-	-
11	G	F	F	16	-	-
12	G	F	F	17	-	-
13	G	F	F	16	-	-
14	G	F	F	17	-	-
15	G	F	M	15	-	-
16	G	F	M	16	-	-
17	G	F	F	15	-	-
18	G	F	F	16	-	-
19	NL	I	M	10	-	-
20	NL	I	F	14	-	-
21	NL	I	F	13	Allergy	13
22	S	F	F	17	-	-
23	S	F	F	14	-	-
24	S	F	M	16	-	-
25	UK	I	F	14		
26	UK	I	F	17		
27	UK	I	M	15		
28	UK	I	M	14		
29	UK	I	M	15		
30	UK	I	M	14		
31	UK	I	M	15		
32	UK	I	M	14		
33	UK	I	M	15		
34	UK	I	M	18		
35	UK	I	M	15		
<u>Children with complex mental health conditions</u>						
36	CZ	I	M	14	ADHD	8
37	CZ	I	M	12	ADHD	2
38	CZ	I	M	12	ADHD	4
39	CZ	I	F	16	ADHD	9
40	G	S	F	15	ADHD, depression, suicidal thoughts	6/7
41	G	S	M	14	ADHD	11
42	G	S	M	15	ADHD	7
43	G	S	M	16	ADHD	5-9

**Table 2.2 continued: Overview of all children participating in the study**

ID	Country <sup>1</sup>	Type of interview <sup>2</sup>	Gender <sup>3</sup>	Age	Health conditions	Age at diagnosis
44	G	S	M	15	ADHD	NK
45	G	S	F	16	ADHD	NK
46	G	S	F	18	ADHD	NK
47	G	S	M	16	ADHD	NK
48	G	S	M	16	ADHD	13/14
49	G	S	M	15	ADHD	10/11
50	G	S	M	16	ADHD	6/7
51	G	S	F	17	ADHD	8/9
52	G	S	M	15	ADHD, depression	7
53	G	S	M	15	ADHD	6
54	NL	I	M	11	ADD	NK
55	NL	I	F	11	ADHD	6
56	NL	I	M	10	ADHD	5
57	S	I	M	14	ADHD	12
58	S	I	M	10	ADHD	3
59	S	I	F	15	ADHD	7
60	S	I	M	12	ADHD	11
61	UK	F	M	15	ADHD, (assessed for bipolar)	10
62	UK	F	M	15	ADHD	NK
63	UK	F	F	15	ADHD, epilepsy	10
64	UK	F	F	14	ADHD, epilepsy, asthma	NK
<b>Children with complex physical conditions</b>						
65	CZ	I	M	11	TBI	9
66	CZ	I	F	17	EPI	8
67	CZ	I	F	18	EPI	10
68	CZ	I	F	16	EPI, brain tumour in early childhood	13
69	G	I	M	13	TBI	NK
70	G	F	F	NK	Epilepsy	NK
71	G	F	F	NK	Epilepsy	NK
72	G	F	F	NK	Epilepsy	NK
73	G	F	F	NK	Epilepsy	NK
74	G	F	M	NK	Epilepsy	NK
75	G	F	M	NK	Epilepsy	NK
76	NL	I	F	18	Acquired brain injury, epilepsy, Hashimoto thyroiditis	6 months
77	S	I	M	14	TBI	12/13
78	S	I	M	15	TBI	12/13
79	UK	S	M	16	Epilepsy	10
80	UK	S	M	18	Epilepsy	16

**Table 2.2 continued: Overview of all children participating in the study**

ID	Country <sup>1</sup>	Type of interview <sup>2</sup>	Gender <sup>3</sup>	Age	Health conditions	Age at diagnosis
81	UK	S	M	17	Epilepsy	6
82	UK	S	F	16	Epilepsy	15
83	UK	S	F	17	Epilepsy	16
84	UK	S	F	17	Epilepsy	6

<sup>1</sup> CZ = Czech Republic; G = Germany; NL = Netherlands; S = Spain; UK = United Kingdom

<sup>2</sup> I = Interview; F = participant focus group interview

<sup>3</sup> F = female; M = male

NK= Not known

**Table 2.3: Descriptive characteristics of the study population – children**

Characteristics	All (n = 84) Value - n (%)*	Czech Republic (n = 18) Value - n (%)*	Germany (n = 29) Value - n (%)*	Netherlands (n = 7) Value - n (%)*	Spain (n = 9) Value - n (%)*	United Kingdom (n = 21) Value - n (%)*
"Healthy" children	35 (42)	10 (56)	8 (28)	3 (43)	3 (33)	11 (52)
Complex mental health conditions	29 (35)	4 (22)	14 (48)	3 (43)	4 (44)	4 (19)
Complex physical health conditions	20 (24)	4 (22)	7 (24)	1 (14)	2 (22)	6 (29)
Age, years						
<u>All children</u>						
Range	10 - 18	10 - 18	13 - 18	10 - 18	10 - 17	14 - 18
Mean ± SD	14.8 ± 2.0	14.2 ± 2.3	15.7 ± 1.1	12.4 ± 2.9	14.1 ± 2.1	15.5 ± 1.3
<u>"Healthy" children</u>						
Range	10 - 18	10 - 18	15 - 17	10 - 14	14 - 17	14 - 18
Mean ± SD	14.8 ± 1.9	14.0 ± 2.2	16.0 ± 0.8	12.3 ± 2.1	15.7 ± 1.5	15.1 ± 1.3
<u>Mental health conditions</u>						
Range	10 - 18	12 - 16	14 - 18	10 - 11	10 - 15	14 - 15
Mean ± SD	14.3 ± 2.1	13.5 ± 1.9	15.6 ± 1.0	10.7 ± 0.6	12.8 ± 2.2	14.8 ± 0.5
<u>Physical health conditions</u>						
Range	11 - 18	11 - 18	13	18	14 - 15	16 - 18
Mean ± SD	15.9 ± 2.1	15.5 ± 3.1	13	18	14.5 ± 0.7	16.8 ± 0.7
Gender, female						
All children	35 (42)	7 (39)	14 (48)	4 (57)	3 (33)	7 (33)
"Healthy children"	15 (43)	3 (30)	6 (75)	2 (67)	2 (67)	2 (18)
Children mental health conditions	9 (31)	1 (25)	4 (29)	1 (33)	1 (25)	2 (50)
Children physical health conditions	11 (55)	3 (75)	4 (57)	1 (100)	0 (0)	3 (50)
Mental health condition child						
ADHD	29 (100)	4 (100)	14 (100)	3 (100)	4 (100)	4 (100)
Autism	-	-	-	-	-	-
Other	-	-	-	-	-	-

**Table 2.3 continued: Descriptive characteristics of the study population – children**

Characteristics	All (n = 84) Value - n (%)*	Czech Republic (n = 18) Value - n (%)*	Germany (n = 29) Value - n (%)*	Netherlands (n = 7) Value - n (%)*	Spain (n = 9) Value - n (%)*	United Kingdom (n = 21) Value - n (%)*
Physical health condition child						
Traumatic Brain Injury	5 (25)	1 (25)	1 (14)	1 (100)	2 (100)	-
Epilepsy	15 (75)	3 (75)	6 (86)	-	-	6 (100)
Rare disease	-	-	-	-	-	-
Other	-	-	-	-	-	-

\* Percentages are based on totals for each category, and may not total 100 because of rounding

**Table 2.4: Overview of all parents participating in the study**

ID	Country <sup>1</sup>	Type of interview <sup>2</sup>	Gender <sup>3</sup>	Age	Number of children	Age of children (years)	Health conditions	Age at diagnosis
<b>Parents of "healthy" children</b>								
1	CZ	F	M	39	3	5, 8, 10	-	-
2	CZ	F	F	31	1	4	-	-
3	CZ	F	F	48	4	7, 10, 19, 24	-	-
4	CZ	F	F	27	1	8 months	-	-
5	CZ	F	F	38	1	14	-	-
6	CZ	F	F	36	4	1, 3, 4, 5	-	-
7	CZ	F	F	34	2	2, 4	-	-
8	CZ	F	M	28	2	2, 4	-	-
9	CZ	F	F	33	1	5	-	-
10	CZ	I	F	36	3	3, 4, 7	-	-
11	CZ	I	F	42	2	10, 13	-	-
12	G	F	M	34	1	2	-	-
13	G	F	F	34	1	9 months	-	-
14	G	F	M	37	1	9	-	-
15	G	F	M	32	2	2, 4	-	-
16	NL	I	F	34	2	2, 4	-	-
17	NL	I	F	35	1	1	-	-
18	NL	I	M	35	2	7, 15	-	-
19	NL	I	F	35	2	7, 15	-	-
20	NL	I	F	48	3	9, 11, 13	-	-
21	NL	I	F	33	3	1, 4, 6	-	-
22	NL	I	F	38	2	7, 9	-	-
23	NL	I	M	43	4	4, 7, 10, 12	-	-
24	NL	I	F	42	4	4, 7, 10, 12	-	-

**Table 2.4 continued: Overview of all parents participating in the study**

ID	Country <sup>1</sup>	Type of interview <sup>2</sup>	Gender <sup>3</sup>	Age	Number of children	Age of children (years)	Health conditions	Age at diagnosis
25	S	I	F	41	2	10, 14	-	-
26	S	F	F	55	1	16	-	-
27	S	F	M	51	2	14, 19	-	-
28	S	F	F	45	1	15	-	-
29	S	F	F	41	4	14, 15, 17, 19	-	-
30	S	F	F	52	2	17, 19	-	-
31	S	F	F	41	2	9, 12	-	-
32	S	F	M	43	1	5	-	-
33	S	F	F	43	2	1, 6	-	-
34	S	I	F	37	1	1	-	-
<hr/>								
<b>Parents of children with complex mental health conditions</b>								
35	CZ	I	F	51	2+1 <sup>4</sup>	12, 27, 33	ADHD	2
36	CZ	I	F	46	1	14	ADHD	8
37	CZ	I	F	35	2	5, 9	ADHD	3, 5
38	CZ	I	F	36	1	11	ADHD	8
<hr/>								
39	G	S	M	45	1	NK	ADHD	6
40	G	S	F	53	2	NK	ADHD	NK
41	G	S	F	32	3	NK	ADHD	4
42	G	S	F	49	1	12	ADHD, anxiety disorder, sleep disorder	6/7
43	G	S	F	36	NK	NK	ADHD	NK
44	G	S	F	49	NK	11	ADHD	6
45	G	S	M	37	2	NK	ADHD, depression, anxiety disorder, enuresis	6/7
46	G	S	F	53	6	NK	ADHD, autism, depression	14/15, 5/6 and NK
47	G	S	F	38	NK	NK	ADHD	7
<hr/>								
48	NL	I	F	42	2	10, 12	PDD-NOS	5 and 6
49	NL	I	F	48	3	9, 11, 13	ADD, anxiety disorder	NK

**Table 2.4 continued: Overview of all parents participating in the study**

ID	Country <sup>1</sup>	Type of interview <sup>2</sup>	Gender <sup>3</sup>	Age	Number of children	Age of children (years)	Health conditions	Age at diagnosis
50	NL	I	F	33	3	1, 4, 6	PDD-NOS	2
51	NL	I	F	34	1	10	ADHD	5
52	NL	I	F	48	3	15, 16, 23	ADD	7
53	S	I	F	36	1	8	ADHD	7
54	S	I	F	49	4	11, 16, 27, 30	ADHD	11
55	S	I	F	45	2	12, 14	ADHD	12
56	S	I	M	50	2	12, 14	ADHD	12
57	S	I	F	32	3	4, 9, 10	ADHD	3
58	S	I	F	45	1	15	ADHD	7
59	S	I	F	45	4	7, 10, 12, 13	ADHD	11
60	UK	F	M	51	2	18	ADHD, autism	11 and 18
61	UK	F	F	45	2	18	ADHD, autism	11
62	UK	F	F	43	2	11	ADHD	5
63	UK	F	F	45	3	13	ADHD	8
64	UK	F	F	38	2	10	ADHD	5
<b>Parents of children with complex physical conditions</b>								
65	CZ	I	F	37	2	8, 11	TBI	9
66	CZ	I	F	44	2	7, 18	TBI	5
67	CZ	I	F	35	2	7, 1	EPI	5 months
68	CZ	I	F	36	3	2, 12, 17	EPI	5 months
69	G	I	F	22	2	3, 1	Epilepsy	NK
70	NL	I	F	35	1	0	Down syndrome	0
71	NL	I	F	48	3	15, 16, 23	Chronic fatigue syndrome	14 and 15
72	NL	I	M	43	4	4, 7, 10, 12	Acquired brain injury	0
73	NL	I	F	42	4	4, 7, 10, 12	Acquired brain injury	0

**Table 2.4 continued: Overview of all parents participating in the study**

ID	Country <sup>1</sup>	Type of interview <sup>2</sup>	Gender <sup>3</sup>	Age	Number of children	Age of children (years)	Health conditions	Age at diagnosis
74	NL	S	M	47	4	9, 12, 15, 17	Addison's disease	13
75	NL	S	F	46	4	9, 12, 15, 17	Addison's disease	13
76	NL	S	M	52	2	11, 17	Addison's disease	11 and 14
77	NL	S	F	45	2	11, 17	Addison's disease	11 and 14
78	NL	S	F	51	3	17, 19, 21	Addison's disease	17
79	NL	S	F	33	2	1, 4	Crouzon syndrome	0
80	NL	S	F	42	3	8, 11, 15	GESD-type 9	0 and 4
81	NL	S	F	46	2	15, 16	Neurofibromatoses type 1	1
82	NL	S	F	36	4	11, 14, 16, 19	Trigoncephalies	0
83	NL	S	F	46	2	4, 7	Neurofibromatoses type 1	0
84	NL	S	F	50	2	15, 18	Ehlers-Danlos	15 and 18
85	S	I	F	44	1	9	TBI	NK
86	S	I	F	53	2	14, 29	TBI	NK
87	S	I	F	39	3	3, 15, 20	TBI	NK
88	S	I	F	49	1	13	TBI	NK

<sup>1</sup> CZ = Czech Republic; G = Germany; NL = Netherlands; S = Spain; UK = United Kingdom

<sup>2</sup> I = Interview; F = participant focus group interview

<sup>3</sup> F = female; M = male

<sup>4</sup> 2 children and 1 grandson with ADHD in custody

NK = not known

**Table 2.5 Descriptive characteristics of the study population – parents**

Characteristics	All (n = 88) Value - n (%)*	Czech Republic (n = 19) Value - n (%)*	Germany (n = 14) Value - n (%)*	Netherlands (n = 29) Value - n (%)*	Spain (n = 21) Value - n (%)*	United Kingdom (n = 5) Value - n (%)*
"Healthy" children	34 (39)	11 (58)	4 (29)	9 (31)	10 (48)	-
Complex mental health conditions	30 (34)	4 (21)	9 (64)	5 (17)	7 (33)	5 (100)
Complex physical health conditions	24 (27)	4 (21)	1 (7)	15 (52)	4 (19)	-
Age, years						
All						
Range	22 - 55	27 - 51	22 - 53	33 - 52	32 - 55	38 - 51
Mean ± SD	41.3 ± 7.0		39.4 ± 9.1	41.7 ± 6.2	44.5 ± 6.3	44.4 ± 4.7
"Healthy" children						
Range	27 - 55	27 - 48	32 - 37	33 - 48	37 - 55	-
Mean ± SD	38.9 ± 6.7	35.6 ± 6.1	34.3 ± 2.1	38.1 ± 5.1	44.9 ± 5.8	-
Mental health conditions						
Range	32 - 53	35 - 51	32-53	33 - 48	32 - 50	38 - 51
Mean ± SD	43.0 ± 6.7	42.0 ± 7.8	43.6 ± 7.9	41.0 ± 7.3	43.1 ± 6.7	44.4 ± 4.7
Physical health conditions						
Range	22 - 53	35 - 44	22	33 - 52	39 - 53	-
Mean ± SD	42.5 ± 7.3	38.0 ± 4.1	22	44.1 ± 5.7	46.3 ± 6.1	-
Gender**, female						
All children	72 (82)	15 (88)	9 (65)	24 (83)	16 (84)	4 (80)
"Healthy children"	25 (74)	9 (82)	1 (25)	7 (78)	8 (80)	-
Children mental health conditions	26 (87)	4 (100)	7 (78)	5 (100)	6 (86)	4 (80)
Children physical health conditions	21 (88)	2 (100)	1 (100)	12 (80)	4 (100)	-
Mental health condition child						
ADHD	28 (72)	4 (100)	9 (64)	3 (50)	5 (100)	5 (71)
Autism	5 (13)	-	1 (7)	2 (33)	-	2 (29)
Other	6 (15)	4	4 (29)	1 (17)	-	-

**Table 2.5 continued: Descriptive characteristics of the study population – parents**

Characteristics	All (n = 88) Value - n (%)*	Czech Republic (n = 19) Value - n (%)*	Germany (n = 14) Value - n (%)*	Netherlands (n = 29) Value - n (%)*	Spain (n = 21) Value - n (%)*	United Kingdom (n = 5) Value - n (%)*
Physical health condition child						
Traumatic Brain Injury	8 (33)	2 (100)	1 (100)	2 (13)	4 (100)	-
Epilepsy	3 (13)	2	-	-	-	-
Rare disease	11 (46)	-	-	11 (73)	-	-
Other	2 (8)	-	-	2 (13)	-	-

\* Percentages are based on totals for each category, and may not total 100 because of rounding

\*\* Gender of parents participating in the study.

**Table 2.6 Overview of number and type of interviews in each country**

	Total	Czech Republic	Germany	Netherlands	Spain	UK
<b>Total</b>						
# in-depth interviews	80	23	2	25	19	11
# focus group interviews*	9 (52)	2 (14)	3 (18)	-	2 (11)	2 (9)
# interviews secondary analysis	40	-	23	11	-	6
<b>Children – total</b>						
# in-depth interviews	38	13	1	7	6	11
# focus group interviews*	5 (26)	1 (5)	2 (14)	-	1 (3)	1 (4)
# interviews secondary analysis	20	-	14	-	-	6
<b>Children – healthy</b>						
# in-depth interviews	19	5	-	3	-	11
# focus group interviews*	3 (16)	1 (5)	1 (8)	-	1 (3)	-
# interviews secondary analysis	-	-	-	-	-	-
<b>Children – mental</b>						
# in-depth interviews	11	4	-	3	4	-
# focus group interviews*	1 (4)	-	-	-	-	1 (4)
# interviews secondary analysis	14	-	14	-	-	-
<b>Children – physical</b>						
# in-depth interviews	8	4	1	1	2	-
# focus group interviews*	1 (6)	-	1 (6)	-	-	-
# interviews secondary analysis	6	-	-	-	-	6
<b>Parents – total</b>						
# in-depth interviews	42	10	1	18	13	-
# focus group interviews*	4 (26)	1 (9)	1 (4)	-	1 (8)	1 (5)
# interviews secondary analysis	20	-	9	11	-	-
<b>Parents – healthy</b>						
# in-depth interviews	13	2	-	9	2	-
# focus group interviews*	3 (21)	1 (9)	1 (4)	-	1 (8)	-
# interviews secondary analysis	-	-	-	-	-	-
<b>Parents – mental</b>						
# in-depth interviews	16	4	-	5	7	-
# focus group interviews*	1 (5)	-	-	-	-	1 (5)
# interviews secondary analysis	9	-	9	-	-	-
<b>Parents – physical</b>						
# in-depth interviews	13	4	1	4	4	-
# focus group interviews*	-	-	-	-	-	-
# interviews secondary analysis	11	-	-	11	-	-

\* In brackets number of participants of the focus group interview

## Chapter 3 – Reasons for using primary care

Most of the children and parents we interviewed rarely used primary health care services. Almost all, whether healthy or with complex needs, said that they mainly visited the surgery for routine preventive examinations, vaccinations, and for treating minor acute issues such as infections. For more urgent issues (i.e., injury after car accident), A&E was used. Out of hours services were used when the GP surgery was closed. Some children with complex health care needs also visited the GP for specific issues related to their conditions (i.e., diagnostic process). A few children and parents mentioned that they sometimes visited the GP for medical reports, blood tests, prescriptions or sexual health. The following subthemes are discussed below as well as suggestions for improvement: acute health issues, preventive health care services, vaccinations, specific reasons for seeing the GP in complex care cases, and sexual health.

### 3.1 Acute health issues

Several parents in the Czech Republic, Spain and the Netherlands said that they do not go to a GP when their child first appeared to have a health problem. They waited a few days to see whether the symptoms continued or worsened. Some participants from the Czech Republic said that, before going to see the GP, they bought medicines in a pharmacy, such as paracetamol. One mother from the same country said that she would rather use alternative treatments (homeopathy) and only see the GP with her child if it was really necessary.

Few parents of healthy children in the Czech Republic spoke about using A&E services. They used these services only when there was an urgent acute health problem and the surgery was closed. Sometimes they were referred there by a GP. A barrier to visiting emergency was mentioned by one girl in the Czech Republic, who said that if she did not feel well she always hesitated to visit the A&E department of the local hospital because she was worried that a doctor with bad reputation, who worked there, would treat her:

*"There is one doctor, who is known here for not being a really good doctor, in our town. So we were always pondering if we should go to the emergency, when I had stomach ache or something like that; if we should go or not. So it was like "What if the doctor is there?" because he wouldn't do anything about my injury." (ID6, CZ, F, child)*

#### 3.1.1 Mental health conditions

Like parents of healthy children, parents of children with ADHD visited a GP if their child had an acute issue. Parents from the Netherlands, for example, visited the GP when their child had a hip injury which hindered the child during sport activities, or an ear infection, or if they wanted to be sure about something.

Only two parents of children with ADHD from the Czech Republic mentioned their children were transported by ambulance. In both cases the school called the ambulance. In one case, the child's nose was bleeding which didn't stop. After the girl was transported by ambulance, she started to be afraid of death and suffered from anxiety for some time. The

mother commented that it was not caused by the experience with the health care but because her daughter is very sensitive, which she considered to be a symptom of ADHD.

*"My daughter's nose was bleeding for half an hour. At school they called an ambulance because they did not know how to stop it. And my daughter was starting to think that she would die, right. She was scared. She is hypersensitive, so she said: I will die, I will bleed to death.' Because she was bleeding really extremely. So they stopped and they informed me from the school that I should pick her up. So I came for her (...). But her feelings did not disappear. The experience was terrible for her, she had nightmares about it, she was crying all the time and she was afraid of it. It was an experience that she fixed in her mind. She is always, when she experiences something traumatic, well these children (with ADHD) are a bit different, right." (ID37, CZ, F, parent)*

In the second case the ambulance was also called because the child was hit by a car during a school trip.

Of the children with ADHD, children in the Czech Republic, Spain and the UK said they used A&E mostly when they injured themselves in sports activities, a common reason for children with ADHD. One male participant from the UK, who attended a specialist school, said that he also went to A&E when he got into fights with other children, though he was getting better at managing his anger.

### **3.1.2 Physical health conditions**

Among the reasons why children with complex physical health conditions and their parents visited the GP for acute health issues were migraine, low blood pressure, broken bones, foot infection, extreme pain due to an injury, high fever, and accidents. Similar to "healthy" children, parents and children did not always visit the surgery immediately; they waited and see how the symptoms developed. For example, a mother in the Netherlands talked about a situation in which her son was extremely tired. She decided to visit a GP when her son fell asleep in the middle of the day and his school results suffered from this tiredness. One girl with epilepsy from the Czech Republic said she did not visit the GP if she had minor acute issues because she could usually buy medicines from the pharmacy or find it at home in the first aid kit. When she knows that a prescription (for antibiotics) is needed she visits the GP.

In the Czech Republic and the Netherlands several children with TBI, epilepsy, rare diseases and their parents said they used A&E because of their condition. One of the children with TBI and epilepsy in the Netherlands visited the A&E department regularly due to seizures. One of the children with epilepsy from the Czech Republic did not call an ambulance after her first seizure. She did not want to bother anyone at night when it happened and went to the A&E the next morning. She felt lucky that there was a neurologist who knew what to do.

A mother from Netherlands described how the GP helped her to manage an urgent issue. She said that her GP did not want to wait for an ambulance when her son had his first epileptic seizure; he brought the mother and the son to the hospital himself. The GP also gave the mother his mobile number so that they always could get in touch.

### 3.2 Preventive health care services

Preventive health care services for children includes screening procedures or preventive health examinations offered to all children that aim to assess the child's physical, psychological, and social development and wellbeing. With regard to these preventive health care services, participants in our study talked predominantly about going for preventive examinations with their children and vaccinations. The organisation of preventive health care services differs between countries (see Chapter 1 for the differences in systems between the countries). Experiences with preventive health care services seem to be related with participants' attitudes towards the system. Thus, participants' attitudes are also presented in this section.

#### 3.2.1 Preventive child health examinations

All parents and children who participated in the study used primary care services for routine preventive examinations. Several parents in the Czech Republic, Germany and the Netherlands stated that it was important to have these examinations because they may help to find if everything is ok with the child or not. One parent from the Czech Republic thought that preventive examinations were especially useful for first time mothers who needed more help with their young children.

The existence of different systems of preventive health care services in the five countries was reflected in participants' experiences. Some parents in Germany complained about mandatory routine examinations for children. Generally speaking, the parents thought those examinations were reasonable and should exist, but they that they were way too strict in a lot of cases. Some parents even considered them to be an infringement of privacy, as a following excerpt shows:

*"If someone comes to your home and looks how you treat your child, not that I have something to hide, but I still think it is a big infringement of privacy." (G, parent)*

In the Netherlands, parents also have to go for several preventive examinations with their children but recently one of the consultations has been removed from the schedule. One parent thinks it is a pity, as illustrated by the following excerpt:

*"It is not that much anymore. With my oldest daughter, the oldest one, I had to go a lot more often, and it has become less common now. They deleted a few visits from the schedule. So, now you bring a visit with 2 years, she will be almost 3 years, with 3 years we will have to go there again, and that's is quite a long period of time."*

#### **Yes. Do you think it is too long?**

*Yes, on the one hand I think: you definitely need it, but on the other hand, I think that might be the only examination that's still there at that age. So there is a kind of examination of your child, how is she doing. Yes, I don't know. My children go to kindergarten, but maybe not all children. Sometimes it might be good to keep an eye on how the children are doing." (ID16, NL, F, parent)*

### **3.2.1.1 Mental health conditions**

Only parents of children with ADHD from The Netherlands talked about preventive child health services. Most of them related their experiences to the mental health problems of their children and their role in getting a diagnosis. In one case, the preventive child health care services referred a child to the youth mental health care organization. Although one participant saw the relevance of the preventive health examination, this mother considered the visits as fossilized and predictable.

*"Yes, preventive child health services, I actually saw it a bit, which is disrespectful, as a fossilised and predictable ritual. With your first child....It is good that they give vaccinations and stuff like that. I think it is good that there is someone who is registering (growth and development of child). The "growth books" and stuff like that. But to say, I was looking forward to the visits? No. I am not saying that it should disappear, but not" (ID52, NL, F, parent)*

Sometimes a preventive examination may initiate a GP-visit for a health issue. One mother of a child with PDD-NOS from the Netherlands said that she did not notice that her son had an ear infection because he had a high pain threshold due to his condition. When he visited the school doctor for a preventive health examination, this school doctor examined his ear and referred him to the GP to get medication for the infection.

### **3.2.1.2 Physical health conditions**

Children with physical health issues and their parents had similar experiences with preventive examinations as healthy children and their parents.

### **3.2.2 Vaccinations**

Vaccinations were one of the main reasons for using primary care services in all five countries. Participants differed in their attitudes towards the vaccination programmes. Some parents in Czech Republic, Germany and the Netherlands said that vaccinations were important for preventing diseases as is illustrated by the following excerpt:

*"If the vaccination is helpful, please go ahead, because I don't want be blamed for anything that will happen because of not giving this vaccination .....Suppose she gets the disease and it becomes fatal, that you think afterwards: I had to get that vaccination."(ID17, NL, F, parent)*

Parents in the Netherlands commented that they had been vaccinated themselves and did not perceive any negative consequences, or they did not know anyone who disallowed their child from being vaccinated. Furthermore, some parents in the Netherlands commented that the National Immunization Program is well-conceived; if it was bad for children they would not offer it. They noted that vaccinating is also important to protect all children in a community.

One parent from the Czech Republic said that she is glad that her children were vaccinated because she does not have to worry about her children getting the diseases. The same

participant also described how her attitudes towards vaccinations changed, as the following excerpt shows:

*"When I had my first child, I was very alternative and I hated that they would inject my baby, who was less than three months old. This was unbearable idea for me, at the end I just somehow coped with it because I did not want to have the problems that would follow after not having the vaccination – like I wanted him to go to the kindergarten in his three years, right. I know mothers, who did not let their children to be vaccinated, who stand by their decision. Now, I have more experience, I have three children and I can see that the vaccination did not harm my children. And I am now calm because I know that they won't get the ugly infections. So, after the experience I have from my motherhood, after the seven years and a half, I am a supporter of compulsory vaccinations. I don't like it but I have no other proven effective way and I don't want to neglect anything. So I hope that people, who are responsible for it, know what they implement. It is quite good I think." (ID10, CZ, F, parent)*

Some participants spoke about their concerns about vaccinations. A few parents in Germany, for example, commented that even though vaccinations were important and necessary in general, not all of them needed to be done.

One of the children in the Czech Republic did not like that the vaccinations are compulsory. She expressed that everyone is responsible for his or her own health and thus the vaccination should not be compulsory.

*"I was thinking about the vaccinations, for example, in Germany, it is obligatory, right and even though 75 % of the population goes for vaccination. Then there are people who don't let themselves to be vaccinated and then there are issues from both sides – people who don't go for the vaccinations and those who have to take care of them. But I think it should be obligatory.*

#### ***How do you think it would help if it was obligatory, how would it change?***

*Well, in theory, I think that the number of people who would be vaccinated wouldn't change. Those, who go for vaccination would go even if it was obligatory, they would drop minimally. There would be no punishments for not going like they are now, I don't know what happens nowadays but something does if it is compulsory. So the people would let the child to be vaccinated, or even themselves to be vaccinated but they would take it as their own responsibility. They would go there from their own will." (ID2, CZ, F, child)*

Several parents of girls talked specifically about the HPV vaccination. In the Netherlands some parents had let their daughter vaccinated, others had not. Reasons for not getting a vaccination were that the vaccine has not been proven to be safe and that the long-term consequences are not clear at the moment. Parents in the Czech Republic and the Netherlands, whose daughters were younger than 12, at the time of the interview, were not sure yet, whether they will let vaccinate their daughters. In the Netherlands most of them said that they will deepen their understanding before they will take a decision. In the Czech Republic, one mother said that she will decide together with her daughter when the time

comes. In Spain, two mothers told us how their daughter did not feel well physically after the HPV vaccine. One of girls confirmed us this problem: she explained that she fainted.

In the Netherlands, parents also talked about the role of the professionals of the preventive child health services in relation to providing vaccinations. They stated that the professionals should take more time to provide more explanation about the vaccinations. According to these parents, they should inform them about the pros and cons of the vaccinations in such a way, that a parent is able to make a deliberate decision. Others noted that this information should also be available for example on the internet, or via TV commercials. One parent noted that the government only provides information about the relevance and not about the side effects of the vaccinations. You can only find information about the side effects on forums. Two parents in the Netherlands talked about their first visit to the preventive child health services in which they were told that there was a pertussis epidemic in their region and they could vaccinate their child earlier. Both parents agreed to do this, but the way the professionals handled felt as scaremongering.

### **3.2.2.1 Mental health conditions**

One mother of a child with ADHD in the Czech Republic believed that her child's condition was caused by a vaccination. She does not trust vaccinations nowadays, which has an impact on her decision related to HPV vaccination for her daughter:

*"The vaccination against the HPV, I know that I won't let my daughter go for it. I know, when someone has a cancer diagnosed in a family, then perhaps they go but. They have a commercial for that on TV - I think all these things, vaccinations are only something to make a profit on." (ID37, CZ, F, parent)*

In contrast, one mother of a child with ADHD, also in Czech Republic, said that to ensure that all children are vaccinated, it should be done at schools like it was in the past.

### **3.2.2.2 Physical health conditions**

Although all parents of children with a physical health condition in the Netherlands were aware of the recent debate on the immunization program and were critical about the programme, their children participated in the immunization program and got all the vaccinations. One mother noted that the only thing she knows is that if her child doesn't get the vaccinations, her child will become very ill when he gets one of the diseases included in the programme.

In the Czech Republic, one mother said that vaccination might be a reason of her child's epilepsy. She decided that she won't let her younger child to be vaccinated. She also described how the system of punishment for not having the child vaccinated could be bypassed in the Czech Republic.

*"Well, nothing happens when your child is not vaccinated. A GP asks you why you don't have it and that's it. The only consequence is that they won't accept your child in the kindergarten. They accept him only for the compulsory year. The child cannot go to summer camps, school trips and similar activities. Nothing else happens. (...) But there is a*

*paradox. If you have a proof that the child cannot be vaccinated, suddenly „He cannot go to the kindergarten“ or „He cannot go for a school trip“ don't apply anymore. They just accept the child to the kindergarten, the child goes for the trips to summer camps because then the child is perceived as vaccinated even if it is not the case. (...) so I am going to ask the doctor for the medical certificate confirming that my daughter is in risk because of a family burden (epilepsy).” (ID68, CZ, F, parent)*

On the other hand, another mother of a child with epilepsy in the same country suggested that more strict penalties should be applied when the child is not vaccinated.

### **3.3 Visiting GP for mental health conditions**

Many participants said that they do not visit the GP very often because they visited secondary care specialists about their ADHD. However, several participants mentioned that they visited their GP for blood tests, advice, or a referral for psychiatric or psychological care.

Even if a diagnosis of autism or ADHD is given by specialists, some parents mentioned the GP in relation to the diagnostic process. The GP has mainly a role of referring the patient to specialists. In the Czech Republic, Spain, and the Netherlands, parents visited the GP to get a referral for psychiatric/psychological examinations when they suspected something was wrong with the child. One parent in the Czech Republic said that at first, the GP did not refer the child to further assessment because she did not consider the child's problems as a symptom of ADHD. Some parents in the Czech Republic, the Netherlands, and the UK were advised to see the GP because of teachers' suspicions of ADHD/PDD NOS.

Even if medication was usually prescribed by psychiatrists, some parents in the Czech Republic and Spain said they had to go to the GP for blood tests, which were then sent or brought to the psychiatrist for assessment. In the Netherlands and Spain, some participants said they visited the GP in order to get medication prescription for AD(H)D.

*“Yes, yes I call and they give me an appointment with her [taking about the GP]... and now I will have to call again to the 012 and get the appointment because the prescription will expire.” (ID53, S, F, parent)*

Among other reasons for visiting a GP for ADHD was asking for help or advice. One mother from Netherlands said that she visited the GP when she had questions regarding the dosage of the medication, while other participants visited psychiatrists to get this information. In the Czech Republic, one mother visited a substitute GP to get a confirmation that her child was free of contagious diseases, needed for summer camp for children with ADHD. She complained that she was refused. Paradoxically, the GP stated ADHD of her son and past allergic reaction to a wasp sting as the reasons for her decision.

One mother in the Netherlands said she rarely visited the GP because she felt a lack of understanding from the GP, who did not have any knowledge about autism – her son was his first patient. Some parents in Spain said they had private health insurance and took their child for certain problems to this service instead of the GP in the Primary Care centre.

*"It takes a long time and I needed something immediately... so I thought that if I start here now they will send me for the first consultation in three months, so I said to myself I need this now, I need this now! And I went to a private consultation. There they gave me the appointment in 15 days. So from the first time I decided to go to a specialist, it took me 15 days to get the appointment." (ID59, S, F, parent)*

One mother from Netherlands commented that she visited the GP with her daughter because her daughter felt unhappy and did not want to live anymore.

*"The last time...I think... that was for <<my daughter>>. Yes, I think so. And that was not so much because she had physical complaints, but mental complaints. I did not know what to do with this. Then I visited the GP to tell him: 'Listen, I don't know what to do'. And then I was referred by him. Because my daughter who had really such a thing saying I do not want anymore. Well, that was the alarm bell for me. She was really freezing in her hand, and saying: 'Mom, I am so unhappy. I do not feel like it anymore'. And then I visited the GP again to ask, what are we going to do?" (ID49, NL, F, parent)*

### **3.4 Visiting GP for physical health conditions**

Children and parents said they mostly do not visit the GP for the physical complex needs like TBI or epilepsy. They visit specialists of secondary care for regular examinations for the child's condition, where they usually get medication prescriptions. Some of the participants said they have various health care professionals, who they visit to treat their issues (neurologists, speech therapists, psychologists etc.). With respect to the primary child health care, participants consider visiting the services mostly for acute problems (i.e. migraine, accidents, low blood pressure etc.), getting painkillers, vaccination and going for preventive routine examinations.

*"In fact, I can't say much about the primary care center, because I have not had much with them, not even before the injury, or after, they have not had any follow up with him (...) When we left the hospital we went just to get the prescription, they asked how he was, and that is all, not even an X-ray to see how he was, absolutely nothing." (ID 87, S, F, parent)*

Specific characteristics of the health condition were among other reasons why to contact a GP. Of children, a girl from the Czech Republic said she visited a GP with her mother to ask if tingling feeling in arms is normal. The GP referred her to neurologist and the girl was diagnosed with epilepsy. Nowadays, the girl visits the GP when she needs information on some issues related to her life with epilepsy. In the UK, a girl recalled last time seeing the GP about her asthma and epilepsy and getting prescription medications for these, instead of going to the secondary care. One mother from the Netherlands noted that her son with an acquired brain injury has a high pain threshold. Therefore, when he faces a health issue or complains about pain, his mother calls immediately the GP; especially, when her son is complaining about a headache. Further, some parents in the Czech Republic visited or called<sup>1</sup> the GP to answer their questions related to their child's condition (i.e. "Is it safe to

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<sup>1</sup> All parents of children with complex physical needs from the Czech Republic had personal phone numbers for their GPs.

*give paracetamol to a child with NORSE type epilepsy?"*). One mother in Spain went to her paediatrician in primary care just to inform what happened because her son had been admitted in ICU and hospitalized. In the same country, some of the parents said they visited the GP for getting help with application forms needed for getting financial support for carers, assistive technologies, or rehabilitation stay in spa. This does not happen in Spain at all. One mother in the Netherlands visited the GP because she was not able to get in touch with the paediatrician. The GP asked the paediatrician to call the mother, which he did after a reminder.

Parents in the Netherlands commented that they have little contact with their GP regarding their child's TBI or rare disease. Partly, because they contact the paediatrician in hospital if they have questions, partly, because they self-manage medication problems. Few children and parents in the Netherlands mentioned that they did not visit the GP because they perceive a lack understanding of their problems. They did not dare to visit their GP with the same health problem again until the situation got worse, as is illustrated by the following excerpt:

*"You notice that you are really getting afraid, you don't know any more when you need a doctor because they laughed at you every time. So, that child also knows that; I don't say anything, or I don't want anymore. Because if the GP said that she had nothing, she was not going until it was killing her, and then she went.....But when she had something o, I won't visit a doctor. Most of the time she waited, however that was something I noted, until the weekend or the evening, because then she could go to the out-of-hour services and you know for sure that you will get another doctor, well not for sure, but the chance is great."* (ID84, NL, F, parent)

One mother in the Netherlands said she rather visits university hospital if her child needs a doctor than their GP. She explained she is negative about her GP as he does not follow the advices and care of the university hospital. As a consequence, the mother is frustrated about her GP because her child needs a GP who is involved and is ready to help the child.

Some parents of children with epilepsy and rare disease talked about the role of the GP in getting a diagnosis. Several parents of children with a rare disease in the Netherlands said that they visited their GP often and that the GP referred their child to either a paediatrician, blood tests, or to the A&E at the hospital. See chapter 7 for more information about getting a diagnosis and the role of primary care for children with complex health care needs.

### 3.5 Sexual health

Some people in the UK went to the GP surgery about sexual health issues whether that was for contraception, cervical screening, or sexually transmitted infections (STI) tests. One participant recalled the first time she went to see the GP about going on the pill. She was 16, went on her own, and felt nervous. She now goes routinely every six months.

*"I was really nervous because I was 16 I think, so I was nervous because you do think of maybe a doctor as the same, in the same sort of breath as your mum and dad. So you worry that they're going to, not judge you but yeah, worry that they're going to think things of*

*you or ask you lots of questions, which at that age I'm sure you're not really prepared to answer. So I was worried, but then after I was absolutely fine cos like, after you think oh that really wasn't that bad, you know.*

***Can you remember the appointment, can you remember the kinds of questions that the doctor might have asked or anything like that?***

*I think the doctor asked why I wanted to go on the pill and why the pill specifically because there are obviously other contraceptives available. I think they asked if I had a boyfriend. They didn't go into detail about amount of sexual partners or anything like that. But yeah I think they just wanted to know if I was actively having sex and why I wanted to go on the pill, yeah.*

***Did they give you any information about the other -***

*Yeah I got leaflets, I remember I did get leaflets about all the kinds of contraception and all the pros and cons and, and [pause 4 secs] you know about risk of pregnancy, I guess that they're not 100% effective and things like that, yeah." (ID26, UK, F, child)*

### **3.5.1 Mental health conditions**

One young girl from the Czech Republic with ADHD said that she was sent for an examination with a gynaecologist (considered as a primary care professional in the Czech Republic) by the police. It was part of investigation which she chose not to go into details about.

### **3.5.2 Physical health conditions**

One girl in the Czech Republic with epilepsy said she did not visit the GP surgery to get contraception. She believed she was taking so much medication for her epilepsy that contraceptives would be another burden on her body.

## **3.6 Improving services**

*Preventive routine examinations:*

- Parents in Germany said that the preventive examinations are important but way too strict. Some of the parents felt that the system of preventive examinations sometimes violates privacy. The system of preventive examination should be modified
- There was a lot of controversy over the compulsory vaccination programmes. Some parents had no doubts about having their child vaccinated while others wanted to decide by themselves and have more freedom. Some suggestions were mentioned by the participants.

*Vaccinations:*

- Parents in the Czech Republic noted that in order to ensure that all children are vaccinated, the vaccinations should be given at schools.

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- Furthermore, they suggested that if the child is not vaccinated, there should be more strict penalties for the parents.
- According to a young girl in the Czech Republic – the vaccinations should not be compulsory, people would go for the vaccination anyway but they would do it from their own will
- Some parents in the Czech Republic and the Netherlands said that they missed information on vacations, such as leaflets with side effect. More information should be provided about the pros and cons of vaccinations to the parents so they can make deliberate and informed decision.

### *Visiting GP for complex health conditions:*

- Some parents in Spain would like to visit the primary care service for a follow up care after hospitalization. Follow-up appointments should be scheduled.
- Some parents did not visit their GP very often because they thought he did not understand the condition. GPs should be informed also about disorders that are mostly handled by the secondary care.

## Chapter 4 – Accessing primary care services

Access refers to the ease with which primary care services for children can be reached (Kelley & Hurst, 2006). In this section we discuss children's and parents' experiences of opening hours, making an appointment, distance (or travel time) to the surgery, physical access to the surgery, registering with a GP other kinds of appointments, and waiting time at the surgery. Furthermore, suggestions for improvement are presented.

Many participants talked positively of the public health services in their country, not only primary care. Most felt that they have had access to whatever they have needed: specialists, tests and treatments.

### 4.1 Opening hours

For most participants in all five countries having a surgery that was open at convenient times was important. The primary care centres in all countries usually closed between 5 and 8 pm. Some parents in the Netherlands noted that it was acceptable to them because they could always get medical help elsewhere, whether at the out-of-hours service or the A&E department of the hospital. There is health care available 24 hours a day, seven days a week. This was also the case in the Czech Republic, Germany and UK. Parents in the Czech Republic were also unhappy when their children's GP was absent during office hours, mostly because of illness or vacation, because they had to go to a substitute GP elsewhere.

One young participant in the Czech Republic would prefer earlier opening hours of her GP surgery so that she could visit the doctor early in the morning before school.

*"They could be open from 7am, because for me it is important to take school into account, so I could be there the earliest possible and I would not miss many classes. Well, it's not because I would like to force the doctors to go to work so early because I know that getting up early is not very comfortable but for me as a student, it would be definitely better – about 7am. And for my parents too, perhaps, because of their work." (ID10, CZ, F, child)*

Having the option of getting an appointment in the morning or evening is available to some people in Spain, which benefits parents because they can get an appointment convenient to them and their working hours. One of the parents explained that appointments are only available in the mornings and this forces her to ask for leave from work.

### 4.2 Booking an appointment

Although the system for booking an appointment varies from country to country, the main concern for participants when booking an appointment was getting an appointment at a convenient time without too long a wait. The initiative to book an appointment mostly came from parents in most of the countries in this study, who called the surgery itself or a centralized number (Spain). Most of the younger children disliked calling the surgery themselves to make an appointment and asked their parents to do it for them. One child from Germany told us:

*"Everything depends on if I'm in the mood. If I want, I call myself, but mostly, when I do not want to, my parents call." (ID11, G, F, child)*

It was often the mothers in all five countries who called to make an appointment as this often had to be done during school hours. One child in the Netherlands mentioned that he and his mother made an appointment for a follow-up consultation directly after the first GP-visit, through the receptionist. Some participants in Spain told us that there have been changes in accessing the paediatrician and paediatric nurse in primary care. Before, patients had to get an appointment with the doctor and this automatically gave the patient an appointment with the nurse. Nowadays, patients need to book the appointment with the nurse and it is more difficult to get an appointment with the doctor at the same time, so they feel that the system of making appointments has deteriorated. On the other hand, participants noticed some positive changes. Before, it was more difficult to get an appointment as patients had to call at specific times but nowadays they can book the appointment online.

Some people did their best to get appointments either before school or in the afternoon if they finished early. Lots of young participants in all countries preferred not to miss lessons if they were at school, college or university but it was not always possible to get an appointment at these times.

For visits relating to acute issues a reservation system is not used in most of the GP surgeries in Germany and Czech Republic.

Some parents in The Netherlands also talked about making an appointment with out-of-hours services. Although it is always possible to make an appointment, one father noted that it is difficult to find which number you should call. Another parent commented that she had to wait a long time before getting in touch with someone. Most of the time, parents are called back within 30 minutes. When participants in Germany or Czech Republic had an emergency or needed assistance for an acute problem they have had to attend the primary care centre without an appointment. Usually this was not a problem, but there were complaints about the organization of the system because they had to go through the receptionist to get an out of hours appointment and a physician assigned to assist them. This meant that they needed to wait to be attended first by the administrative personnel and frequently there is a queue and it is a slow procedure, especially when the child is not feeling well.

#### **4.2.1 Waiting time to get an appointment**

Participants waited different lengths of time to get an appointment, depending on how busy their local practice was, and people had very different perceptions of what was a short or long wait. Some children in Germany for example complained that if they called the practice themselves, they did not always get an appointment quickly, but if they insisted and called multiple times, then it could be quicker. Some parents in the Netherlands told us that they had to call as soon as the surgery opened otherwise they were unable to get an appointment for the same day, or they would have to wait a long time before the phone was answered.

The surgery one participant from the UK was registered with was often so busy that she would not get an appointment for three or four weeks. If she wanted to see the doctor that day, she said she would have to say that it was an emergency. She said that she now prefers looking up her symptoms online and getting a natural remedy than seeing the GP. She pointed out that long waits to see a GP can be inefficient for the NHS if it forces people to go to Accident and Emergency (A&E) instead:

*"If I want to see the doctor, I would definitely say it's an emergency appointment just so that I can have a doctor ring me, even though I don't like having to do it on the phone, it's better than waiting two weeks.*

**How does that make you feel like when you think you have to wait two weeks to get seen?**

*Well it just forces me to like go to A&E or something. I don't really want to go to A&E and wait there for five hours just waiting there, and they say something like, "Oh it's nothing serious." So yeah, it's just the fact that knowing that I've got to wait two weeks forces me to go to the A&E or something which is something I really don't want to do. " (ID25, UK, F, child)*

One girl in the Netherlands found it annoying that she had to wait a week to get an appointment. She had to put up with her problem for longer.

*"My mother called and then we could come for a visit the next week. The only thing is that it took a bit long. A week, yes. Because everything was fully booked and I could only next week, so I had to wait for a week....*

**And if you look back at the whole process. What do you think could have been better?**

*Ehm, the time that I had to wait. That time, I was very annoyed by my sneezing and so on. So my mother had called. And I had to wait for an additional week. So then I still had a cold." (ID21, NL, F, child)*

Most parents noted that for an “urgent” problem, they could often get an appointment for the same day. However, one mother from The Netherlands said that she often had to convince the doctor’s assistant of the urgency of the problem. This was annoying because, as a parent, she wanted help for her sick child quickly.

*"Yes, that is most of the time difficult. If you have an appointment that has no urgency, then it will be your turn often next week. Then it will take a week. And if you need an appointment, suppose I wake up and I am very ill and I will call, then you definitely have to call between 8 and 8.30, or something like that, in order to get an appointment for the same day. And if you would like to come the same day, then you need to have the gift of the gab in order to get an appointment for the same day, really, especially if they are fully booked. So, I think that is sometimes difficult." (ID16, NL, F, parent)*

One parent in the Netherlands said that it was easier to make an appointment for the same day when a child had a health problem compared to when she needed an appointment for herself.

Some participants in Germany complained about having to wait months for an appointment at some specialists (eye doctor) and then additionally wait couple of hours when they are there.

#### **4.2.2 Doctor's assistant and receptionist**

In order to make an appointment, parents in the Czech Republic, Germany, Netherlands and Spain mentioned that they had to call the doctor's assistant (nurse) who has a gatekeeper function. He or she asks the parent questions about the health problem and decides how urgent the problem is. One mother from the Netherlands said that she does not always want to discuss the health issue with the assistant; she prefers to discuss this with the GP:

*"What I sometimes find difficult is that when you call the doctors assistant in order to make an appointment, that they want pre-information and that you have to tell them the reason for the visit. I don't think so. Then I say, "I won't tell you. I would rather discuss that with the GP". I find that always a bit unfriendly." (ID24, NL, F, parent)*

One participant from the UK felt that receptionists at her local surgery 'do not follow their job description' – they were often rude instead of polite. An 18-year-old female from the UK felt that a few receptionists gave her 'a grilling' before booking her an appointment. Occasionally she told the receptionist that the reason for her visit was private when she did not want to give this information out loud in a busy surgery. Some parents in the Czech Republic had similar experiences. A father from the Czech Republic described issues around making appointments caused by the nurse (receptionists):

*"In our case, the nurse takes the calls and sometimes it is hell, it is trouble to agree on something. She is the gatekeeper before I get to the doctor's office. My advantage is that I am a man and I am able to get her sympathy. (...) Then she is more willing. My wife still struggles with her. So, when we need to call there or solve a problem quickly, I call there. It is our tool, we have no other option." (ID1, CZ, M, parent)*

Some of the participants in the UK, the Czech Republic and Spain we talked to recalled negative experiences with some receptionists (practice nurse in the Czech Republic). One young person from the UK felt that some were 'condescending', and another that some were abrupt when they should have been more sensitive and approachable.

In many GP surgeries in the UK, people can check-in by putting in their details on a touchscreen. Some people we interviewed checked in digitally and found it convenient because the receptionists were often busy and had a long queue of people waiting to see them. Participants also liked that it was private. One of the benefits of touchscreen check-in was 'less human interaction', and one UK participant mentioned it was often quicker and better if he was a bit 'groggy' in the morning. Some people who were concerned about

privacy and confidentiality preferred checking in digitally because they disliked being asked questions by receptionists.

#### **4.2.3 Mental health conditions**

Like the healthy children, children with ADHD used primary care services mostly with the help of their parents. This means that parents decided if and when the children saw the GP. All participants in the Netherlands noted that a doctor's assistant has a key role in making an appointment. One parent commented that it depends on which doctor's assistant you get on the phone whether it is easy to make an appointment or not. Some parents in the Netherlands did not like the fact that the doctor's assistant asked a lot of questions. One mother said that she was a bit scared to call because of her previous experiences. She also said that it was very hard for her to get an appointment when she had questions regarding the autism of her children. This annoyed her because she felt that the doctor's assistant should know about this as it should be noted in their records.

*"Well, actually in the first instance, I did really not dare to call, because you always [pause 11 seconds]. Because I do not really have good experiences with the GP, let's say it that way. Neither with those who are in front of it, nor with the doctor's assistant. You cannot get through if I had questions about it. About his autism. The doctor's assistant is always there, also with the previous GP, so she knows us all our lives. Yes, she knows me like 42, for 40 years she's known me. But I never get through. And that is really.., that is really annoying....And then I think: you know how our family is doing, you receive all information from the paediatrician as well as from the youth mental health organization. And we want some understanding." (ID48, NL, F, parent)*

#### **4.2.4 Physical health conditions**

Most of the children with TBI and epilepsy felt able to call the doctor and book their own appointments. In order to make an appointment with a GP, parents of children with complex physical health conditions in all countries noted that they had to call the doctor's assistant or a receptionist. One mother from The Netherlands noted that it was dependent on which doctor's assistant she got on the phone whether it was easy to make an appointment or not. The assistant would ask some questions in order to decide whether a patient could have an appointment or not. For one mother this felt unfriendly because she wanted to discuss these things with the GP and not with the doctor's assistant. Another mother said that she sometimes had to push in order to get an appointment. One mother commented that she first notified the doctor's assistant that she was calling for her son who has a brain injury for whom a health problem might be more urgent than for her other children. It is therefore important to get an appointment as soon as possible.

### **4.3 Distance to the surgery**

Most participants had no problems accessing GP services because they were usually nearby and they could go by car, bike (Netherlands) or walk. The distance to the local surgery was for one mother in the Netherlands a reason to change GP when she had children:

*"Before we had a GP in the city centre, close to the hospital, or no, the other hospital. That was our family doctor, so yes, my granddad visited this GP for many years, he is not living anymore, and my father and mother and I visited this GP for years, and then it is not easy to leave this surgery. But at one point I said, suppose something happens to the children and my husband is at work, I have to go by bike to the surgery as public transport is not that good here. So I said, ok, let's see if there is a GP nearer." (ID22, NL, F, parent)*

In Spain the primary care centre usually assigned to a patient is the nearest to their home.

Several parents in Germany, UK and the Czech Republic mentioned that there is a difference between accessing GPs in big cities compared to villages. Parents living in cities said they are able to choose their doctor and there are several surgeries near their homes.

Participants from smaller villages, though, complained that there is no surgery in their area. Thus, when the child is sick, parents from rural areas have to travel elsewhere with their children. In some cases this was a barrier to visiting the GP at all because travelling with an ill child was considered complicated. A mother of a healthy child living in a village in the Czech Republic commented:

*"When our son was born, we had our GP five minutes from our house. Recently, I have moved to a village and there is no GP for children. I was in a situation when my child was sick but when I imagined that, I don't have a car, that I would have to wait for the bus, travel to the city and there I would end up in a full waiting room, I rather stayed at home and tried to cure him by myself." (ID2, CZ, F, parent)*

In rural areas in Germany, GPs usually take over the tasks of a paediatrician. The absence of a GP was not only a problem in rural areas but also in some socially excluded localities of cities in the Czech Republic and Germany. Some parents in the Czech Republic suggested that there should be a doctor travelling to these villages to visit ill children at home, if needed, to improve accessibility in villages. Two participants from the same country mentioned that they were offered a visit by their children's GPs in the case of emergencies. GPs usually have some out-of-office service but they do not travel out of their city or to a larger area. Some disadvantages of doctor visits at home were also mentioned: some people might overuse the service, and the quality of care might be lower because the GP would not be able to examine the child as much as in the surgery (equipment, blood tests).

#### **4.3.1 Physical health conditions**

Because it was difficult to get to the doctor, children with TBI and epilepsy in Germany were dependent on their parents to take them there by car.

#### **4.4 Physical access to the surgery**

Physical barriers to accessing the GP surgery were mentioned by one participant in Czech Republic, who said:

*"The stairs annoy me really; there is a small lift so I could not fit in with our stroller. And if you have a stroller, you have to open the door manually. (...) these are details but if you are*

*limited somehow by the stroller or crutches, these details are worth noticing. That's what I would change if I was a doctor working there." (ID64, CZ, F, parent)*

One mother from the Netherlands complained that it was hard to find the direction to the office of the Preventive Child Health Services. She also had difficulties parking her car.

#### **4.4.1 Physical health conditions**

One of the parents of a child with TBI from the Czech Republic mentioned physical barriers to accessing the surgery. There was no lift and she had to take the staircase with her young children.

### **4.5 Registering with a GP**

People in all five countries often changed surgeries when they moved to a new area or sometimes when they were dissatisfied with the care from their GP. When registering with a (new) GP, parents looked at the Internet for reviews, were informed by friends, or visited the practice to get acquainted with the GP and see if he or she would be a good doctor for them. One parent chose a GP specifically who had young children himself:

*"What I really liked is that they both have children, young children in the same age as our children. Then they can easily imagine how we and the children feel and they know how to treat children instead of an elderly man who is already frustrated and desirous of retirement. It is an example, but it could be. Yes, I think there is a difference in that. That is why I consciously opted for those GPs" (ID22, NL, F, parent)*

Registering with a new GP can be hard for some young people in the UK, who are at a time in their life when they move around a lot. In the UK anyone over the age of 16 can register with a GP by themselves. New university students are often given information about registering with a doctor in their first week of term. While this was quick and easy for some participants, others had moved around several times in the same city and wished the process was easier.

#### **4.5.1 Physical health conditions**

One mother of a child with a rare disease from the Netherlands wanted to change her GP as the doctor was not involved in her son's care with a rare disease. Due to policy of the municipality, however, she was unable to register with another GP. It felt as if she had no choice.

### **4.6 Other kinds of appointments**

Most participants in all five countries preferred face to face appointments and felt they were more reassuring. One young person in the UK felt that it could be hard to explain things over the phone and easier to show what is wrong in person. Another, also from the UK, felt that it was important to see the GP face to face because the problem could be serious and hard to diagnose over the phone.

In the UK as well as in the Netherlands telephone consultations between patients and doctors have become more and more a part of normal everyday practice. When one young

girl from the UK needed to speak to a GP about mental health, she found it very hard to open up and talk about how she had really been feeling. She felt that it might have been easier to talk over the phone or in writing. She also liked the idea of talking to a professional in an informal setting rather than at the surgery. Some people in the Czech Republic and Germany liked the possibility of a telephone consultation because they could speak to a GP first to find out whether they need to go to the surgery or not. One young person told us that he was communicating with his GP via WhatsApp. It was fast and easy and, therefore, very convenient:

*"Yes, over WhatsApp, it is ok, if it is something urgent, maybe then but. If it is not, then you go there and sit in the waiting room for some time. It is a part of it." (ID16, G, M, child)*

Other participants in the German focus group disliked the idea of using WhatsApp or Skype to communicate with the GP. They felt that it was too clinical and there was no personal connection.

All young participants were in favour of GP surgeries using modern technology that could save patients from going into the surgery, but some wondered if emailing the GP might involve a long time for a reply. Email consultations may be used for certain kinds of medical issues such as test results, medication queries, questions about referrals and recent appointments, and queries relating to reports and forms. The questions are answered by a GP. One young participant from the UK thought that an online consultation might be useful for something like a rash that could be photographed and sent to the doctor. She also liked the idea of booking GP appointments online, which she thought was good for young people who dislike talking on the phone, but also felt that 'there's a lot to be gained from sitting opposite somebody and going through' the issue.

#### **4.7 Waiting time at the surgery**

In relation to the waiting time to see a GP, most of the parents spoke about the time they spent in the waiting room. A few participants from the Czech Republic said they usually waited a very short period of time and sometimes did not see other families in the waiting room. One of them said that this is thanks to the system of making appointments in advance. Another participant mentioned that it is because of the general structure of the GP's office hours.

*"She takes acute cases from 7-9, children for check-ups after the illness from 10-12, in the afternoon there are preventive check-ups." (ID10, CZ, F, parent)*

However, the majority of parents said that they often had to wait a long time in the waiting room. To avoid the waiting, some participants in the Czech Republic called the practice nurse by phone in advance to ask if they could come and what was the best time during that day. One mother always used email to get this information. One young participant said that to wait for one hour in the waiting room was "part of the deal" of going to the doctor. Parents in the Netherlands mentioned waiting times of 0.5 to 1.5 hours. This was unpleasant when they had a child who was sick or who needed breastfeeding for example.

As a consequence, one mother from The Netherlands said that she always tried to get the first appointment of the day. This is illustrated by the following quote.

*"And then you make an appointment and then it is like: can you come this afternoon at 14.00 hrs? And then you make sure that you are there at 14.00 hrs, even a little earlier, because that is how you are raised. You have to be on time. And then you just have to wait for an hour. That you finally go to the doctors assistant and say: 'will it still happen today, otherwise I will go back home, because I have a child of two, three months old that needs to be breastfed, and I won't do breastfeeding here in a blaze of glory'. So, and it is actually every time like this. So now, if we make an appointment, I say: 'I do not want another appointment than 8.15 hrs.' And even then, he will stretch it out till 8.40 hrs, while you are the first." (ID17, NL, F, parent)*

One participant from the Czech Republic said that because parents wanted to avoid waiting, they came to the waiting room 30 minutes before opening time. Too much bureaucracy and chitchat between the GP and patients were blamed for the longer waiting times by one participant in the Czech Republic. Most of the parents and children in Germany had the feeling they had to wait generally too long, although it was justified because sometimes the reason was that there was an emergency to attend to which was a priority. They also felt that it was because of a lack of staff. One child in Germany said that the long waiting time was ok for him – it meant that many people visited the GP because the doctor was really good.

Some participants in the Netherlands complained about the long waiting times at the A&E department. One mother said that she had to wait more than 3 hours with a child having pain.

#### **4.7.1 Physical health conditions**

Regarding waiting time to see a GP, one mother in The Netherlands noted that this is sometimes too long for her son with a brain injury as he becomes impatient.

*"I remember that he recently visited the GP with his father and that he had to wait.....Yes, and it felt too long for him, and then he is a bit impatient. And he does not feel good what he can say and cannot say. And then it is like: 'oh, why does it so take long!' and 'my dear, well when does the doctor come?' And then you also sit very near to each other." (ID73, NL, F, parent)*

#### **4.8 Accessing secondary mental health care services**

In terms of access, children and parents talked about their experiences of secondary care services. To receive an ADHD diagnosis for their child, parents in Germany needed to see a lot of different specialists who performed different tests. Sometimes they needed to wait several months for different appointments and even had to travel long distances several times. Most parents were overwhelmed and stressed by the process. They wished for a quicker, easier and less complicated procedure for them and their children because they felt the urgency and wanted to help their children. Long waiting times were also very stressful

for children with ADHD according to participants in the Czech Republic, Germany, Spain and the UK.

Knowing what services existed, what kind of healthcare they provided, and how to access them was a subject that all parents in the UK felt strongly about or, as Pam put it, '*having it all laid out for you....a road map basically*'. Others also felt that this would be helpful as, currently, there was 'no pathway' for parents to follow.

*"There's no pathway, there's no road...there's no kind of, right OK we're coming under this umbrella; there's loads of things we could be looking at. If we go down this road, these are the services you can go down. Go down this road; these are the services. Like if you don't go down this road, then this is all you're going to be able to go down in to connect to. And then you kind of, I guess have a head at certain points when certain things start coming out and they're growing up and they're changing and you see more of one side than another and all the rest of it. If you kind of know that there is this pathway, like maybe we need to start considering that because that's the only way we're going to get to get that other service, then it would just make you think a few steps ahead of yourself, which is instead of ending up at this place and you're in desperate need and then someone goes, 'Well actually if you were thinking about this we could access to that.' And it's like, 'Well if you'd told me that six months ago we could have started that process and got into line and got all our paperwork ready for whatever."* (ID64, UK, F, parent)

Parents also wanted to know which hospitals had paediatricians, ADHD clinics, ADHD consultants and specialist nurses. They felt that this information should be given to parents when a child is diagnosed. Some parents from the UK felt that a visual diagram (a 'spider map', 'flow diagram' or 'underground map') of the various services and what to try if something does not work would be helpful:

*"It should be let's use the whole remit of all of the services because all the children are different. What suits one won't suit the other."* (ID60, UK, M, parent)

Some parents from the UK felt that it was difficult to access services and that, 'unless you cause a problem' and become a 'pushy parent', it was difficult to get a referral to a good hospital. Several said that, in the absence of the care they wanted, they had had to rely on the internet for information. Accessing services was also difficult when '*there's ten other people in that waiting list, or a hundred other people waiting*'.

Getting the right treatment was also highly time-consuming due to the high number of appointments children needed. This was especially a problem for families living in rural areas or small cities, where some of the different specialists were unavailable. Being overwhelmed was a common experience for these parents. For example, for some appointments with a paediatric cardiologist, even when mandatory as in Germany, they sometimes had to wait up to nine months.

*"Now we wanted to know what the deal was. We took the whole vacation time to do the complete diagnostics. This proved to be extremely difficult because the diagnostic of the*

*whole physical part we knew, but there were also all the interviews etc. for the psychological part. We thought during the school holidays we would be finished. We as parents needed to be very persistent to get the appointments in different hospitals we needed, for example for an EEG or for the cardiogram. For this we needed to go another city that was 30 kilometres away, only to get one appointment for the doctor, who could do the cardiogram. Not the child cardiologist, those seem to be very rare. I'm not sure, but the clinics seem to be very overbooked. I called one and I have been told we need to wait about nine months." (G, F, parent)*

In Spain, accessing mental health specialists is difficult, because of long waiting lists. For this reason one of the participants explained that she decided to visit a private psychiatrist.

## 4.9 Improving services

*Opening hours:*

- Although some participants were satisfied with their surgery opening hours and felt that '24 hours a day' GP services were unrealistic, others wondered why some practices were closed over lunchtime, weekends or in the evening. Several people wondered if GP surgeries could open on weekends, and have more late openings in the evenings, perhaps until 8.30pm, saying that young people were more likely to go at later times instead of during school. Extended opening would also be useful for people who were working and at college. Several people felt that more young people could access GPs if surgeries were open 24 hours, and that there would be less need to go to A&E if they needed medical advice.

*Making appointments:*

- One parent in the Netherlands suggested that GPs should have a certain degree of flexibility in their schedule so that it was always possible to book an appointment for the same day.
- In order to avoid missing important appointments our participants recommend having some way of sending reminders to parents, for example text messages with a reminder of the next vaccine.
- Long-term appointments for follow up should be provided always from one visit to the other.

*Distance to the surgery:*

- Two participants from the Czech Republic mentioned that they would prefer it if the substitute GP worked in their GP's office, not elsewhere, to be more accessible. Some parents wished for the possibility of home visits by the doctors for their children if they are really sick, especially when living in rural areas.
- GP home visits were suggested by participants in the Czech Republic and Germany as a solution for families living in the countryside.

*Physical access:*

- There should also be easy access to parking places when attending the hospital or health care centres.

*Waiting time:*

- Young people especially felt that improving access included making it easier to get appointments, shorter waiting time in the waiting room, and more GPs as most surgeries are usually busy.
- When attending the out of hours service, the procedure is to go first to the administrative reception and sometimes it is a very slow procedure or there is long queue. This should be organized in a different way so that patients would not need to wait a long time if they had an acute problem with the child.

*Other kinds of appointments:*

- There should be easy access to the paediatrician by phone or email or any other communication service to discuss minor issues, questions and doubts and avoid having to make an appointment.
- Some participants also liked the idea of Skype consultations, and felt that it was important for GP practices to keep services up to date using modern technology.

## Chapter 5 – The surgery environment

The most important topics in terms of the surgery environment were waiting rooms, consulting rooms, and medical equipment.

### 5.1 The waiting room

Most participants talked about the waiting room in the interview, including the organization of the waiting room, its equipment and the overall atmosphere. Participants described various kinds of organisation of the waiting rooms. Some GPs in the Czech Republic have separate waiting rooms for children with minor issues and for children with contagious diseases, which was appreciated by parents. Some practices in Germany even had a special room only for breastfeeding. Participants from the Czech Republic explained that the waiting room is sometimes shared by two GPs.

Some parents in the Czech Republic, Netherlands and Germany noted that the atmosphere in the waiting room was pleasant. Participants in Germany described it as colourful: there were flowers and the radio was playing. Some participants in the Netherlands described the waiting room as modern, decent and had a lot of windows. Another girl mentioned that was important that there were enough chairs in the waiting room.

*"It looks all very nice and neat. That is also nice to see, actually.*

**Yes, can you explain what nice and neat is?**

*Well, it is actually quite modern, white, and you came across a room, for example, that was a waiting room with a glass wall and so. That looked very beautiful. Yes, that is where you came then, and how it looked like over there. Nice desk too, with nice glass and white ([laughs], that is something I always like. And then we sat in the waiting room, well, that one was more cosy, less modern, but more cosy.*

**And what made it more cosy?**

*Well, there was a brown floor, for example. That made it a lot more cosy, and a wooden table, yes, with some magazines and flowers on that table, some chairs around it. So that looked very beautiful. And there was also a LEGO corner for kids. So that's nice." (ID20, NL, F, child)*

Other participants, however, were dissatisfied with the waiting room. In some cases, such as Germany, the waiting rooms were described as very full, with lots of old people. One mother from Germany, for example, commented that the waiting room was too small. It was always full and felt close. Many parents noted that the waiting room and the offices were very hot in Germany. One mother from the Czech Republic said that since there was air conditioning in the GP's waiting room, the waiting was much more pleasant. Parents from Spain felt that some waiting rooms in small centres should be improved because there were not enough chairs in the waiting room, there were only two small toilets and there was very little space.

In addition, the waiting room for adults was just next to the one for children. The problem with this was that it was easier to get a contagious infection while waiting in the waiting room.

Some participants from different countries complained about the noise in the waiting room, mostly from small children who were very loud, crying or being annoying, but some knew it was something that was impossible to change. A few participants said that the TV in the waiting room was too loud and that it was not possible to lower the volume. One participant said she did not like that there was just regular TV programmes including the news, which she considered inappropriate for children. One participant complained that:

*"The chairs are uncomfortable. It's like they probably got it from a garage sale or something like that. It's just, I don't know, it's not welcoming at all. So having those posters up on the wall, as in like lung cancer and that and that. Yeah, have pamphlets on the table, so if someone wants to read it, read it. But like really on the wall too? A huge poster covering the whole wall that you're going to die from cancer. That's not really helping anyone. So, yeah, just try to use a little colour and your imagination to brighten it up a little bit, and yeah....Probably, actually having magazines that are up to date. That's a good thing. Most people are interested. Having a variety of them helps a lot and just putting posters up, even if you get posters, like pictures. Like, you don't have to go all out. I mean, I understand there's a budget for every company. But still, just having a poster would be a lot better than having a poster of like dying from, you know, lung cancer or something like that. To me, that's a little bit extreme. So have the pamphlets there. You know, put in like actually chairs, actual chairs. If you go to IKEA, it's not that expensive. So yeah, make it a little bit less stressful and cold." (UK, M, child)*

Leaflets and posters picturing illnesses were perceived as stressful and causing anxiety by a girl in the Czech Republic. Participants from the UK also discussed the leaflets and posters in GP surgery waiting rooms. Some felt that most of the information at their local surgery was about pregnancy, the flu and smoking, and that information on contraception and STIs (sexually transmitted infections) might be more helpful to young people. Other young people noted that there were no posters at their surgeries that were relevant for young people as they were all aimed at older patients. Posters of illnesses more common in their age group would be helpful. One male participant felt that topics of interest to young people included spots and skin health, and another thought that more information on sports injuries would be useful. A female participant recalled that there were posters at her surgery about sex and contraception but nothing about mental health. Several people felt that leaflets should be tailored to specific age groups, and include information that is social as well as health related, such as leaflets about meeting new people and relationships, and a leaflet about trusted health websites. Up-to-date magazines for different age groups would also be useful.

*"I do think that they could spruce it up a little bit.....I think as helpful as all the information that they put on the board is, you know, the TV is about like health and stuff. They could put like the news or anything that appeals to everybody on there so that people are*

*entertained. Recent magazines, not ones from like ten years ago. But I think the children's area is how it is and it's fine because children are easily entertained, so I think that's fine.*

***Are there many things that, looking round the surgery, the waiting room, that you feel are relevant for your age group?***

*[Pause 3 secs] Mm not really. Only if they're talking about like yoga for people who wanna get like fit. But mostly it's just about pregnancies or like cancer and stuff like that and like old age.*

***Do you think that it could have something for your age group, and if it did, what kind of things do you think are the main issues that people, younger people of your age group would be most interested to see posters on, or leaflets on?***

*I think they should have more things for my age group. I think they could have things about like mental health and sexual health and things that young people are confused about, not just things that older people feel that young people care about. I think they should actually speak to us and see what we're actually confused about at this stage and then put those on the wall." (UK, M, child)*

One participant from the UK felt that young people were often scared to see the GP so surgeries needed to 'entice them to go'. He felt that activities and posters that young people could engage with would be useful, including health quizzes on relevant topics. People also thought that it would be useful to have some posters about what to expect when visiting the GP and their rights such as privacy, and being able to decide whether they want a parent or friend at the appointment with them.

In Germany, all comments about privacy and confidentiality were related to the waiting room. Two parents said that the waiting room of the GP is separated from the pharmacist with a glass wall. When you are waiting you can see who is visiting the pharmacist and you can hear them talking. This was also mentioned by some participants in the Netherlands. One mother, for example, noted that she could hear the doctor's assistant speaking on the phone.

When speaking about colours, children preferred white because it is brighter than black. One girl in the Netherlands disliked the orange and yellow walls of the surgery. Some participants from the UK felt that more colour would make surgery waiting rooms look 'cheery' and 'warmer'. A male participant felt that colour would 'liven up' surgeries and, if they looked more modern, they would feel more welcoming. One female participant recalled that her village surgery had 'a really nice community feel' and had art work on the walls made by children from the local primary school.

Most participants liked waiting rooms that were adapted for children. All parents agreed that there were some toys children could play with. In the Czech Republic, some parents said that because of that some of the children literally looked forward to going to the doctor. Similarly, parents from Germany said that some waiting rooms in the practices of paediatricians were better equipped for waiting with children. The waiting rooms were

much bigger, with a big playing corner, a lot of toys, bright colours and so on. The parents liked it very much and it was one of the reasons to see a particular doctor. Most parents from the Netherlands described the waiting room as child-friendly, mostly because of the toys or the books and magazines that were available. This offered a welcome distraction to the children. One parent commented that it was also nice for the parent as the child has something to do while they were waiting for a consultation. Parents also appreciated it when there was something to read for them as well.

Children felt it was important that they can entertain themselves when they had to wait. Two children from the Netherlands said they preferred to read a book or a magazine; another girl said that she played with her telephone. Although the children in the Czech Republic and the Netherlands said there were toys and books and magazines to entertain themselves, these were not always age-appropriate. For example, there were only toys for children aged 3 or 4 years or there were only magazines for girls or magazines for parents but not for teenagers.

***"How do you feel, when you go to the doctor?***

*I1 (ID8): When we go there, I don't want to go so much.*

*I2 (ID7): Me neither because it is boring in the waiting room.*

***Is there anything that could be changed in order to make it more pleasant for you?***

*I1 (ID8): In the waiting room, there could be more magazines or something like that. (...) But nowadays, it doesn't matter so much because everyone has a mobile phone." (ID7, CZ, M, child; ID8, CZ, M, child)*

A young participant in the UK also stressed the importance of having and being able to access Wi-Fi, and several people felt that having a TV in the waiting room would help pass the time when appointments were running late.

### **5.1.1 Mental health conditions**

Parents of children with ADHD or autism had similar ideas about the waiting room. Participants from the Czech Republic thought that equipment and atmosphere of the waiting room was very important for the participants because children spent a significant amount of time there. One mother in the Netherlands said that the atmosphere in the waiting room was quiet without pieces of flair that helped her and her child to relax. The waiting room should be a nice place for children, with painted walls and pictures. All participants said that the waiting room is equipped with toys for little children which was also valued by participants from the Netherlands. One mother noted that her child always would like to play there even when they walk by the surgery. Older children usually use tablet or cell phones to have some fun said one of the participants. Furthermore, parents in the Netherlands commented that there was something to read for them as well such as magazines or information leaflets. One of the participants in Czech Republic liked privacy of

the GP's office – before entering the waiting room, the patient has to ring a bell and no one excepting the patients and their parents may enter.

Some parents in the Netherlands were negative about the waiting room of their GP, because it was small and was not child-friendly, because there were no toys to play with. One mother found the waiting room cold and bare; for children the waiting could be more cheerful according to this mother.

Two participants from the Czech Republic said their children are hyperactive in the waiting room because of their ADHD and they have to admonish the children to calm down.

### 5.1.2 Physical health conditions

Like the children and parents of healthy children, children with physical health conditions and their parents from different countries described how the waiting room looked. Some said that it was nicely decorated; there were toys for children and other things that might make the waiting room comfortable for patients, for example magazines. A boy from Germany liked the waiting area in the doctors' practice more because there were more colours, plants, but also space in general as in the hospital.

*"The practice was maybe a little bit nicer. More colours, more plants as in the hospital." (G, M, child)*

One of the participants in the Czech Republic said that a nice waiting room and surgery in combination with nice personnel is a reason to look forward to going to the doctors'. She just noticed that the waiting room could be bigger. Similarly, participants from the UK felt that surgery waiting rooms were often too cramped and said they would prefer more space.

A participant from Germany said the waiting room in the hospital is located next to children emergency room, which is very annoying, because the children are very loud most of the time. One child noted that he often sees familiar faces in the waiting room; they also come for check-ups and they sometimes talk to each other. For some the noise was annoying but for others it can be so quiet that it is uncomfortable. One girl would like it when there is music playing in the waiting room, because this may break down the barriers to start a conversation – as is illustrated by the following excerpt:

*"When you are in the waiting room, there is no music playing, I think. To me, this feels sometimes a bit uncomfortable. If there is quiet music, the barriers may be broken down to start a conversation" (ID76, NL, F, child)*

One of the participants from the Netherlands made a very interesting comment about the waiting room and the specific condition of her son. She noted that this waiting room is a bit too small for her son who has an acquired brain injury. He does not like it when he has to wait in a waiting room that is chock-full. On the other hand, the mother noted that she likes it that it is a small surgery located in a small village, where all people know each other. All other people waiting know her son and accept his behaviour.

## 5.2 The consultation room

Some participants talked about the consultation room. For one child from the Netherlands the size of the room mattered. She preferred a smaller room because this felt more intimate compared to a large room. However, too small a room felt oppressive. Some parents in Spain also mentioned that sometimes the room was so small that some examinations could not be well-conducted, for example there was not enough space for assessment of a child's ability to walk.

Participants from Spain and the Czech Republic explained that, usually, the GP's consultation room and that of the nurse were separated by a door and there was always someone coming or going, but they do not think that is lack of intimacy but a way to communicate about their clinical evaluation.

According to parents from Spain, it is important that there is decoration inside the consultation room, as while the professional is writing in the medical record, the children are looking around and it is nice to see a clean and well organized room. In some places in Spain the consultation room is nice and different from the one of the adults, with drawings made by the kids; in other places it is just white walls or with some poster with beautiful babies images and publicity of some nutrition brand. One child in the Netherlands made a comment about the odour of the consultation room, which she did not like.

### 5.2.1 Mental health conditions

Only some participants in the Netherlands talked about the consultation room. One boy noted that there should be no toys in the consultation room as this may distract him from the conversation with the physician. Another complaint was from a mother from the Netherlands who thought that the consultation room was too small. For example, when her husband joined her and her child, which she sometimes prefer as two note more than one, one of them had to stand as there were not enough chairs in the room.

### 5.2.2 Physical health conditions

Two participants in the Czech Republic said that there is older equipment in the surgery. One of them said her GP uses a typewriter instead of a computer. The participant commented that this is a reason why the GP cannot communicate with specialists and she has to give her the medical report from neurology printed on paper.

One participant said she feels uncomfortable when doctors wear a white coat because she associates it with negative memories. She would recommend wearing coloured cloth – not only at the GP's office but also in a hospital.

In particular, one participant from Netherlands and one from the Czech Republic noted that the surgery is and smells fresh.

### 5.3 Improving services

#### *Waiting room:*

- The waiting room is that it should be light and cheerful, which could help the children to eliminate their fear from the examination or the blood tests.
- Children and parents think it is important that they can entertain themselves when they have to wait. They advise having a playground or toys, or magazines or papers to read.
- The waiting room could be improved by having more interesting and up-to-date magazines. Magazines should be not only for little children but also for teenagers and parents.
- Participants from the UK felt that a TV would help. Two parents from the Czech Republic mentioned there is TV in the waiting room; one of them said that she would prefer if the program were oriented to children (fairy tales) than to advertisements aimed at adults.
- One participant in the Netherlands would prefer to have some music playing in the waiting room, as this may help to break down barriers in order to start a conversation.
- One participant in the UK noted that a massage chair would be good.
- This participant also felt that '*people just keep looking at you, it's just annoying*' and that privacy in surgery waiting rooms should be improved, and others agreed.
- One girl in the Netherlands noted that the chairs in the waiting room should be placed in such a way that it is possible to make contact with other patients.
- Parents of children with ADHD in the Czech Republic said their children are hyperactive in the waiting room because of their ADHD and they have to admonish the children to calm down. It was suggested that a spacious waiting room would be helpful with respect to children with ADHD.
- One mother in Spain suggests putting leaflets and posters with ADHD information in Primary Health Care waiting room.

#### *The consultation room:*

- One child in the Netherlands recommended not building too large consultation rooms as this is not so intimate.
- One participant said she feels uncomfortable when doctors wear white coat because she associates it with negative memories. She would recommend wearing coloured cloth – not only at the GP's office but also in a hospital.

## Chapter 6 – Relationships with primary care professionals

This section includes data about children's experiences of visiting health care professionals (doctors and nurses). Some of these were positive and considered as values; others were negative and considered as problems. We also included participants' suggestions for improvements .

Looking at this theme across countries there are more similarities than differences. Parents' and children's perspectives were also quite similar although we show some special situations that can enlighten deeper understanding of the perceived needs and can give some clues about future training skills that health care professionals should gain when treating children and adolescents.

### 6.1 Values: what makes a good GP

Most of healthy children and their parents we spoke to in all countries were quite satisfied with their primary health care professionals. Issues about communication skills, positive attitude towards the child or adolescent and parents, a trustful relationship and professionalism were the main aspects that were valued by the participants.

**Communication skills:** Openness to discussion, communication and taking into account the parents' opinions about treatment were seen as a sign the parent is respected by the health care professional. Other communications skills that were valued were being empathetic, easy to talk to, and really listening to what the child or parent is saying. Parents and children appreciated when the health care professionals explain the logic behind a decision, the reason why they are doing some examinations, and the next steps. The people we spoke to valued getting information from a health care professional in a way that is easy to understand – without using medical jargon. Participants appreciated information on medication was being prescribed and possible side effects and, when relevant, contains leaflets or website addresses (see more about health information in chapter 10). In countries where different languages are used it is valued if the health care professional is able to speak and understand the local language, as one mother in the Netherlands noted. In this way children can express themselves in their own language as well during the consultations.

**Attitude:** Children and parents appreciated their health care professional if he respected his patients and their parents. Participants who had positive experience with their GP described him as a person who is friendly, kind, patient, calm, welcoming, supportive and who understands his patients, instead of 'patronising' or 'condescending' them. Some mentioned they appreciated when the GP treated young people like adults and who treated his patients as individual persons (they asked about school or hobbies). Some participants said they liked that the GP knows how they are called, they shake hands with the patients; they are relaxed and informal. Being relaxed and comfortable with a GP was important to many of the participants who wanted to talk about mental health. Other participants, too, felt that it was helpful when the GP came across as relaxed, informal and '*try and make it as casual as possible*'.

*"What I think they should do – they should, they should be relaxed. I know being a doctor's really stressful and it's very...well I don't know that, I don't know why I'm saying that. But I know it can be stressful because of having a job like that is stressful. But I feel like they should be...they should relax themselves, should be relaxed. They should interact, they should ...because if you, if you just...if you tone it down...if you tone down your, if you tone down the professionalism to some extent and to more of a social...to more of a...to more of an informal sort of stance, then it would definitely have... it will definitely...you'll definitely engage with teenagers that way. Because teenagers don't like formality, and I feel like it's important to engage with teenagers and so it'll be a bit more...to be a bit more chilled."*

*(UK, M, child)*

**Building a trustful relationship** was important to participants. Several parents appreciated when they knew that the GP trusts them. On the other hand, one mother in Spain who is a doctor herself felt that the trust of the GP that she is able to handle the health problem is sometimes overwhelming for her. Similar experience had one mother from the Czech Republic who is also a health care professional. As an aspect of a trustful relationship, parents appreciated when the GP was able to explain what is going on, and were able to answer their questions clearly. Reassuring was also seen as an important aspect of a trustful relationship. A mother in the Czech Republic said that especially parents, who have their first child need reassurance.

Some examples of respect and building relationships were mentioned by parents, such as involving the child in a physical examination. A mother in the Netherlands talked about her daughter who was invited to use the stethoscope and to listen to her lungs and heart. Several parents noted that the doctor and nurse know all children's name. Cordiality, sense of humour, trying to ease the consultation and helping the children to handle their fears support a trustful relationship. One mother in Spain valued the empathy showed by the doctor understanding that she is a very apprehensive mother and did not tell her everything about the test and diagnostic possibilities until it was confirmed or dismissed in order to avoid more concern. Furthermore, in order to build a trustful relationship, it is important to get along well and connect. Being accessible, for example on the phone to sort out simple doubts, is also helpful.

**Professionalism** based on being experienced and knowledgeable, being a professional and having notes read before seeing a patient and not in front of them is valued by participants. They appreciated thoroughness of a GP. Some parents said the doctor is responsible and does not want to neglect anything. There is a belief that a GP who also assist adults has a wider perspective of health care issues. Another issue that arose is related to the background training of the physician. Some commented that paediatricians are better than GPs because they are more able to communicate with children and are experts in children's' health, as is illustrated by the following excerpt:

*"I think it makes total sense that there are paediatricians, same as it makes sense that there are primary school teachers, because they need special education to work with children." (G, M, parent)*

GPs are also considered as having a lot of medical knowledge. Furthermore, it is important that a GP takes actions and does not automatically follow the protocol. This means that participants value flexibility.

### **6.1.1 Mental health conditions**

Children with ADHD and their parents spoke about similar values as healthy children and their parents, although some nuances were identified. Some parents said they value that physicians explain what will happen and do a thorough examination in order to look for a cause of a health issue. One participant in the Netherlands related this to being taken seriously. One mother from the Czech Republic liked her GP because the GP wanted to exclude all the other possible causes of her child's problems before she sent them to a specialist to examine the child for ADHD. She said:

*"She also tries to find out- With my daughter, she tried to exclude all the other symptoms, not only the mental ones, because she had stomach ache, often she had headaches, the GP tried to find the cause. She sent her for blood tests. If I go to my own GP and I tell her that I would like to go for blood tests, she says there is no need for that and we will see and sometimes she does the blood tests. But this doctor knows, she does the tests and finds out if we need the antibiotics or not. I am really happy with the doctor. We go there rarely but if we go there, I am satisfied with her." (ID37, CZ, F, parent)*

Health care professionals are appreciated when they are able to help, give good advice, tackle the problem and show interest in the child and the family, for example by asking the parent how they manage the situation.

Regarding communication, children with ADD and their parents valued health professionals taking into account the child's condition when communicating with the child.

*"I am really satisfied, she asks even about things she doesn't need to, she knows how to communicate with my son, right. She just knows: '[son's name], sit down. Now we are going to do that and that', she explains everything to him. 'Now we are going to listen.' That's what I like about her. She knows that my son is quite wild, so she gives him a toy and things like that. (...) She knows how to communicate with him, what to do with him, with children." (ID37, CZ, F, parent)*

One mother in the Netherlands noted that her GP used visual cues and explained the issue step by step and very clear, as is illustrated by the following excerpt:

*"This GP explains really good, also to the oldest one.*

***Can you explain how the GP did that?***

*Well, he explained in detail what my son had, and pointed this out at a skeleton. And my son had just learned about the skeleton, so, yes, he did know a bit how that is looking like. But she was pointing to where the problem was and, well..... And I think there are better in explain things. The really tell them step by step what they will do. And that is especially for my youngest son very nice, that he knows what is going to happen." (ID48, NL, F, parent)*

Participants also value that the physician treats the child as “normal”

***“What made you feel comfortable with him? How did he treat you? [Talking about the specialist]***

*He treated me well, normal, just like Normal!*

***Maybe you spoke about football with him?***

*Sometimes*

***Jokes?***

*Yyes, he joked with me” (ID58, S, M, child)*

Children with ADHD often see a psychiatrist or psychologist for their ADHD. They value this relationship and appreciate that they can talk with them about the problems they perceive in their daily live as the following excerpt shows:

*“I always open up to him, I always have a good cry, I sit there and first I am a bit shy before I start talking. And then I talk to him and he always gives me advice. He prescribes some medication, asks me if the one I take now is ok with me and he has a tendency to take care of me. He asks me questions all the time, if I am fine, how is it at home, how is it at school, if I trust my mother yet, if the medication started to work and so on. So I think he is a good doctor. (...) I am always relieved after the visit, even if I were there for just one minute, I would be relieved. (ID39, CZ, F, child)”*

In relation to professionalism, one parent in the Netherlands valued that her GP followed an additional training about mental health conditions as is illustrated by the following quote:

*“My GP, yes, I think he is really good. I know that they are doing a lot of further education. I know that in the practice, especially the male GP of the duo, did a course on ADD, on medication. Thinks like that. He really has knowledge about it. So, I trust him based on his knowledge” (ID52,NL, F, parent)*

In some cases, parents/children consider private doctors as more experienced and better trained than doctors working in public services.

### **6.1.2 Physical health conditions**

Children with physical health conditions and their parents spoke about similar values, although some nuances can be identified. In addition to the values described above, they valued from the GP to be a link between the family and the specialists. Some participants said their GPs helped them, for example, by communicating with specialists at the beginning of their health issues, helping getting appointments, helping with application for rehabilitation or application for financial support, as is illustrated by the following excerpt from a child in the Czech Republic.

*"It was a luxury, the doctor helped us, it is not his duty, but he helped us to get the forms (for the allowance for carers) from the department of social care and he helped us to fill it in and he helped us to apply for it" (ID65, CZ, M, child)*

In particular, children with epilepsy usually often visit a hospital and have conversations with different doctors. They noted that they become experts about their condition and every aspect related to that. In most of the cases they know exactly why and how a seizure can be triggered in their particular case. Because of that, they often have good and long conversations with doctor, who take them seriously and talk to them like to adults, which they like.

Some participants in the Czech Republic and Germany said that information on living with TBI or epilepsy was provided more by the GP than by a specialist. Participants found this helpful, as it helped them to talk about problems at home or at school, and about their private life. Participants in Germany also valued that their whole life was taken into account when making treatment decisions. Some participants in the same country valued that their GP became an intermediary between the child and the parents or an intermediary at school. One boy, for example, said that his parents were overprotective. After his GP talked to his parents, they gave him more freedom. The boy commented:

*"She (the female doctor) supports me that I should have more freedom. Now I am allowed to do more stuff on my own." (G, M, child)*

Some other values that were mentioned by children with physical health conditions and their parents were: being flexible to protocols; being attentive like for example sending a congratulation card after the birth of a child; by informing about the situation of their child when visiting the GP for other issues.

Some participants spoke also about nurses in primary care. Positive descriptions include being communicative, kind and empathic. They said the nurse is able to provide reassurance and advice. The nurse was seen as a silent support to the doctor, very kind, and supportive. Teamwork between the physician and the nurse is highly valued.

## 6.2 Problems

Negative experiences were also shared by the participants. These were mainly about communication issues, a lack of trust, a lack of time, and power relationships.

**Communication:** Some participants recalled that the GP talked more to their parents than to them, which some of them disliked, as is illustrated by the following excerpt from an interview with a child in the Czech Republic.

*"I think the doctors should speak more with the child. (...) I don't know why they cannot ask the child directly. When I am ill and I go to the doctor, I lie down, the doctor examine me, leave me lying there and then he speaks with my father about everything. 'Since when does she feel sick?' and I could be sick earlier, I just didn't say that at home, right? And I think it is wrong, they should talk to the child who is sick. (...)" (ID2, CZ, F, child)*

Another aspect of bad communication was banalization of their feelings. Children in a focus group in the Czech Republic agreed they do not like when doctor or nurse used a typical Czech phrase: "*Don't be afraid of the injection, it will be just like a little bee sting*". One of the participants commented: "*It always reminds me how it is painful from the bee and it doesn't calm me down at all.*" A few participants also perceived that the physician did not really care about the child. A boy in the Czech Republic shared his negative experience:

*"Well, it was terrible, I felt horrible and she said it would be just a viruses and then I ended up at home for a month and I felt really ill for the whole time. But it was just a 'viruses'.*

***What could have been done in such a situation?***

*Well, she didn't even examine me. She just said it is just a little viruses." (ID1, CZ, M, child),*

Some parents described problems also in the communication of the GP with the child, for example the GP did not understand why a child cried. On the other hand, some parents noted that the health care professionals only asked the child. Although they think that children should be involved in the conversation, there should also be questions asked to the parents for clarification. One of the children in the Netherlands mentioned that the health care professional asked too many questions which irritated her. Another child noted that it was not always clear to whom the question was asked: to the parent or the child. This child also mentioned that she had expected that her GP would ask more questions about her feelings, instead of general questions about her troubles, like the duration of the troubles, which is illustrated by the following excerpt:

*"They mostly asked thing about my data and about my length, but not about how I felt. Yes, really quick, what is the problem and further nothing. I had expected something different.*

***What did you expect?***

*Well, I expected them to go more into the subject or that they would ask more questions about what actually the problem was and how I felt about that. Well, that is actually what I had expected to happen more" (ID20, NL, F, child)*

Some participants noted that asking about sensitive questions is not always done sensitively or appropriately . There is one clear example of a negative experience in Spain in which an adolescent daughter was asked directly if her father had touched her inappropriately or if she was abused. Another example is the way in which health care professionals asked about sexual relationships in front of parents, as is illustrated by the following excerpt from an interview with a child in Spain.

*"She was shocked when they asked almost like if her father had raped her, can you understand? So it is a very hard question for a 13-14 years old girl....*

***Did you ask why they would ask these questions?***

*Yes, and they told me that they have to do them... it is like a screening looking for sexual abuse in the family environment." (ID30, S, F, parent)*

Also non-verbal communication is important which is not always perceived as good, as this illustrated by the following excerpt:

*"People give you a hand, they'll see you into the eyes, and they'll get in touch with you. ... But with him, that was not the case. So that was something that could have been different, I think" (ID20, NL, F, child).*

Some parents experienced a paternalistic relationship; they have felt and think that this is not what they prefer. This also happened with some nurses as they tried to take over the doctors' role as was perceived by some participants in the Czech Republic. Some parents felt disrespected or not taken seriously. Some nurses made parents feel inferior and not being listened to. In line with this finding, some children from the same country said that they had also negative experience with the nurse. The nurse was perceived as very important person, who may have impact on the overall atmosphere at the GP's office as the following excerpt shows:

***"What is the overall atmosphere at the doctor?"***

*It always depends on the nurse, who is there. The one is grumpy, so then it is quite hectic. Everything is so fast then, just 'undress, no on the weighing scale, don't move, don't breathe, now breathe, now that.' It sucks. But if there is a good nurse, it is fine, she makes jokes, it's fine. But I never know when I go there." (ID2, CZ, F, child)*

**Lack of trust:** Some participants noted that they had lack of trust in the professionalism of the GP. For example some parents in the Czech Republic believed that their GP prescribed medication only because some pharmaceutical company pays him to do that, or that their GP over-prescribed medication for their children. One important issue that rose in relation to the trustful relationship was confidentiality, sometimes children or adolescents would feel afraid of talking about certain topics because they were not sure if the GP would inform the parents.

***"Did you feel that you could trust the GP, that what you were saying was confidential?"***

*Yeah and no. I think for a lot of young people it's very unclear about what's confidential and what's not. And whether they use it to tell your parents if you're under sixteen, and that kind of thing. So, to be honest, I wasn't really worried about it but I think for a lot of young people they do get very confused about whether it's going to be kept confidential or not.*

***"So more information even in surgeries?"***

*Yeah...[talked together] Yeah, literally just some information to tell you whether or not it will be confidential" (UK, F, child)*

**Lack of time** is viewed and experienced frequently and is considered an important problem by participants in the UK.

**Power relationships:** One mother in the Czech Republic noticed that she felt uncomfortable when the nurse was rude to parents from a minority group of population in front of the people in the waiting room. Judging the parent and his care about the child is also perceived as a problem, see the following excerpt:

*"The bulge was still there after two months, and we went to the GP and said: 'she has a bulge and it not going away, what is it?' The GP said first, 'it is a hump or so'. But I said: 'it is there for two months; that is strange. It is not going away. So what is it?' Then he asked whether I had dropped her on her head. I said: 'no, I did not let her fall.' But at one point, he asked me ten times if we had really not dropped her. Because at that time when I was with the GP, it was very purple and blue, so it maybe seemed like that. So at one point, I was really angry and when I left...angry, I was irritated. And when I was leaving, he asked: you did really not let her fall? So when I got home, I was really angry and annoyed." (ID16, NL, F, parent)*

**Impersonal organization of care:** Some participants in the Netherlands found that the organization of the service is sometimes impersonal, for example calling the next patient with a buzzer. Furthermore, some parents in the Netherlands also noted that they were not informed about having a consultation with a GP in training and were not asked permission before.

One of the consequences of having problems in primary care was parents deciding to change their GP. One parent in the Czech Republic for example said she changed the GP because she did not have a good relationship with the GP and there were issues around communication.

*"She had perfect facilities, and she wanted everyone to be happy but it didn't work for us. (...) We were not able to find a common ground and I think there were also some personal antipathies. When he was little, he wasn't even a year and he got salmonellosis, and I noticed that she didn't take me seriously. When she was asking about the number of stools, I said something and she wrote something else and I notices. And I said it was ten and you wrote it was two stools. And she said she thought it was two stools and the others were just little farts. Since then it was getting worse. (...) We weren't able to find a common ground afterwards. At the end it turned out, when we were also on the ultrasound, that his intestine was totally destroyed, and there were many villas. At the end I decided to change the GP."(ID11, CZ, F, parent)*

### 6.2.1 Mental health conditions

Similar problems were described by children with ADHD and their parents. Some more specific peculiarities are related to the participants who had diagnosis of a mental condition.

In relation to communication, parents found it important that they had a role in giving consent. Children found it important that they have a role in decision making and choosing from different treatment options. There was a particular example of an adolescent diagnosed with ADHD who explained that she had to ask questions immediately otherwise

the question will stuck in her head and will distract her, as is illustrated by the following excerpt:

*"If you do not ask a question to your doctor, then you are always in the head with this question, and then you are not able to concentrate for example. Or you are working and think constantly, what is happening now. And if you ask the doctor, then you just know and then it's out" (ID55, NL, F, child)*

Many participants described a delayed diagnosis, attributed to a lack of understanding of mental conditions and taking them seriously. In some cases, physicians do not consider ADHD appropriately, sometimes because they give this label to too many children, or in other cases because they do not consider it a 'real condition', or do not have the necessary skills to diagnose and treat mental conditions.

*"We would say that the first difficulty in relation to this problem that all parents have to deal with is the one you find with the diagnosis. It is complicated by itself, usually the diagnosis is delayed and until now not completely defined. I ask myself if it is a difficulties of the medical class to achieve this diagnosis and to achieve a therapeutic option... and we can understand that for others and for society in general, including teachers and family members it can be complicated to get along." (ID55-56, S, F-M, parents)*

This can also be related to parents feeling ashamed talking about problems regarding ADHD. Sometimes it is difficult to talk to the physicians and explaining issues related to the mental condition, or asking them questions that they should be the ones to answer. Some health care professionals have shown rude attitudes and lack of understanding about the behaviour of the child

*"Once I had to go to the toilet ... and I went in and out and the girl told me "don't go in and out so many times" in a rude ton (...) but in the waiting room there is no toilet and you have to go outside (...) and my father was outside and I wanted to talk with him and I would come in and out again, and I had to go outside again to the toilet." (ID58, S, M, children)*

In the UK, there are some concerns about the genuineness of professionals. Talking about professionals at CAMHS, one participant in the UK said:

*"They're just doing it for the money, they're not in it to help people. They say they are, but I don't reckon they are; they're just more in it for the money exactly" (UK, F)*

### **6.2.2 Physical health conditions**

Specific to physical complex care conditions we can find that there are some problems in relation to the trust on competence and communication skills of physicians. On the question about the competency of their GP or paediatrician in regard to epilepsy our participants were much divided. Some of them told us that they trust their doctor and let him treat them for seizures; other children did not think they were competent enough. But even some specialists like neurologists were described as incompetent or were accused as being bad in communication, for example telling them how bad and limiting the disease is.

*"Wow, my first neurologist, I was there and he told me that I will never be able to go to a disco with my friends and such things. I only waited for him to tell me to hang myself." (G, child)*

Negative experiences with diagnosis and health care professionals also indicate the lack of trust that is build up in the construction of the illness experience

### 6.3 Other issues

Other issues that were raised by participants are related to gender and age of the health care professional, rewards for the patients, and private versus public services health care professionals.

Although most participants did not emphasize role of sex of the GP or nurse, some participants talked about the gender of the health care professional. Some specific issues were raised. Some people said they preferred seeing a GP of their own gender – especially when it came to sexual health. One girl in the UK said she specifically asked to speak to a female GP when she wanted to talk about the pill One participant in the Czech Republic related the gender of health care professional to a power relationship between the health care professional and the parent. This is illustrated by the following excerpt:

*"In our case, the nurse takes the calls and sometimes it is hell, it is trouble to agree on something. She is the gatekeeper before I get to the doctor's office. My advantage is that I am a man and I am able to get her sympathy. (...) Then she is more willing. My wife still struggles with her. So, when we need to call there or solve a problem quickly, I call there. It is our tool, we have no other option." (ID1, CZ?, M, parent)*

One parent in Spain, used the gender issue to educate her children in equal consideration to male and female.

*"For us it is like a family way of thinking, we treat the same male or female gender, the reality of doctor-patient relationships don't you think? We make it natural, not by being a boy or a girl you have to keep quiet for some topics and talk about others." (ID25, S, F, parents)*

Age is another issue that some participants in different countries raised. Opinions and experiences related to the age of the GP differed among participants. Some prefer older doctors because they are more experienced than the young ones and they also have their own children, but on the other hand they can be more rigid and less open to discussion. They could also be seen as they can “unlearn” or forget how to do certain medical procedures. Some preferred younger doctors who are open to discussions about treatment, or alternative care, some are more skilled if they need to do some test, or can be more approachable; however they could be seen as more hectic. Some children and adolescent would prefer a younger doctor, because they are young themselves too.

Rewards like sweets, little toys and so on are incentives that are positively valued especially for younger children. Some participants in the Czech Republic said that because of the

reward they were looking forward to a speech therapy or a dentist when they were younger.

Some participants in Spain said that they do not use private services, because the experience with the public services is very satisfactory.

*"You see, so you can imagine my trust on public health care services, during my pregnancy (...) I did a private insurance (...) but I kept on using the public services because all my experiences were positive and why would I change it." (ID25, S, F, parent)*

### **6.3.1 Mental health conditions**

Participants spoke about their beliefs about age of the health care professional and thought that older ones were more forgetful and less adjusted in the use of technology. About gender differences there were some interesting beliefs: considering male professionals to be more honest, female to be more like mothers, male to male communication was considered more like a man to man conversation and with females to be more at ease and less strict.

### **6.3.2 Physical health conditions**

No specific issues were identified.

## **6.4 Improving services**

Different recommendations and solutions provided by the participants in order to solve the problems experiences are presented here.

*Communication skills:*

- Health care professionals should develop good communication skills (especially when doing test or uncomfortable exploration, avoid banalization of parents and patients concerns, being more tactful when asking about sensitive questions).
- Improve communication skills: avoid jargon, show interest on the feelings and life impact of the health condition, explaining to the child, giving information adjusted to the age, listen and facilitate open communication reassuring, training in how to connect with children with ADHD or autism.
- Explain everything to the child and anticipate to what is going to happen.

*Attitude:*

- Improve attitude: being enthusiastic (to avoid distraction of the child with ADHD), taking it seriously, body contact with small children, kind, friendly, honest, genuine, providing safe environment, relaxed, careful, using humour, give time, easy access, treating them as „normal“, showing real interest and not monetary interest, avoid medication when possible, patient.
- Health care professionals need to pay more attention to the patient.

*Trusting relationship:*

- Health care professionals should build adequate relationships based on respect and trust, and show interest and care being kind and empathetic,
- Consider the patient and the parent in the discussion, promoting equal relationships.

*Professionalism:*

- Have good training in mental health conditions

*Time related:*

- Health care professionals should allow enough time to sort out all questions in the consultation.

*Other suggestions for improvement:*

- There should be more open information about the profile and expertise of doctors online, this way it would be easier to know who to choose. This is less interesting for health care systems where patients cannot choose the physician as it is assigned, for example, Spain.
- Health care professionals taking care of children should wear colourful clothes.

## Chapter 7 – Continuity of care

Continuity of care refers to the degree to which the care needed by a patient is coordinated among practitioners and across organizations (ISO/TR 18307: 2001). Within this theme the following subthemes emerged: seeing the same doctor, coordination of care, getting a diagnosis of a complex health condition, role of primary care in the care of children with a complex health condition, and transition to adult care. Finally, some suggestions for improvement are presented.

### 7.1 Seeing the same doctor

Long term relationships with health professionals appear to be important to almost all children and parents whether they are “healthy” or have complex health care needs. Seeing the same doctor every time was often perceived as helpful in building a trusting relationship between the child/parent and primary care professional. According to parents in the Czech Republic, Germany and Spain, this may also help children have less fear when visiting the GP. All participants appreciated it when a primary care professional knew a lot about them, their medical history and their family, and did not have to ask questions about your medical history. This is illustrated by the following excerpt from a “healthy” child from Germany:

*“I think it is better to see the same doctor every time, especially the same GP. Because I know, the doctors ask you about your medical history everytime. And then you do not have to tell them the same things all over again.” (ID12, G, F, child)*

Some young people in the UK noted that seeing a doctor who knew them also helped when it came to getting tests done quickly if something was wrong, getting referred if necessary, and making sure they got their results. Some participants (e.g., in The Netherlands and UK) preferred to wait a few days longer to get an appointment with their own GP than having to visit another doctor.

*“I had the GP for the whole life and I don't know, about two years ago, her son took the surgery after her. My GP is still there on Mondays and sometimes on Fridays. So we try to get appointments for Monday and Friday. There is an old nurse who knows me, so we try to get appointments when she is there (...). And, not that the (new) doctor would be bad, not at all, he is really professional, he is really good but it is my personal issue. I am used to my GP for my whole life and I don't like changes, I don't like changes related to my personality – about the relationships, I don't like if something is changing. It takes a long time for me to get used to it (new relationship).” (ID10,CZ, F, child)*

In contrast, there were also children and parents in the Netherlands and the UK who were less concerned about seeing the same doctor every time, particularly those who rarely saw a GP. One of the participants from the UK noted that she was happy to see any available doctor because she felt that they were all professionals. A parent in the Netherlands and

some young healthy people in the UK felt that they would have to wait too long to get an appointment if they waited to see a specific GP.

For young people in the UK, seeing the same doctor mattered more to children who had a long-term condition or mental health issue. They felt that seeing the same GP as often as possible saved them having to explain their story again to different doctors. Participants who wanted to talk to the doctor about mental health liked seeing someone who knew them slightly and who they felt comfortable with.

Although seeing the same doctor every time was important to almost all participants, many recalled seeing different professionals every time they visited the doctor. Parents in the Netherlands commented that they do not like visiting out-of-hour services as it felt unfamiliar to not visit their own GP. Some parents in Spain recalled that when there was a substitute GP, parents had to ask for an additional appointment because the substitute GP recommended visiting their own GP, for example when they visit a GP for receiving the results of a blood test.

Parents in the Czech Republic also talked about continuity of care in the same place, i.e., primary care facility. As children do not like changes, some parents prefer if a substitute GP worked in the office of their own GP and not elsewhere.

### **7.1.1 Mental health conditions**

In line with the above, many children with complex mental health conditions and their parents also preferred seeing the same primary care professional every visit as they did not have to explain the health conditions of their child again. An additional reason that was mentioned by children with ADHD was that seeing the same doctor every time helped them to communicate more easily:

***"This doctor is always the same?"***

*no, they change, they change*

***Yes and how do you feel about it?***

*I don't like it*

***Why?***

*Well, because each time my mother has to explain everything again ...and they have changed many times" (ID58,S,M,Child)*

***"And the nurse? Was it the same or did it change?"***

*No, the nurse is the same, thanks God, the nurse is the same for many years, she knows the children since they are very small*

*(...) sometimes, when you reach there and simply, they say "Hello" and they call you by your name and they would chat" (ID57, S, F, Parent)*

*"Well, she is totally great. I liked her so much. (...) She was kind and I was always looking forward to my mum saying that we had to go to the GP. I was looking forward to it so much! And she (the GP) always gave me colouring books or tattoos. She was really great but she left because she was ill and now there is another one and I have not got used to her yet. I knew the first GP since I was small. (...) I could tell her that I didn't like the wooden thing for the tongue (tongue depressor), and she just said: 'let's look at your throat' and I said 'I don't want the stick' and she said 'don't worry, I will do it without that, just open your mouth.'" (ID39, CZ, F, child)*

Parents also noted the importance for their children with ADHD to visit the same GP every time, as a substitute GP cannot estimate the child as he does not know the child and its medical history. For some parents in the Czech Republic it was important that their own GP knew the family situation and thus could offer some support (i.e. asking parents how they manage the situation); the substitute GP does not. In Spain some parents talked about follow-up care for their child with ADHD which was important but not possible as they saw a different professional each time.

In contrast, children mental health conditions in the Netherlands do not have problems with seeing a different GP every time. This was also noted by their parents, as long as the other GP is aware of the child's mental health problems.

***"How important is it for you to see the same GP every time?"***

*It is not important to me, but I assume that the one I am talking to is aware of what happened before. He does not need to know it from the top of his head, but he has to be able to recall it. So, if I say for example that my child has an ADD diagnosis, that I do not look into glazed eyes like what are you talking about? But that he says, oh yes." (ID52, NL, F, parents)*

Several children complained about having different doctors every time they visited the surgery, which is illustrated by the following excerpt from a girl with ADHD from the UK:

*They don't tell you when they change your doctors. Like some...like I've got...they've changed my doctors how many times now and I don't like changes and they know that, but they keep changing my doctors and I don't like it. So I don't...I did have trust in this one doctor and then they left and they keep changing my doctors around and I don't like it.... There's some doctors I know there cos I've done with them before and I had more trust in them. And then they just give me doctors I don't know and I don't feel safe round them.... (ID64, UK, F, child)*

### **7.1.2 Physical health conditions**

Children with complex physical health conditions and their parents also valued seeing the same primary care professional every time. According to several parents this was especially important for children with a complex physical health condition such as TBI. Two parents from the Czech Republic commented that when the GP knows the patient or his family, it is easier for him to predict what issue the patient probably needs help with. As mentioned above, some parents in the Netherlands do not have a problem seeing different GPs every

time. They implied that this is a consequence of having more and more surgeries with several GPs appointed. As long as all GPs in the surgery are aware of the child's condition, it should not be a problem. In Spain, parents complained about a lack of follow up and recommendations by the GP. As one mother said, each time she visited the GP with her son, they saw a different doctor and she was tired of repeating the whole story again. Another mother noted that she always reminded the different physicians of her child's TBI just in case current health problems could be related to the brain injury.

Children and parents also talked about seeing the same health care professional for their check-ups (mostly secondary care) for their health condition. Several parents in the UK noted that they saw a different neurologist every time they went to the clinic for their epilepsy. They found these frequent changes in staff confusing and frustrating, because they felt each time they had to start from the beginning. Those who saw the same consultant every visit stressed how important this was for them. One girl in the UK described this as 'hitting the jackpot'. In the Czech Republic and Spain, parents commented that the relationship with the GP or some physicians had improved with time as they met frequently and built a relationship. A mother of a child with epilepsy from the Czech Republic commented:

*"I was visiting the GP with my daughter before and, because she was not ill very often, we went there only for the preventive check-ups. Thus, she did not know the child very well and she was not able to estimate little nuances, we had even a minor conflict because of that (...). So we had to get used to it. But now, with my son, because he is a premature baby and because he has health issues, we visited the GP so many times during the year. So we built a relationship with the GP which feels meaningful. The relationship with the patient or even parent-doctor-patient relationship has its significance and the care is now much better according to me. She is open now, I am also more open. It is reflected in the care for my daughter, too." (CZ, F, parent)*

The importance of visiting and communicating with the same GP was obvious in the Czech Republic - all parents with a child with physical complex needs said they had the personal phone number of their GP and, if it was needed, they are able to call the GP for help or advice even out of hours.

## 7.2 Coordination of care

Coordination of care refers to the deliberate organisation of patient care activities between two or more participants involved the patient's care to facilitate the appropriate delivery of health care services. Organising care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care (McDonald et al., 2007, Schultz & McDonald, 2014).

"Healthy" children and their parents spoke little about care coordination. They noted that if a child had a specific problem, the GP would refer the child to a specialist in secondary care. Several parents noted that all doctors asked the same questions. According to them,

primary and secondary care professionals should communicate more with each other. In the Czech Republic and in the Netherlands, several parents commented that the communication between primary and secondary health care was mostly done by the parents themselves as they had to bring a letter or a report to their GP. One mother in the Czech Republic handed over this report in person and noted that her GP did not look into these reports as the GP did not even ask her for the papers. Some parents in The Netherlands recalled that their GP phoned them to inform them about the child's situation after receiving such a letter or report. Other children and parents recalled that their GP had not phoned though they had wanted them to because they felt they had needed follow-up care, as is illustrated by the following quote:

***"And when she was discharged, did you hear anything from your GP?"***

*Mother: No.*

*Father: No, actually never.*

*Mother: No...you had to deliver a letter at the GP's office. I suppose that in this letter had been written that she had undergone surgery. But we were not contacted or so, no.*

***No. Would you have appreciated it if that had happened? If they had called?***

*Father: Well, I think that a GP, yes, he is aware of the situation obviously, but I would have liked it if he let you know that he is aware. And asks, "is everything ok?", "is there anything you want to know?" (ID18, NL, M, parent & ID19, NL, F, parent)*

Parents are not always aware of the fact that health professionals share information. For example, one mother in The Netherlands told us that she did know that her GP would be informed about the hospital admission of her child, but she was not aware that also the preventive child health services would be informed as well. This mother was astonished when the preventive child health services asked how her child was doing after the hospital admission.

In Germany, parents also talked about the care coordination within the surgery. They recalled that they first had to tell the nurse about their health issue and subsequently they have to tell the same thing to the doctor. This is illustrated by the following excerpt:

*"And then, when the nurse comes, it is redundant, if she asks you and then you need to tell the doctor the same thing, the communication between those two should be better." (G, F, parent)*

### **7.2.1 Mental health conditions**

Only children with ADHD in Czech Republic and The Netherlands talked a little about care coordination. They noted that they had to deliver reports from psychiatrist or hospital to their GPs. One child in the Czech Republic also noted that his GP was aware of the medication the child was using.

Parents of children with ADHD talked a bit more about care coordination. Many parents commented that it was important that the GP was informed by the psychiatrist about their child's condition. The GP should know, for example, about the type and dose of medication. Communication between health professionals is mostly based on medical reports.

Sometimes parents have to bring this report to the GP themselves, or sometimes primary and secondary health care professionals call one another. One mother in Spain explained how she had to be the one who made that different health professionals get in touch with each other about the care of her child, which was difficult. Some parents in the UK also felt that communication between primary and secondary care was not optimal.

*"I don't go to the GP as often as to the psychiatrist. When we go to the GP because he (son) is ill, I bring the medical report about the examination from the psychiatrist to her. If the psychiatrist gives me that I bring it to the GP myself. (...) Sometimes the psychiatrist needs blood tests."*

#### **If they do the blood tests where do they take the samples?**

*I go to the GP, the GP prescribe referral for the blood test and then we can go anywhere where they take the blood. (...) We go to the centre we have next to our house. It is a health centre with several doctors and the blood station, or how it is called. (...) The results are then sent to the doctor who is listed on the referral – to the GP. And then we go for the results to the GP and we bring it to the psychiatrist. It is complicated but it is just once a year so I don't mind." (ID36, CZ, F, parent)*

### **7.2.2 Physical health conditions**

Only some children with complex physical health conditions in Czech Republic talked about care coordination. In line with "healthy" children and children with ADHD, they noted that they usually brought the printed medical record from the specialist to the GP.

Parents of children with complex physical health conditions in the Czech Republic, the Netherlands and Spain shared their experiences of care coordination for their child. Many parents in the Czech Republic and the Netherlands noted that communication between different health care professionals was predominantly done by medical records or letters from the hospital to the GP. Several problems were encountered regarding the communication via medical records. More information about experiences with medical records is presented in the following chapter 8.

### **7.3 Getting a diagnosis for a complex health condition**

Children with complex health care needs and their parents also shared their experiences of getting a diagnosis for their child.

#### **7.3.1 Mental health conditions**

Participants' children were diagnosed with ADHD at different ages and through various routes. Parents often knew that something was different about their child well before they had received a diagnosis. To get a diagnosis of ADHD, most parents went to see the GP who referred the child to other services such as a psychiatrist or psychologist of a (youth) mental health organization or to hospital. Children were referred based on parents' suspicions, information from teachers or based on the GP's own suspicions of unusual behaviour.

*"The doctor was really kind and she referred us to psychiatric centre for children. So it was the GP's idea. (...) The GP wrote a referral. So there was a reaction from both sides, mine and the doctor's, we both agreed that there could be an ADHD when I told her about the it (behaviour)". (ID35, CZ, F, parent)*

However, one parent in the Czech Republic noted that it was not necessary to have a referral from the GP in order to visit a specialist, which this parent appreciated. Sometimes children were referred by preventive child health services or their teacher to a mental health organization (The Netherlands and UK, respectively). Parents from the UK recalled seeing the GP and being referred to other services. One couple discussed being referred to Children and Adolescent Mental Health Services (CAMHS) before they were referred to hospital. The father felt that CAMHS '*was a waste of time*'. They were given six weeks of family therapy until they had a session with a trainee psychotherapist, who suggested that their son might have ADHD. When these parents got home and looked up the symptoms online, they felt convinced that their son had ADHD. They were referred to a local hospital by their GP and recalled that, although the hospital appointment came through quite quickly, the consultation itself was very short: '*we were literally in there five minutes...this chap never even looked at us*'. They felt that they had to '*fight for the diagnosis*' and kept having to go back as they were often told that there was nothing wrong with their son. It was only when they took their son to an appointment without preparing him for it that the consultant diagnosed him. In between appointments they read more about ADHD and felt convinced that their son had ADHD. Another mother explained that the GP referred her son to hospital straight away but, when they got to the hospital, they were told that no appointment had been booked for them. Hospital staff had lost the GP's letter but the next appointment came through quickly.

In most countries, an ADHD diagnosis was given by a psychiatrist or psychologist who performed various tests, gave some questionnaires to parents and teacher and conducted observations in the classroom. Many children and parents in different countries reported that getting a diagnosis of ADHD took some time because of waiting times or the need to see many different specialists. Many children wished that their diagnosis had been given earlier so treatment could have started earlier. Parents in Germany described this period as overwhelming and stressful and they felt helpless and confused. They also noted that some doctors dismissed ADHD as not a "real" condition. As a result, it sometimes took some time to find a doctor who took their concerns seriously. One mother in the UK noted that it took around eight months of tests before her son was given an ADHD diagnosis. She believed that her son also had autism but assessing him for this was never discussed with her. She questioned whether having a diagnosis of autism would be of any help.

Having a diagnosis was important to parents in The Netherlands because they know how to interact with their child and it helps to get professional help. Another mother from the UK found it hard to believe that her 'very, very calm, very easy going' son, who was being tested for epilepsy, actually had ADHD. It was only when she saw how he interacted at school with other children that she realised that there was a problem. They saw two consultants and her

son was diagnosed at the third appointment. Tests were also being carried out to determine whether he had autism too.

### **7.3.2 Physical health conditions**

Although some children got a diagnosis soon after seeing a doctor, for many getting a diagnosis of epilepsy was a long struggle, frequently taking months and sometimes years. Most children were referred to a specialist (e.g., neurologist or paediatrician in secondary care) by their GP. Going for tests and the process of being diagnosed was often a worrying time for many children. It is a very frustrating and confusing time according to children in Germany and the UK.

One of the Czech children described that her GP was the one who initiated the whole diagnostic process of epilepsy on the basis of issues her mother described to her. She not only referred her to a specialist but also helped with hospitalization; she called specialists and helped her to get appointments and tests.

Of the parents, only parents in the Czech Republic and the Netherlands talked about how they perceived the role of their GP in getting a diagnosis. Some were positive as their GP took their concerns seriously. In the Netherlands, one mother recalled that their GP did not want to wait for an ambulance when her son had his first epileptic seizure; the GP brought the child to the A&E himself. This GP also visited the child in the hospital several times during the diagnostic process. In contrast, other parents were negative about the role of their GP, because the GP did not listen to them and did not take their concerns seriously. Those parents perceived a lack of understanding and felt angry and powerless. Several parents recalled that their GP did not have any role in getting a diagnosis.

One of the parents in the Czech Republic had a positive experience with the GP after her child was diagnosed with epilepsy. She was interested in the cause of the illness and the GP helped her to search for the possible cause and run some tests.

## **7.4 Role of primary care for children with complex health conditions**

Children with complex health care needs and their parents talked about the care they received and the role of primary care professionals in managing the condition.

### **7.4.1 Mental health conditions**

All children with ADHD and autism and their parents noted that their GP was rarely involved in their treatment, except for some blood tests because of medication. Some young people and parents felt that GPs dealt with physical health issues while other professionals focussed on mental health. In Germany, children commented that a GP was not qualified enough to treat their condition and was not allowed to give a prescription for medication. Some GPs were more familiar with mental health conditions and had done further training, while others were less knowledgeable about mental health conditions. As a result participants perceived a lack of understanding.

Almost all children visited a psychologist, psychiatrist or paediatrician regularly to get prescriptions and to talk about their lives and problems at school or at home. Several parents in the UK questioned whether the frequency of those appointments was sufficient. Children in the Czech Republic, Germany and The Netherlands found these visits helpful, but not absolutely necessary. In contrast, children in the UK were less positive about CAMHS. They found the appointments 'boring' and the professionals irritating, and had concerns about the genuineness of CAMHS professionals. See for example the following excerpt:

*"[I went] Every few months, quite boring. You sat in a waiting room till your name was called. You went in, you sat there for like forty minutes to an hour, them going, "How can we help you?" or silly questions like that, don't know, sat there. You just agreed with them and they'd bring out medications.....Really annoying because every few months you have to take a day out of your day; you sit there and listen and say the exact same questions."*

*(ID61, UK, M, child)*

Many parents in the UK felt passionately about psychological support or mentoring for their child as well as or instead of medication. One mother (mentioned above) felt that, because she and her husband had managed their son by themselves, they 'had no help whatsoever' but 'in the ideal world what I want is...one to one support' such as a clinical psychologist. Several parents felt that the first professional that their child with ADHD should see is a psychologist. Another mother would also have liked her son to see a psychologist rather than be offered medication straight away.

*"If he had a one to one, a psychologist, or somebody that could help him come with some learning strategies and just some understanding around his condition, so that he can manage his condition....He's got to live in that world out there where people do judge you, and he just needs to be able to manage some of his behaviours so that he can get through life; he can manage a job; keep a job. You know whether he has...because he has no friends and no social network whatsoever; he's just got us. But just so he can live as independent a life as possible – that's what I want for him, and I can't do that; I need somebody else to do that." (ID61, UK, F, parent)*

In Germany, parents of children with ADHD were ashamed and do not talk with doctors about their troubles, because some doctors in Germany do not see ADHD as a "real" condition.

#### **7.4.2 Physical health conditions**

Children with physical health conditions considered their specialist as the most important doctor in relation to their condition. They visited their specialist regularly for check-ups. The frequency of those visits varied between the five countries. Some participants in the UK felt that the time between the appointments was too long and that the appointments were too short. One girl in The Netherlands considered those check-ups as useless. Parents in the Czech Republic and Germany complained that they sometimes need to travel a long way in order to visit their specialist which is leading to some financial burdens and time problems. Some parents of children with TBI recalled the pathway after discharge from hospital which is different. Some children went to rehabilitation services before being transferred to

primary care services which was sometimes arranged by the physiotherapist from the rehabilitation services. Other parents, predominantly in Spain, felt that continuity of care after discharge from hospital was inadequate. They said that they needed support and follow-up in the primary care after discharge from hospital, but they did not get it. One mother got this support through a private neurological service; another one did not have a follow up appointment after the hospitalization of her son at all. In contrast, one mother in the Netherlands said that her GP visited them regularly as a kind of follow-up care.

*"And that part of aftercare, <> as GP was always involved. There had to be just a little thing, or he came on his bike, even on Sunday, so-called to drink a cup of tea, but also to see how everything was going. Yes, we have always had a very good contact with him"*  
*(ID73, NL, F, parent)*

Some parents in the Netherlands as well as in Spain felt the need for a social worker or a personal coach who would have asked them what kind of help they would need after discharge from hospital and how they could help them in arranging this help. Also some other children went to rehabilitation services or a psychologist learning to cope with their condition. In Spain some participants commented in addition that these services are done privately and they have to pay for it, and services are sometimes far from home. One parent in The Netherlands told us that her son will follow an online rehabilitation program in order to learn to cope with his condition. Some parents also talked about using social care services. For example to get financial support or help with searching for a living place for a child with TBI or assistive technologies.

The role of the GP in the care for children with TBI, epilepsy and rare disease varied. Several children and parents noted that their GP was supportive and interested in the child's situation. This included, for example, the doctor providing important information about the condition, offering help with applications for rehabilitation or financial support, visiting the child at home regularly, or asking about the child's situation if the parent was visiting the GP for another reason which was noted by several parents in the Czech Republic and the Netherlands. The diagnosis was also taken into account in primary care itself (suitability of vaccinations, handling fever). Some children in the UK noted that their GP was in charge of their repeat prescriptions. In Spain children did not talk about their physical health condition with their GP – none of them had visited the GP in relation to their condition. Parents in The Netherlands thought that their GP should know about their child's condition. Therefore, many parents gave an information leaflet about the condition to their GP. Sometimes the GP did not follow the care advised by the specialist in the hospital. One mother noted that this made her feel frustrated and uncertain about what to do, as illustrated by the following quote:

*"If they say in the university hospital: ask if your GP could do that, or this is something you can ask your GP to do, or for this prescription you can visit your GP. He simply does not do that. And every time you seem to defend the university hospital, you have to defend those people who have been taking care of the child for 4,5 years, because he has another vision. Then I think: put your own vision aside as you have no experience with these kind of*

*children, all you can do is to help us, and uhm, please make sure you work together with such an university hospital. But he does not.....I really understand that a GP does not have enough knowledge to do really something with it. But if you swallow everything what has been said in the hospital and put your own vision to the parents, yes, I really do not understand that. I think this is so badly. Just call the university hospital and talk to them, but do not make us extra insecure." (ID79, NL, F, parent)*

One of the parents in the Czech Republic said that she needed more information about epilepsy than the GP provided at the beginning. She searched online and in social media for people with epilepsy instead. Other parents said that their GP was very helpful, provided information about the condition and its consequences. One of the mothers said that it was the GP who informed her about the possible consequences of TBI (for example school performance). She got information that even the specialists did not offer.

## 7.5 Transition to adult care

Children in Czech Republic talked about the transition to adult care as this meant having to get used to a new doctor. The transition was seen as a step to taking more responsibility for their own health. One girl in the Czech Republic was worried about the transition very much; she even said it was a "taboo" topic in her family because it felt too stressful. She commented that it would be very hard for her to build a new relationship with the GP.

In Spain, children attend paediatrician services until they are 14. Some parents thought that this is too early because at that age children are still kids. However, they valued that once a child is transferred to an adult GP, the health services make sure that the child is transferred to the family's GP even if the GP has his quota closed.

### 7.5.1 Mental health conditions

In the UK, some parents of a child with ADHD were concerned about transition to adult care. One couple, whose son had ADHD and autism, were concerned about the legal rights of their son when he turned 16 and 18, as illustrated by this quote:

*The issue is that they're classed as a certain age, and obviously [our son's] classed as an adult, particularly once he was sixteen, but obviously more now he's eighteen. But yet their mental age doesn't match.... he's an eighteen year old adult but mentally he's not, and he can't function as an adult at the moment and, you know and it's just...the whole system doesn't work; there's no transition system; there's no understanding and that's a huge concern that I've got.... there's no...not a great deal of understanding from services that...just because he's eighteen doesn't mean he's an adult. (ID60, UK, M, parent & ID61, UK, F, parent)*

### 7.5.2 Physical health conditions

One parent in the Netherlands with a child with a rare disease noted that it would be hard to say goodbye to the pediatrician in hospital as they would have to bond again with a new doctor. In Germany, children and parents did not talk about transition to adult care.

## 7.6 Improving services

### *Seeing the same doctor:*

- Seeing the same primary care professional should be promoted as much as possible as this may help to build trusting relationships. It was important to feel that someone understood and remembered things about the child from one visit to another.
- In order to facilitate this, parents in Spain recommended more work stability and better working conditions for health professionals.

### *Coordination of care:*

- Several parents in Czech Republic, Netherlands and UK noted that communication between primary and secondary care could be improved. In several countries parents noted that they were the messengers between different health care professionals. Parents suggest that shared medical records would help.
- In the Netherlands, parents felt a need for a social care professional or a personal coach who could help them arranging care after discharge from hospital.
- Several parents in The Netherlands suggested that the system is too dependent on the GP. They felt that it should also be possible to go directly to secondary care without a referral, or that a doctor's assistant could take over some of the GP's tasks, such as a referral for a blood test.

### *Getting a diagnosis:*

- Waiting for a diagnosis was a tough period for parents in Germany, Netherlands and UK. They would have liked more information and explanation at this time, and less waiting between appointments.
- Role of primary health care in caring for children with complex health conditions:
- Parents in Spain felt a need for follow-up guidelines in a protocol. They think there should be a follow-up after a few months after discharge from hospital in order to make sure that everything is going well.
- In the UK, parents of children with ADHD felt strongly about the availability of psychological support or counselling or a mentor for their children. They felt that support for their children to learn life skills and anger management was important as well as coping mechanisms.
- Parents in the UK also felt a need for some sort of support for themselves too, such as counselling, when their child had severe ADHD. They felt that they would benefit from learning more from a psychologist about their child's condition.

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- Parents in the UK felt that it would be helpful to have more GPs with specialist knowledge in ADHD.

### *Transition to adult care:*

- Parents in Spain suggested that children should continue visiting the paediatrician until they are older. Currently, they visit their paediatrician until they are 14 years, then they are transferred to an adult GP. Parents think children are still considered "kids" at 14.

## Chapter 8 – Medical records

Medical records refer to a personal health record for each child, usually maintained and used by one health care provider or organisation. Medical records were mentioned by some parents, children and young people. There were some mixed feelings which are presented here as well as suggestions for improvement. There is no information regarding medical records available from Germany.

### 8.1 Positive aspects

Access to medical records can be useful in terms of sharing and knowing more about the medical history of a child, as illustrated by the following excerpt from a mother in the Netherlands:

*"Yes, it is also useful when you get to the A&E that all doctors know about you. That you don't have to tell them about your allergies, but that they are able to check this in the system" (ID17, NL, F, parent)*

In Spain some places have shared electronic medical records accessible to most health care professionals involved in a patient's care. This is positive because a mother and child's information can be shared between professionals. Parents consider this as an improvement for health care services in the last years.

*"Because my child is not of that area, they can't enter and see the history, and this for me is very complicated, I have to bring and take, bring and take and take and bring from one center to another, because they need everything in written and they communicate through me... and what I miss is the simple access to the medical record of the child and have this control" (ID57, S, F, parent)*

Some young people from the UK felt that online medical records that could be accessed by health professionals would make it easier to register with a new GP when people moved house. One male participant, for example, a care leaver, had moved home several times in the same city and wished the process of registering with a GP was easier. He felt that, if medical records were linked electronically across practices, changing surgeries would be easier. Another male participant recalled having lower back pain for several weeks when he was home from university over the summer holidays. It was confusing knowing which GP he should see and he travelled back and forth for several months between his home and university doctors. He also felt that shared online medical records might have made it easier to sort out his problem:

*"I think it was when I got to about June, July time last year and I started getting pain, which they diagnosed as being kidney stones. And I kind of wanted to get to the bottom of what that was at the time, figure out what it, what was causing the pain because I didn't know, it was just, just pain. So to try and get some insight into it and also try and alleviate some of that, was the main reason why I went."*

***Was that around June-July last year?***

*So yeah, just after I finished my degree.*

***Were you back in your home town or still at the University City?***

*That's where the difficulty was, is I had the, I had the issue from that point until I'd gone to Uni, so it was a mixture of both places, which made it difficult because what happened was neither GP practice was willing to help me as such because they were putting the issues on the other one. ... So they were like, "Oh you were resident in [the university city] so that practice should handle it," whereas the practice in [my university city] said, "Well you actually live in [name of home town], you should handle it there." So I think for a long period of time, for months, nothing actually happened. And neither practice was willing to sort of do much." (ID34, UK, M, child)*

## **8.2 Problems**

The main concerns about medical records are confidentiality. This concern can have a negative consequence as children and young people can decide not to share too much information with health care professionals because they are unsure about how much is shared with parents or other professionals. For example, a child from the Czech Republic said that only people who need the information should have access to it but the fewer people the better because there this is personal information. One girl in the Netherlands also talked about her parents having no access to her medical record:

*"She first explained to me that the information would be treated very confidentially and then she asked me some questions, about what I wanted, what people around me could know about me. So then I said that my father, because I did not have a very good contact with my father at that time, I preferred that he would rather not know that I was visiting her. So then I told, and it is still in my record [laughing]. ....But then they wrote that as if I did not want to tell my mother neither, so both of them do not have access to my data, by phone. So I have to call myself (for a result of a blood test)" (ID20, NL, F, child)*

Parents in the Netherlands also had concerns because they questioned whether all health care professionals should have access to the medical records and should know, for example, whether a child has psychological problems, or that only some health care professionals should have access, such as the GP, pharmacist and A&E who have to deliver care in urgent situations.

Another problem experienced by some was when professionals did not record everything about the patient and all actions taken depended on the what was noted in the medical record.

*"Once they made a mistake, they had put the vaccination twice in summer, on both sides, and when I went again for the last one, they said that this was not done, that it was not there, and they had to put the vaccine again, and I had to go again... it was as if they had done nothing*

***So they put the same vaccine twice?***

Yes

***And this was the last time you went***

*No, I had to go again for the other vaccine" (ID23, S, F, Child)*

### **8.3 Mental health conditions**

In most cases the communication between GP and psychiatrist/psychologist is based on medical reports that parents and children get from the specialist and give to their GP. Anecdotally there is a telephonic communication between both professionals. This means that usually sharing the information about the child relays on the parents.

The medical record is also valued as an instrument that can be used to facilitate the information about the child when there is a change of physician who attends the child and does not know the complete medical history of the child.

### **8.4 Physical health conditions**

Printed medical records are an instrument used by the GPs and specialists and usually are given through the parents to other health care professionals. Some problems have been identified in the Netherlands. Parents/children noticed there are mistakes in the registration of information about the child, which can be a problem in order to get diagnosis and treatments. On the other hand some participants think that too much information is registered, and if it is too much, other health care professionals would not read it. This might hinder the physicians to ask good questions and provide good care. As is illustrated by the following excerpt from an interview with a Dutch mother having two children with a rare disease:

*"The thicker the record, the less it is read. Because I know that both children have a very thick record, especially the oldest daughter has a very thick record as she has visited many, many physicians when she was young. And the paediatrician said to me: 'sorry madam, I won't read that record. You tell me in three sentences what your daughter has, but I won't read it.' Then I think, yes, what is going on? Of course, it takes a lot of time, but you cannot expect from a parent to tell in three sentences what a child's health problem is. That is not working. Then write down the most important point, so that you don't have to read the entire record." (ID84, NL, F, parent)*

When the child is often absent from school due to medical condition, they might require information about the medical record of the child at school or contact the physician. Confidentiality is important in these cases as only part of the information is to be shared with the school.

## 8.5 Improving services

### *Medical records:*

- The possibility of having a centralised electronic medical records, accessible to all health professionals could be a good idea because health professionals are then aware of all health problems of each person.
- Sometimes access to administrative services that need electronic access are collapsed and slow, this should be improved

*"The problem is that sometimes Internet is collapsed"(ID23, S, F, child)*

- One of the improvements suggested by parents of children with ADHD and physical health conditions was to have some type of system that communicated directly to involved professionals and it would be independent of parents. It could be interesting to have a medical record accessible to all the health care professionals who are involved in the care of the child, although in some cases parents are afraid about what impact it would have on the professionals if they knew about the condition of the child.

*"Well, I think there could be software, for example, where they (doctors) would send medical records to each other instead of through papers. Because, in fact, the paper might be lost because you don't go to the GP immediately, right. And there is, after all, some information about the little child. So I think that there would be no harm if an internet thing existed. Nowadays, the internet is very fast, so I think that sharing information would be better on the internet or in some emails. The doctors would share information between each other, and the communication would be better, after all. I don't know, how fast they send it to the GP if the child is hospitalized, or when the child gets some medications"(ID38, CZ, F, parent).*

## Chapter 9 – Independence and autonomy

Autonomy refers to the right of patients to make decisions about their medical care without their health care provider trying to influence the decision. In this theme, we will discuss children's experiences of visiting the GP surgery alone or with someone else, making decisions and taking medications. Suggestions for improvement will also be included.

### 9.1 Going to the surgery alone or with parents

Almost all the children we interviewed said they visited the GP with their parents, mostly with their mothers, although this also depended on which parent was available and their work commitments. Sometimes both parents attended the consultation, even in a case from Spain where the parents were divorced but always tried to visit the doctor together.

In many cases children and young people prefer to see the GP with their parents, especially if this does not interfere in having the opportunity to be taken into account. Sometimes it is the preferred way because waiting is boring and going with someone is better, sometimes, it is better because the child perceives the support of the parent. One of the Spanish participants said that she trusted her mother to talk with the doctor or nurse because she had more experience in health issues. Two participants from the Czech Republic said they would rather go to the doctor with their parents than on their own because it felt more supportive. Similarly, in the UK, participants who liked having a family member at the appointment said that it felt supportive and 'comforting', and that it helped having someone there who would think about the questions to ask and remember what the doctor had said afterwards:

***"Have you ever been on your own to the doctor, or not yet?"***

*Not yet, no*

***Would you feel comfortable going or do you prefer going with your mum, what would you...what do you think's most comfortable.***

*I'd prefer going with either of my parents but I wouldn't mind...I like...it wouldn't be bad if I went by myself....I'd be a bit like nervous for the first time I reckon, but if I went like more than once by myself, I'd be fine I think." (UK, M/F, child)*

The disadvantages of visiting GPs with parents were also discussed. Several participants recalled that the doctor often spoke to the adult rather than to the child, which they found annoying.

*"I remember one [GP] diagnosed me with hay fever which is a large inconvenience – hay fever's horrible. But I remember that one, they completely basically ignored me and listened to my grandmother. And the other one, which was a lot more recent actually, it was more of when I was fifteen, which is only a few years ago, that I had a ...I was in because of my eczema. And even at fifteen I was basically being ignored in favour of them*

*listening to my parents – at the time my mother came with me. So they listened to her on the latter and I was just there, so yeah, even at fifteen they basically blanked me out, so yes.*

***So if we go back to that appointment when you went with your grandma.***

Yes.

***That was about hay fever. Did they ask you anything at all like, you know, are you sneezing a lot, are your, you know, eyes itchy?***

*They asked me a few questions but I answered to the best of my abilities at eight. And they basically just looked at my Gran and she repeated basically what I'd said. But they listened to her and wanted her to speak as well. Even though she repeated what I said, they still wanted her to be the one saying it, which was yeah.*

***When you left that appointment, what did you think? Do you remember what you thought at that time when that appointment finished?***

*I can remember thinking I hope this goes away but also that I was slightly annoyed that they had not paid any attention on mine to what I'd been saying. (UK, M, chid)*

Some participants said that some topics are uncomfortable to speak about in front of parents. One girl from the Czech Republic and one from the UK felt awkward when talking about 'something girly' in front of their fathers. The girl from the UK commented that she occasionally asked her dad to wait outside when she wanted to speak to the doctor by herself. Young people in the UK often felt that GPs should ask parents or guardians to wait outside or leave the room at the end of the consultation so that they could speak to the doctor alone if they wanted to. On the contrary, the girl from the Czech Republic said it would be funny if she asked her dad to leave the surgery and wait outside for her.

***"Has the GP ever asked to speak to you on your own at all or whether you would like to?"***

No.

***Is that something you would like or has it...how do you feel, has it been...?"***

*It's never really occurred to me but I think it might be nice if they did ask me that cos it's kind of hard to let your parents know 'I don't really want you here mum', something like that. Maybe if the kind of doctor said that, it might be easier, yeah.*

***So maybe at the end of the consultation to say, "Can I speak to you on your own for a few minutes," would that help?***

*Yeah, that would probably, I think, would be easier to say something which you might not want to say in front of your parents." (ID25, UK, M, child)*

Some participants from the UK, who saw the GP about mental health, also found it hard to speak to the doctor openly in front of their parents. An 18-year-old girl commented that she often 'talked a complete load of rubbish' when her parents joined her.

***"Should the GP ask, "Would you like to speak by yourself?" or things like that. Any thoughts on that sort of thing?"***

*I think definitely they should always ask like if they want...if the person wants to speak to the GP by themselves, because like there have been times when I've went with my parents...with one of my parents, and then I've talked a complete load of rubbish because I did not feel comfortable about talking about anything realistic at all [depression and self-harm].*

*But then it, the times when I went by myself and that was still difficult as well. So I think the GP, or the health professional in general, should really just ask the young people what they feel like they need. (ID26, UK, F, child)*

One girl from the Czech Republic said she would prefer going to the doctor alone because she did not want to talk about her problems in front of her mother but was afraid of doctors (she described having a white coat syndrome). It is a compromise for her to go there with her mother. Some children were wary of how their parents might feel when they went with them to see the GP. Some participants in the UK felt that young patients might 'dull it down' how they have been feeling when they talk to the GP in front of their parents in case they worry about them afterwards.

Some young people we interviewed saw primary care professionals on their own. They went to see the GP by themselves at different ages depending on whether a parent was free to go with them and if they felt comfortable doing so. Some could not remember when they started going on their own while others recalled the first time they went. One participant from the UK, who went on her own around the age of 16, wanted to get the contraceptive pill. The youngest participant who said he sometimes goes alone was 10 years old and from the Netherlands. He visited a physiotherapist on his own; and sees this also as a situation in which he can practice his traffic skills because he goes by bike. Some participants in the Czech Republic believed that children are allowed to visit the GP alone when they are 15 years or older.

Sometimes children and young people visited the GP with another family member (grandparents, aunties, siblings). One 16 year old participant from the Czech Republic said he visited the GP with his brother. He felt that going to the doctor with parents was embarrassing at his age but that was better to go with someone and have their support. Participants in Spain explained that, in some occasions, they have sent their child with a family member, especially if it was a routine examination. The assigned person could be a grandparent, an aunty or an older sibling. In one case the mother explained that she sent her daughter with a family member and they asked for the mother to come because she had to give her consent for some issue.

Factors influencing the decision to visit the GP alone or with someone else included: age, the reason for the visit, level of control by the parents, accessibility and transport. Age seemed to be an important reason for visiting the GP with parents or alone; most of the participants in some of the countries were under 15. When they were younger the health care professional would speak more to their mother, but as they have grown older there is more direct communication with them, and this is valued positively by participants in Spain, the Czech Republic, and the Netherlands. A few participants in the UK felt that there was 'a bit of a haze' between the ages of 16 and 18 – young people were not always seen as adults but were often ready to see the GP by themselves. Some participants said it becomes embarrassing to visit the GP with parents at a certain age. In the UK, some parents started waiting outside the consultation room themselves when the young person had reached a certain age. One participant recalled that her mum had made her go on her own to their local surgery, which got easier when she passed her driving test at 18. Before that, her mum would drive her there and wait outside.

The reasons for the GP-visit were also an important factor in deciding if the child has to be accompanied, as is illustrated by the following excerpt from an interview with a parent in the Netherlands:

*"At one point, you have to teach your children to be independent. Yes, so also do it yourself, experience yourself. ....It depends on the reasons why they visit a primary health care professional. Yes, if for example a tooth has to be pulled out, then I will join, because I want to why this tooth has to be pulled, and that is why I would join. But if it is a regular check-up, fine, go on your own. Yes, there is nothing wrong with that. Yes, let them go." (ID22, NL, F, parent)*

For certain issues where they might not need an examinations (for example medical certificate proving that they are free of contagious diseases and do not need to undergo examination) adolescents in the Czech Republic could go alone. In the Netherlands, one child mentioned that she would like to visit her GP on her own if the health issue was not too serious. A 16-year-old in the UK found it difficult talking about mental health in front of her parents but felt she might have found it easier going to the appointment with a friend. She went to the second appointment by herself.

***"When you went to see this GP, did you go by yourself?"***

*No, I went with my parents which was, yeah difficult because I hadn't been talking to them that much about it [depression] so it kind of...*

***So you went with both your parents?***

*Yeah.*

***So it's...how did you feel before the appointment, do you remember?***

*Yeah, I was really like...I was quite distressed really. Yeah, I didn't think it helped that both my parents were there. So I was pretty stressed and I was also...I think I was just kind of*

*upset because I don't want...I wanted to tell them but I didn't want them to have to find out in that way I would have much rather kind of sat down with them at home and explain things. But it kind of felt like, not that it was forced upon me, but that was just the way it was going to happen whether I liked it or not. So....*

***Would you have liked to have gone to see the GP by yourself? Or with a friend?***

*Yeah, I think, I think had I gone by myself I think I would have probably just got really upset and I think it would have been quite nerve-wracking for me. But yeah, I think probably with a friend would have been better because, yeah as I say, it was just really difficult for my parents to find out in that way.....But also it was really difficult because I was speaking to the... this person [GP] that I'd only met like five minutes ago or so, and you know telling her quite personal things really. I just found that quite difficult, and so I think that was why I was...it was just really difficult for me to speak to her." (UK, F, child)*

The level of control that parents want to have in issues related to the child also influences the decision about going together, as is illustrated by the following excerpt:

*"But I'd like to come along because I just want to hear what he has to say. What he does. That's just it, I would like to be kept in the loop of everything. ... Yes, I always want to know what it's like, what is going to happen...I like to have control, so I think that's the way it is". (ID19, NL, F, parent)*

In terms of accessibility and transport, a father in the Netherlands said that he and his wife joined their children because of logistical reasons. The surgery was too far for children to go alone by bike.

Other reasons that were mentioned by children for visiting the GP on their own was that their parents were unable to accompany them because of illness or work responsibilities. One participant in the UK, for example, recalled that he first went by himself when his mum was ill and unable to go with him. Another participant noted that when he went into foster care, aged 15, and started seeing the GP by himself as well.

### **9.1.1 Mental health conditions**

In almost all countries parents went with their child to visit to the GP, as well as to the specialist. Depending on the age of the child, parents in the Netherlands felt it was important that the GP addressed questions to the child – as the child had to learn how to explain their health issue as well. One mother commented that the nurse at the mental health organization really tried to involve the child in his care. She asked the child what he thought about the dosage of the medication, for example. The nurse followed up what the child was saying.

### **9.1.2 Physical health conditions**

Most of the children and adolescents with physical health conditions visited the GP with their parents. Some participants from the Czech Republic commented that they preferred going with their mother because their father usually do not know what to say to the doctor and the children have to describe themselves what is going on. One of these participants

also commented that she prefers going to the GP with her father because she can express herself to the GP better than when she is there with her mother. One participant said that because his GP talks with his mother, he does not like going there so much even if he really likes the GP. In Germany, some children with physical health conditions and their parents preferred to go with their parents, especially because they often forgot their appointments or because it was not easy to get to the doctor, therefore they were dependent on their parents to bring them there by car. One girl in the Netherlands with an acquired brain injury prefer to visit a GP with her mother, because of her speech defect. Her mother acts as a spokesperson of the girl during the consultation. All parents in the Netherlands noted that they join their child, when visiting a health care professional. Especially, when it is about relevant issues.

However, there are some cases where the child visits the GP alone. For example, a girl from the Czech Republic started to visit her GP when she was 12 as the following excerpt shows:

***"So, nowadays you go to the GP alone?"***

*Yes, I always went by myself. I think since I was 12 years old. For example when I was able to go by bus from school, mum was at work, my dad too, so I just went there. (...)*

***You said you started to go to the doctor by yourself when your 12. How did you perceive it?***

*Well, I didn't care. I just knew, where I should go, and that I shall go, so I went there, right? And it wasn't like, like my parents would have to take a day off or something. I was always more self-sufficient (than others)". (ID67, CZ, F, child)*

Also participants from Germany felt comfortable and went alone to their GP. Some children in the Netherlands visit a GP alone, for example when they need a vitamin B injection. One mother noted that when her child is 18, he has to visit the GP on his own.

## **9.2 Making decisions**

Participants who were over 15 said that they made some decisions about their health (mostly related to vaccinations) together with their parents. A female participant expressed that everyone is responsible for his or her own health and thus the vaccination should not be compulsory (see Chapter 3 Reasons for using primary health care for more information about vaccination).

With respect to their involvement in care, there are a variety of experiences. In Germany, a common experience was also to ignore health problems and not tell parents or see a doctor because and just to hope that they eventually went away. In the Netherlands one participant stated explicitly that she was not involved in her care. Another participant stated that she was involved as she had to make the decision for getting a blood test, for example, by herself based on the information the GP had provided. Several parents in the Netherlands talked about shared decision making within the consultation. Although some parents said that they thought it is important that the GP discussed the different options with them, most of them

relied on the opinion of the GP as he was a medically trained professional. Discussing the different options made parents feel that the GP was taking them seriously. One mother explicitly said that she also discussed all options with her child.

### 9.2.1 Mental health conditions

The role of parents in decision making and searching for diagnosis and treatment options was an important issue. In Germany, the most frequent and most important topic in the interviews was drug treatment for ADHD. Almost all parents said that the decision for or against medication was a very hard one and taken only if every other option or therapy had been tried and proved to be unsuccessful. With medication parents felt relieved and not under so much pressure anymore, they felt their children were less exhausting. Participants in Spain and the Czech Republic had the same concerns. Also, in these countries parents did not talk so much about the GP involved in these decisions in relation to the treatment of ADHD. Many parents in different countries thought that they are the ones responsible for the health of their children and therefore play an important role in the treatment of ADHD, and health care professionals can only give advice. This is illustrated by the following excerpt:

*"I think as parents you have to take a decision. And if you put your head in the sand; I do not make a choice for myself... What is the best for my son?...No, you have to take a decision for your child. And therefore, you have to get in his shoes and not think about yourself, how sad you think it is. No.....Other people can say what they think is the best, but it is the decision of the parents. If I do not agree with it, then that is my choice. They can only give advice about what the best is for my child at that moment" (ID50, NL, F, parent)*

In order to make a decision about starting medication, parents searched for information. Thinking about other options for treatment was important to many of them. Participants from the UK had preferred to explore other options before accepting medication for her son's ADHD. One mother said that in Italy, her country of birth, patients are offered psychological support but, in the UK, unless a patient accepts medication, they are given no support. She said she looked online and read books to learn as much as she could but would like a mentor to support her son's social development:

*"Even if they've got an interview, they can call and say, "Look I've got an interview; what do I have to do in this situation?" ....You know, they can help them to do the little things." (ID62, UK, F, parent)*

Some parents from the UK chose not to accept medication for their child for several years. One mother said that she and her husband had been 'working hard for many years' with their son and teaching him coping strategies. Now that he had just started secondary school, though, they felt that medication might be their best option. It was her son who suggested trying medication to help him concentrate after he had tried as many strategies as he could. This mother also had ADHD so she had helped her son to learn about routines and coping strategies. She felt that it was difficult to know what to do and confusing to know which

health professional to see because she and her husband had declined medication when her son was first diagnosed.

Another mother from the UK, whose son was 13, recalled that when he was diagnosed at the age of 8, he started medication straight away. Like some other parents from the UK she felt that, if they chose not to have medication for their child, they would receive no support at all from healthcare professionals. This mother said that one of the reasons she had accepted medication for her son was because she did not want to be taken 'off the books'. Another mother, whose 10-year-old son had ADHD, believed that '*they just want to give you medication and tell you to get on with it and it's pretty much....if he's got ADHD he's got medication, done*' (ID64, UK, F, parent). She had wanted to 'try everything else' before accepting medication for her son but felt that there was no health care or information for parents who chose not to accept medication.

One couple we interviewed, whose son was diagnosed with ADHD at the age of 11 and with autism at the age of 18, said: '*he's just at home, coming out of his room about 15 minutes a day and that's about it*' (ID60, UK, M, parent & ID61, UK, F, parent). Their son decided to stop taking medication at the age of around 14 and is currently on no medication.

### 9.2.2 Physical health conditions

In relation to making decisions, some participants from the Czech Republic said that most of decisions were made on the basis of the mother's opinion. Two of the participants did not want to go to surgery or rehabilitation but when the mother said it is necessary, they had to listen. A girl, who had a brain tumour when she was very young, had to undergo many surgeries already, she does not want to go for another one, which supposes to restore her hand's fine motor skills:

*"In the past, they motivated me with gifts to go to the surgery. (...) So my aunt said she will have manufactured special high heels shoes for me, if I go for the surgery. And my mum confirmed it. But I said: 'you won't bribe me anymore, not me, not anymore. The operation is my decision and either I will go or not.' That's what I told them. I said 'no' several times. Even though, they said: 'Try it, try it for the last time; then I will leave you alone.' What if it won't help? What if it will be back and it would be even worse? I will risk for nothing and they will cut me again and so on. What if it will be back and it will be totally different than it was before? But my mum wants me to go there. Unfortunately, I have to do, what she says, even if I should decide by myself. She has already called to Prague (where the hospital is). I will go there in November. "(ID68, CZ, F, child)*

One girl with an acquired brain injury in the Netherlands commented that she is self-willed and that she decides herself how something is going regarding her health care. It is important for her to have ownership about the care, because it is her body and she knows how she feels and no one else does. Often she suggests something that the health care professionals act on. And if they do not act on it, they have good arguments to do so, which the girl agrees with afterwards. When she was for example at the A&E for a broken finger, the doctor wanted to splint three fingers. The girl wanted to splint two fingers so that she

was able to continue doing her hobbies. The doctor followed her wishes. In order to make decisions, parents in the Netherlands noted that they take a decision based on what is best for the child. One mother noted that the advice of her GP is very important in taking decisions.

Participants also talked about taking decision related to vaccinations. Two participants in the Czech Republic mentioned HPV vaccines. One of them decided to get the vaccine and she was talking about it with the GP, who recommended her the type of the vaccine. The other participant said that it was a shared decision with her mother not to get the vaccine – participant and her mother are worried how all of the pills for epilepsy might affect the body and thus, they try to eliminate other medicines (also contraceptives). A girl in the Netherlands commented that her parents let her decide whether she would get the HPV-vaccination or not. She decided to get it, because she had confidence in doing it and she did not believe the negative stories of girls becoming very ill because of the vaccination.

### **9.3 Taking medication**

Participants said that parents usually pick their medicine up in the pharmacy. In the Czech Republic, children mostly visit the pharmacy with their parents. Participants who were above 15 mostly keep the medication on mind by themselves; parents or friends sometimes remind them taking the pills. One participant said that she uses alarm clock to take the pills and have the medication next to her toothbrush.

#### **9.3.1 Mental health conditions**

Taking medication is an important issue in terms of decision making. Young people with ADHD from the UK discussed this topic in length. For example, two participants felt strongly that being taught coping strategies was highly important and that medication should be a last resort. Two other participants were both taking medication. One girl decided to stop taking medication and said she 'refused' to take it:

*"My mum was like, "You need to take your tablet." I was like, "No, I'm not doing it anymore; I don't want to." I don't want to be having tablets for the rest of my life just because I have some medical conditions, medical health conditions. Like I'd rather just stop it and just learn how to cope myself." (ID63, UK, F, child)*

One participant was prescribed Concerta but also stopped taking it:

*"There's certain things with Concerta and it caused quite a lot of...in fact it made me a bit more angry if anything. But not only that, it caused certain pain, so when I go, when I come back from home I had a massive headache and keeping...this is only year seven, I'd have to come home every day from having a massive headache; have to take an aspirin and lay down because the medication they were issuing wasn't..." (ID61, UK, M, child)*

#### **9.3.2 Physical health conditions**

One of the participants in the Czech Republic was talking about responsibility of taking pills. At the beginning her mother reminded her every time, nowadays she take care of it by herself. She feels it is very important to take medicines because she does not want to have

seizure again. After four years of taking pills, it is much easier for her. A girl in the Netherlands said that she together with her parents decides about the dosage of the medication. This was something the doctor gave her the freedom to do so, which she liked very much. When parents of children with physical health condition, from the Netherlands, talked about self-management, they talked about it in relation to medication use. Parents commented that they decide to increase or decrease the dosage. When children are young and not able to indicate how they feel, parents have to decide for their child based on how their child is looking and functioning. Older children are able to indicate to their parents whether they need more or less medication.

#### **9.4 Independence and taking responsibility**

Some participants spoke about the actions they took to stay healthy: washing their hands regularly, eat healthy, doing sports.

*"To do preventive something for your health. To think for example, it would be good to wash hands often, to eat less sweets, so don't get diabetes, to do more sports. This kind of things." (G, F, child)*

The children agreed that there was a link between unhealthy eating and overweight. Still it was not always easy for them to try to eat healthy all the time, because they did not always have the time to go home or to prepare some healthy food. Based on this topic the parents in Germany had a broad discussion about what is good and what is bad for the children (sugar, smoking, meat, pollution) and what role the state should have in implementing or sanctioning (un)healthy behaviour. Some parents wished for higher taxes on things, which they considered unhealthy (sweets, cars, meat) and for the state to forbid smoking in the city centres.

*"I would like to ban smoking in the city centres. People should be only allowed to smoke in special rooms, not on the street. I would like to protect my children. Smoking causes cancer. Why should someone else poison my child?" (G, M, parent)*

All parents in the Netherlands agreed that a system based on incentives and penalties should not be introduced. Most parents related this to freedom of choice, which parents should have. One parent said that such a system of incentives and penalties feels childish, however, she said that it might be helpful for some specific populations, for example those who forget often appointments. This mother thinks that penalties will work better than incentives. However, another parent thinks the opposite. One father mentioned that it should be better to oblige companies to fulfil specific requirements than to oblige parents to follow for example the National Immunization Program. One mother in Spain thinks that there should be more information about when to put the vaccines and education centre should have more responsibility in reminding and share the responsibility for vaccination.

*"It is our responsibility as parents, but there is a co-responsibility of health policy, because parents are not always well informed, we don't have to know, this is like if you say: "I am driving a car without breaks" that is my responsibility because I have to take my car for*

*revision every year, so you also have to have some responsibility with this (...) so you have to tell the parents: "if you don't want to put the vaccine to your child you have to be aware that I have to register this in the medical record, that you have been informed and don't want the vaccination for your child and you must sign this" (ID 25, S, F, parent)*

#### **9.4.1 Mental health conditions**

One mother in the Netherlands explicitly described two examples of self-management. During the diagnostic period, she did not have faith in the preliminary diagnosis; she took the initiative herself to search further. Secondly, she decided herself that her son would quit with the social skills training as it was too burdensome for him. Some parents from the UK felt that they would benefit from learning more from a psychologist about their child's condition, and others believed that parents also need support, such as counselling:

*"I think, yeah, having a clinical psychologist...you know at the start when you've got the diagnosis, so even if, regardless of whether you're going down the medication route or not, I think having that for that child, but also for the parents because sort of we've come to accept the diagnosis very differently.... a psychologist of some type but not just for [our son]; I think for all of us. We all suffered." (ID61, UK, F, parent)*

She felt that seeing a psychologist should be '*part of the normal process...like taking a tablet*'.

Others felt strongly about the availability of psychological support, counselling or a mentor for children with ADHD and autism.

*"It would be good if somebody came into the school so that if there was issues, there was like...maybe like either a drop-in centre or that they...you could speak to somebody quickly, because if you...if anything kicks off you've got to wait a while for an appointment or to try and speak to somebody." (ID63, UK, F, parent)*

Many parents felt that support for their child to learn life skills and anger management was important as well as coping mechanisms.

In the Czech Republic, some parents said they decided to visit a centre providing support for children with various mental health issues except of visiting psychologists and psychiatrists with their children. In the centre, there are weekly programs for children with ADHD and also support groups for parent of these children. All the parents and children were very satisfied with the service and noticed improvements.

#### **9.4.2 Physical health conditions**

One of the participants in the Czech Republic said that she communicates with her doctors by herself when she needs information on her health. She calls her GP for blood results and discusses some issues with her specialist by email.

*"When I am at school, I cannot call her (the specialist) but I can write her. (...)*

***What do you ask her in these emails?***

*Well, we were talking about the medications, if there is another option because it was totally awful at the beginning. So, if there is another medication, or when it will end (side effects). Or I just wrote her because of a silly thing. I just wanted to buy a 'virtual reality' for my boyfriend's birthday and I wanted to know if I can go or not." (ID67, CZ, F, child) .*

Participants from Germany said that due to the amount of visits to the hospital or conversations with different doctors, the children become experts about their condition and every aspect related to that. In most of the cases they know exactly why and how a seizure can be triggered in their particular case. Because of that they often have good and long conversations with doctor, who take them seriously and talk to them like to adults, which they like. Participants from Germany felt being able to call the doctor and schedule their own appointments. One girl in the Netherlands noted that her mother has a lot of influence on her care as well. They do it together, although she noted that she always tries to convince her mother with arguments.

Parents see their role in the care for their child as being the expert of their child, taking the lead, being assertive and verbalizing their child's health problems, especially when a child is young. One mother in the Netherlands talked about self-management when her child is admitted to a hospital; she always calls in her paediatrician because he is an expert and can inform the other health care professionals what to do. Another mother said that the preventive child health services gave her the freedom to cancel appointments, because this mother had to visit different health care professionals because of the child's health condition.

## 9.5 Improving services

- A girl with TBI in the Netherlands advised the health care professional to discuss as much as possible with your patient as they like that. Furthermore, she advises to see the doctor-patient relationship as an equal one; in that case patients dare more to share their thoughts.
- In the UK children can visit the GP by themselves when they feel able to do so. Many young people were unaware of this and said they would have liked more information about their rights to see the GP alone.
- Participants in Spain think that parents and primary health care should have co-responsibility in vaccines control.

## Chapter 10 – Health information

The role of the GP involves giving information and answering questions about different health issues. Some participants actively sought information about primary health care. Participants valued helpful information and advice from health care professionals. However, health care professionals were not the only sources of information. The Internet, family and friends also influenced parents and children. In the following section, topics that emerged from the interviews with children and parents in relation to health information are presented: topics and reasons, information sources and using the Internet. Finally, recommendations for improvements are presented.

### 10.1 Topics and reasons

Participants searched for information about vaccinations/immunisation, sleeping problems, menstruation, puberty, nutrition, and sexuality. They also searched for information on topics related to health care, such as online reviews about the GP or other health professionals, opening times, or what the preventive examination involved.

Some parents said they searched for information when they did not trust the GP or when the GP did not provide enough information. If the information provided by the health professional was sufficient, people might not need to look for more information online. This is illustrated by the following excerpt from a girl from the Netherlands:

***"And did you search for any information after the consultation?"***

*No, because the GP had explained everything in detail." (ID21, NL, F, child)*

Some children in the Czech Republic searched for information when they were concerned if their disease was contagious.

#### 10.1.1 Mental health conditions

Information about ADHD or autism was very important to parents, especially in order to help their children and to understand them better, how they might feel and behave due to their illness. Getting this information from the GP was very helpful according to some Czech participants. On the contrary, participants from Germany and Spain thought it had been more difficult to get information.

*"This is always a problem to find the right doctor. Where I first did not feel comfortable, was in the child and adolescents' psychiatry, because of the doctor, who was critical of the ADS and ADHD. We were very disappointed, because he sent us home without doing anything. There I was with my son, who was not looked at in any way, we only had three or four talks. And he (the doctor) decided that the child did not have anything. This way I lost a whole year, till I thought again: 'Something is wrong. Why is nobody helping us?' (G, F, parent)*

Topics of interest were new developments in the field of ADHD and being aware of the newest medications and therapies, or general information about ADHD or autism, diagnosis, symptoms.

*"It was actually when we visited the psychosomatic team, that they said that he had an adhesion disorder. Then, indeed, we consulted our former special educational generalist and I started searching for information. Information about autism, what might it be like, whether it's Asperger, or PDD-NOS, or developmental delay. Yes, I did look into it in order to see what fitted them" (ID48, NL, F, parent)*

Parents from the UK and Spain often felt frustrated about the lack of information provided by health professionals. This included information about ADHD, medication, coping strategies, pathways to health care, economic support or other types of support. One father, whose 18-year-old son had ADHD and autism, felt '*a lot of frustration*' and that it was often difficult to distinguish between what was 'normal' behaviour, what was ADHD-related behaviour, and what he should be able to expect from his son. One mother, like several parents, often felt confused about her son's symptoms and whether he was just '*being a boy*' and '*lively*' or whether there was an issue. Now that her son was at secondary school, another mother said that she found it difficult to know what was normal behaviour or '*hormones*'. More information from their GP or consultant would have been helpful. Participants in Spain said that there should be more information available in leaflets, and also media should help disseminate the message and understanding of these children.

Parents from the UK also wanted to know which hospitals had pediatricians, ADHD clinics, ADHD consultants and specialist nurses. They felt that this information should be given to parents when a child is diagnosed:

*"These are the services; these are the, you know, the voluntary...these are the support groups that you can access, you know, can give you that information.... But it just felt like, yeah, you take a prescription and off you go." (ID61, UK, F, parent)*

UK parents felt that a visual diagram (a 'spider map', 'flow diagram' or 'underground map') of the various services and what to try if something does not work would be helpful:

*"It should be let's use the whole remit of all of the services because all the children are different. What suits one won't suit the other." (ID60, UK, M, parent)*

*"It's quite a basic thing isn't it, having a directory of who you have in that service and what their skills and knowledge are, and it's not difficult...You have 'choose and book' appointments at the hospital for certain services [um] and I get that you can't choose and book everything, but there should be a certain element of being able to pick and choose and look at those, you know...who has those expertise in, you know certain conditions and sort of say, 'OK I want one of those two.' Why not? I don't want to go and see somebody that's just got a basic knowledge of that when I think, you know, that's where I need to go. And if I'm, you know not getting on with that one at least I know that there's somebody else in that team that's got some of those skills." (ID61, UK, F, parent)*

Spanish children thought they got some useful information related to preventing further injuries.

*: There is a kind of splint they call it for the head, like a helmet (...) but it was only top lay football, they did not explain anything, they [referring to the primary care centre] only said that I should use it." (ID 77, S, M, child)*

In one case a boy received the information about the seriousness of the injury and that it could have caused his death. Part of the information received was through the hospital discharge report where he learnt about the medications. They would appreciate more information about the consequences of the TBI; uncertainty is very difficult to manage. One of the mothers complains about the lack of information about resources and disability and legal rights of patients. GPs would not give so much information and private specialist were more helpful.

In Spain the topic of social beliefs worry the parents, in relation to how family and teachers treat these children. Sometimes they give them the label of "bad kids" and this is an important concern for parents as this can impact the child and is not helpful. It is not easy for schools, health care professionals and family and parents to deal with this problem. Society is not prepared to manage and accept other type of situations. The way to deal with these children is different from others; the steps you have to use with them for education are different. The main concern about this issue is that the children get isolated and cannot be happy and live happily. One of the parents compares the situation in France, and explains that in Spain these children are isolated and left out, and in France there is integration.

### **10.1.2 Physical health conditions**

All parents in the Netherlands and some in the Czech Republic commented that they had searched for information about the physical health condition of their child. They searched for information at different time points. Some parents searched for information when noticing the first symptoms, others when the pediatrician mentioned a possible diagnosis, some parents searched for information after a certain test, and others after getting a diagnosis. Some parents of children with a rare disease in the Netherlands noted that at one time they stopped searching for information, because there is too much information available what made them uncertain. Parents search for information in order to get advice, tips or a helping hand regarding for example an operation, medication or practical tips. A mother of a child with epilepsy from the Czech Republic said that she had to search to understand a meaning of some words of medical jargon, such as 'atrophy'. One mother of a young child commented that she also searched information regarding parenting tips.

## **10.2 Sources of information**

For healthy young children, parents were the most important source of information. It was parents who they asked first when they were facing a health problem. A few children in the Czech Republic said they sometimes searched for information on the internet. One boy said he also asked his friend when he needed information about preventive examination, which he was afraid of.

Parents said they get information by searching online or as one parent said asking another GP, in his case friend's GP. Leaflets related to vaccinations or medications were also mentioned as an information source. In addition, in the Netherlands, people can use the telephone helpline of the preventive child health services, which you can call if you have any questions regarding the child's health or development.

*"I called that line once, because she had some sleeping problems, that I did not exactly know what to do: yes, what should I do? During the day, one or two sleepers and when then exactly? And well, that was a good conversation. Was also a very nice woman who did not even impose or so, like: you have to do it this way. But more like: well, you could do this, just try it and see how it goes. And if it is not working, please contact us again, because we can have someone come along. So that was all positive. ....*

***And when do you call such a helpline?***

*Well, if you are in doubt, or if you want help, or if you have questions. Yes, then I never actually did, but at that moment I thought: well, you know, let me just try it.*

***Yes, And what do you think of this? Of this kind of service?***

*Well, it is positive in itself. That if you are facing a problem, you know that there is a helpline, that, well, that you can ask for advice.....You get a nurse assigned from the preventive child health services who you contact at all times. Of you can mail her, and you always get a reply from her. And there is that helping that you can call for information, and otherwise you can just get to the appointment and share your story there. So in that regard, there are enough opportunities to get information. "(ID17, NL, F, parent)*

Some people felt that there was a lack of good health information and people take pills without asking the physician.

*"For example, some people abuse of some drugs, and they think they can take it." (ID22, S, F, child)*

### **10.2.1 Mental health conditions**

Other sources of information were named in different countries: books, internet, TV, support groups, leaflets in primary care centres, friends, friends who work in healthcare, friends or family who live in other countries and inform about how this health issue is dealt with. In the Netherlands there is a youth mental health organization, and also teachers were named as sources of information about school questions related to the interaction with the child. In the UK parents also named the in-house courses and telephone helpline of an ADHD charity as sources of support and information.

In the Netherlands one mother mentioned the book "The wonder weeks" which was not helpful for her, because her child had not a "normal" development. Patients associations are also seen as information sources, for example in Spain there is a National Association of ADHD.

### 10.2.2 Physical health conditions

Several parents talked about the role of health care professionals regarding information. Parents also said they ask family, friends, GP, pediatrician or the preventive child health services for advice. Furthermore, leaflets and television are sources of information for the parents. One mother of a child with epilepsy from the Czech Republic said that she got information about financial issues related with medication from a pharmacist.

Some of the parents in the Netherlands noted that they received oral information from the health care professional; other participants in the Netherlands and one mother from the Czech Republic said that they did not get any information about their child's condition. This lack of information distressed some parents. One mother said that if you do not pick information yourself, nothing would be brought to you. One mother got oral information, but she had like it when she got this information also on paper.

A mother from the Czech Republic prepared a list of questions she needed answers for, when her daughter was discharged from the hospital with diagnosed epilepsy. Information that is usually easy to find like causes of epilepsy was not enough:

*"When they were discharging her, I wrote a list. It is normal for you, you have a fever and you take a pill, but if the child is epileptic, can she take the pill? And can she take that pill? (...) So I came with the list but not everyone think about it. As you have a manual, for example there are many brochures for babies. If you have a baby, you should have this kind of water, let him sleep, ventilate the room, bla, bla, bla. There is nothing like that for people with epilepsy. (...). You don't know, you cannot read this information that is 'normal' for us, healthy people. You have to find out. Or trial and error, right. Sometimes nothing else works, than trial and error." (CZ, F, parent)*

A girl from the Czech Republic said she sometimes asked her neurologist for information with regard to her epilepsy. Last time she asked her about an issue related to her leisure time, when she was not sure if she could attend virtual reality game with her friend. She emails her doctor to get these information even out of her visit.

Most parents of children with a rare disease in the Netherlands noted that they search for information via a patient association in different ways. First, by reading the information about the medical condition at the website of the patient association. Secondly, several parents mentioned the journal of the patient association in which they read about the latest developments. Thirdly, parents are looking for experiences of other parents, for example at fora, at Facebook or visiting meetings of the patient association. This helped some parents to see that their child is doing relatively well.

### 10.3 Using the Internet

The internet was identified as an important source of health information for children and parents; therefore, it is described in this section separately. The use of the Internet is common because it is accessible and quick. The type of information children or parents search for related to what the preventive child health examination involved, or they

searched for opening times on the surgery website. However, some people understood that not everything on the Internet is reliable or trustworthy.

Sometimes the information parents found was helpful, sometimes not. One parent commented that her GP does not like it when she searches information on the Internet before the GP-visit. In contrast, another parent said that her GP expects that parents search for information before they visit him.

A girl from the Czech Republic said that she chose her psychologist on the basis of her website. She said that the website should look professional. She commented that it is an important part of self-presentation of the doctor.

#### **10.3.1 Mental health conditions**

Many parents of children with ADHD used the internet as a source of information, however, one mother in the Netherlands explicitly said that she does not look on the internet as you only find negative stories. And in Spain one of the participants explained that she stopped looking at Internet because it would drive her crazy, information is confusing, especially because the variability of cases is huge. People with ADHD are all very different and have different needs, so information in the Internet is not useful for everyone in a generic way.

#### **10.3.2 Physical health conditions**

All parents of children with a rare disease in the Netherlands searched health information on the Internet. Several parents noted that there is also a lot of nonsense information and negative stories, which are terrifying. One mother commented that she limits her search for information because she does not want to take over the role of the GP. One father commented that he realizes that the information available on the Internet is difficult for GPs as well, as patients visit a GP with an instant diagnosis that the GP has to put a lot of effort into invalidating this diagnosis. Several parents noted that it is important that health care professionals advise parents which websites to visit in order to find reliable information.

A mother of a child with epilepsy from the Czech Republic said that even doctors do not know much about epilepsy because brain diseases are very difficult to understand. Because of that she searches also for information that is available on the Internet. She said that about the specific type of epilepsy her daughter is suffering from, there is no information online in the Czech language so she has to translate the text online to understand.

Two parents of children with epilepsy in the Czech Republic said that they search for support and information on Facebook group for people suffering from the condition and their relatives, where they may get answers for their questions.

## 10.4 Improving services

*Topics and reasons:*

- In schools there should be more information about sexual and affective issues.
- In the past, there were some talks about prevention and health education at a community level and this was very interesting for one of the participants and she explains that nowadays it is not available anymore due to the economic crisis.

*Vaccinations:*

- Some parents and children consider they are able to ask the health care professionals about their doubts around vaccination and other health questions, but there are some cases they would appreciate to get more information on the treatment and the illness from the GP.
- Parents in Spain thought that there is a lack of information about vaccinations, changes in the official vaccination calendar, and even about the vaccines that are not financed by the public services.
- Few parents in the Czech Republic wished for information leaflets where, side effects, and pros and cons of vaccinations would be listed.

*Mental health conditions – ADHD and autism:*

- Participants in Spain, consider there is a lack of information about ADHD as well as about the economic support or information about other type of support, for instance, the National Association for ADHD. This should be improved. There should be more information available in leaflets, and also media should help disseminate the message and understanding of these children.
- One of the suggestions from UK participant was that a helpline for children and young people with ADHD, where they could ask for support or have queries answered, would be helpful.
- There is a need of more information about access and availability of services for these conditions. For parents, in UK and Spain, all of this information on a live website that could be updated as necessary would be helpful.
- Participants from the UK also wanted information about life skills and strategies. They felt strongly that having this information from health professionals when their child was diagnosed would have been helpful.
- Other parents in the UK were keen to be taught or informed about strategies that might help their child rather than ‘just throw them off with medication’.

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- Being referred to a psychologist or mentor, or told about courses their children could attend, was important and useful information but none of the parents in the UK had been given this by health professionals.
- Parents in the UK felt that a visual diagram (a 'spider map', 'flow diagram' or 'underground map') of the various services and what to try if something does not work would be helpful.

### *Physical health conditions – TBI, epilepsy and rare diseases*

- There is an advice to health care professionals to explain everything to the child as good as possible, and anticipate the prior knowledge and the age of the child  
*"Tips for health care professionals: try to pay sufficient attention to your patients, and if it is a child, try to explain him or her everything as clear as possible. If the child is older, please evaluate what the child already knows and anticipate." (ID76, NL, F, child)*
- Some parents in the Netherlands advise GPs to provide more information about the physical health condition of their child. Some prefer this information on paper.
- GP should parents refer to some websites in order to prevent that parents will search via Google and find unreliable information.

## Chapter 11 – The role of schools

As outlined in the WHO School Health services questionnaire, school health services can be either:

- School based: there is a school based health care provider either permanent, or part time, and usually there is a special room for consultations;
- The School Health Services is a distinct entity/structure in the health system, but school health services personnel are not based in school(s). School health services personnel perform visits in schools from the catchment area according to existing plans/schedules;
- Certain health services to pupils are offered by health care providers such as GPs and/or specialists based in primary health care facilities, and there is a clear link between primary care providers and schools.

In this theme, we will present what children and parents said about health care provided in schools, about the role of school when a child has an acute health problem or when there has been an accident, about their experiences regarding counselling and the school psychologist, and about health education and promotion. We will also provide experiences regarding the role of school for children with complex mental and physical health conditions. Some suggestions for improvement are presented.

### 11.1 Health care provided in schools

The health care provided in schools varies across countries. Almost all schools in Germany, for example, have school paramedics, who are pupil volunteers. They have a basic medical training and get called when a problem occurs. If something serious happens, the school paramedics would call an ambulance.

School health services in the Netherlands comprise school doctors and nurses who are part of the preventive child health services. The school doctor and nurse are responsible for the scheduled check-ups during school age. Not all participants were familiar with the school health services. Parents recalled receiving a letter at home to inform them of the consultation. Some parents joined the children during the consultation, others did not. During the consultation, the doctor measured the height and weight of the child, and checked their hearing and sight. Children noted that the doctor also asked questions about their home life. Afterwards, parents received a letter at home with the results of the different measurements and tests. For children it felt that the school doctor was specialised in communicating with young people. Some parents commented that the visit took only five minutes, and that sometimes the school doctor commented on the child, e.g. the child was overweight or had dyslexia based on only these five minutes. For one parent, this was a reason to withdraw permission for an additional consultation because this mother did not want her daughter to have a mark for being overweight.

*"And my daughter was seen (by the school health services) when she was in the second class (of primary school), and my daughter is just a bit stocky, that is just a fact. ....So they wanted to see my daughter again next year. I said, no. I said: 'she swims three times a week, next to running, cycling and she is cavorting a lot. She eats healthy, she eats her potatoes and her vegetables, enough vegetables, she eats fruits and chicken breast on bread. And yes, she also get a slice of bread with peanut butter. Is she allowed to?' And I said, 'you want to see her next year? Then I will say no'.....Because you create a stamp for that child; not just her, but also in the class where you leave her. I said,...'you will not do that to that child'." (ID22, NL, F, parents)*

One parent (also from the Netherlands) noted that her children's school had a nurse to whom parents could go with questions about parenting, questions that they did not want to discuss with their child's teacher. Although this parent never visited the nurse, she felt that the nurse was approachable.

In the UK school nurses are qualified and registered nurses who offer support and advice on a range of health issues. They also carry out immunisation and screening programmes. They are often the first place pupils go to if they are feeling unwell or need health advice while at school. The school nurse's day-to-day role varies depending on the type of school. As well as individual health advice and care, it can include supporting schools with health advice for the whole school, such as healthy eating and exercise advice. Some schools also have a school counsellor. In the UK children recalled having injections at school from the school nurse, and being reminded that pastoral care was available.

*"I don't really go to the GP that often. I think it's only for vaccinations. But they do do that in our school sometimes, because I don't really get ill often.... I think it was like tetanus and measles, mumps and rubella I think. That's all I can remember, yeah....It was a nurse. I went to a nurse to go and do it. And the last time I did it, it was with the school nurse. But I did it before that with the nurse at the hospital." (UK, M, child)*

Although the nurse gave one female participant in the UK a leaflet about eating disorders, this participant felt that she did not really know where to go for help after that. She thought that the nurse could have been more welcoming and understanding, and that it would be good if school nurses could help more with mental health issues.

Other participants in the UK felt that it would be good for school nurses to play a bigger role within schools. For one of these participants, '*talking about your health issues at school was better than talking about your health issues at the doctor or with your GP because, at the end of the day, you're in school most of your life*'. She recalled that her secondary school was '*quite resourceful...because we kind of had every single service that a school should have*'. This included a school nurse, counsellor, student support worker, and school social worker.

Some young people from the UK felt that it could be embarrassing if other pupils knew if they went to see the school nurse. One male participant said that there was 'a stigma attached to being seen going to' the first aid room at college and that it would be better if it was somewhere discreet. A few participants recalled that the nurses were not allowed to

give them painkillers without parental permission. Others had never seen the school nurse and a few were unsure if their school had one.

A few participants in the Czech Republic also mentioned that there was a school dentist but they had not used the service.

#### **11.1.1 Mental health conditions**

Most parents of children with mental health conditions in the Netherlands were positive about the school doctor of the preventive child health services. In addition to normal check-up consisting of measuring height and weight, the doctor asked the children how it goes at home and at school. Some parents said that the doctor had some tips for them how to cope with their child's mental health condition.

*"Obviously, school doctors in special needs education are much more concerned with, yes, children who are a little different from other children. And they hear also stories of parents. Also things that are recognizable. She also gives your tips, or, where you could go for professional help. She indeed referred us to a mental health organization. Like, maybe you could do this, or you could try that, but you don't have to. And if it displease you, then we can search further. It was really a nice school doctor." (ID48, NL, F, parent).*

A few participants in the UK, who had had mental health issues (anxiety and depression), felt that it would have been helpful if the school nurse had had more mental health training. Several people felt that school nurses were in a good position to raise awareness of mental health and 'make themselves known' to students with mental health issues.

#### **11.1.2 Physical health conditions**

Only one mother in the Netherlands talked about health care provided in schools and noted that her son is at a special school for children with complex physical illnesses. A social worker, a physiotherapist and a nurse are working at this school. This mother also talked about a health care coordinator at school, whose task was to coordinate the entire care at and around school. The care coordinator aims to provide the right degree of care to a student. This can be a concern within school (counselling, remedial teaching) or outside school.

### **11.2 Acute problems and accidents**

In the Czech Republic, participants noted that, when a child had an acute health problem at school (e.g. headache, stomach-ache), a teacher usually called the child's parents to pick the child up from school. One mother in the Czech Republic said that this was sometimes complicated because of her work.

*"Once they called me from the pre-school early in the morning when I had to take care of my three children and then I had patients ordered, it was Thursday morning and they said: "Your child has red eyes, we cannot keep him here." So I was really mad because the day before she also had red eyes and they did not mind because she was singing in their performance. So I was really mad because then I found out they had eye infection in the*

*"children collective and they did not tell me anything. (...) So, I had to, they kept her there at the end because I was not able to pick her up." (ID10, CZ, F, parent)*

In the Czech Republic when the child is 15 years of age or older, he or she may go home alone if he or she had a minor accident and the teacher allows it. One child in the same country told us that he had a negative experience when his teacher did not believe that he felt unwell.

In the case of emergencies, the school would call an ambulance. Participants in the Czech Republic noted that injuries must be reported to a teacher, who has to make a record of for insurance purposes. This is similar in Spain.

*"Health is not something that the school would pay much attention to. If something happens to someone, an ambulance is called, when it is something more serious. If we injure a finger or something like that, our teacher bandages it and then we go to the doctor with our parents. But everything must be noted. The teacher writes down that it happened at school and then the insurance company can pay the money." (ID36, CZ, M, child)*

Participants in every country commented that very few teachers were trained in first aid. Children in the Czech Republic did not understand why their teachers could not give them any medication, not even medication available without prescription (such as paracetamol for a headache). One of the parents said that her son took painkillers to school secretly and, if he had a headache, he would take a tablet without telling the teacher. The following excerpt illustrates how a girl from the Czech Republic felt:

*"I had a terrible headache at school, so I asked her, school secretary, for some pills and she just said that she cannot give me anything according to the law because I could be allergic or something. So they should have the information on allergy in some students' files. She did not help me at all, right? Both parents were at work and they cannot let me go home by myself. So I had to be at school till the end. It feels really weird because I know they have the pills there but they cannot use it anyway, even if it helped me." (ID2, CZ, F, child)*

One parent in the Czech Republic mentioned that she would not allow teachers to give medications to children but that medical professionals should be easily accessible.

Some participants in the UK remembered seeing a school nurse for minor issues such as headaches and nose bleeds.

### **11.2.1 Mental health conditions**

Children with complex health conditions and their parents did not talk about the role of school in acute problems and emergencies.

### **11.2.2 Physical health conditions**

Children in Germany talked about school paramedics who sometimes assisted them when they had seizures.

### **11.3 Counselling and school psychologist**

Some participants in Czech Republic talked about a school psychologist, who was available for counselling. Only one child sought her support and was satisfied with the service. When a new psychologist started to work at the school, though, she decided not to visit her because she was afraid that the psychologist would not understand her: the psychologist was much older than her.

Counselling was available in some schools in the UK, too, but not everyone knew whether there was a counsellor at their school. One participant recalled having 'a very good counsellor' at his school and another, who was bullied at school from a young age, discussed having counselling at school from around the age of six and then later at secondary school. She said that she found it difficult to open up and trust the counsellor, but felt that it had helped talking to someone. When she started hearing voices, the counsellor advised her to see the GP. Another female participant recalled her school counsellor advising her to see the GP when, after around eight sessions, she was not feeling any better. She felt that it would be helpful if school counselling services were better advertised – she only found out about them through a friend.

#### **11.3.1 Mental health conditions**

Only one parent in the Czech Republic commented that, although there was a school psychologist available if children needed help, she thought that one psychologist was not enough for such a huge school. One child in the same country said that their school psychologist was the kindest person at school and tried to help him.

#### **11.3.2 Physical health conditions**

Only one mother in Spain said that her daughter visits a psychologist in her school

*"There is a psychologist, and once a week she goes with him to class, language, maths, or whatever they decide, once she goes only with him and sometimes with another girl, and they have this class with the psychologist (...) whatever the teacher is going to teach that day, the psychologist gives that lesson, to see the attitude of the child to the new concepts."*  
*(ID85, S,F,parent)*

### **11.4 Health education and promotion**

Participants in Germany also talked about health education at school. Health education was hardly ever given and topics like hygiene were rarely discussed. Participants in Spain noted that some schools banned unhealthy food in the cafeteria and some children had to do class work related to health issues, for example look on the internet for health information. One mother in The Netherlands commented that the school has also signalling function regarding health issues, such as lice.

*"Indeed, health care is very important for teachers. For example, I am also a Lotte, a lice detective team member at school. There is one child in my daughter's class who had lice and net constantly for the last 2 years. And now the Public Health Services is involved, or*

*Youth Care, Public Health Services. I think that is also a responsibility of the schools, yes. ....So the school has a signalling(function)... absolutely." (ID22, NL, F, parent)*

Another mother in The Netherlands noted that her daughter of 15 years received a questionnaire about healthy behaviour. This mother liked this because she hoped it would raise young people's awareness of healthy behaviour. This was relevant as she had noticed that young people hanging around McDonalds and sweet shops.

In the UK and the Netherlands some participants felt that it would be helpful if school nurses or schools gave more information about the range of issues that GPs can help with, and that leaflets and flyers outside the nurse's office would be useful. Many felt that school staff, including teachers and nurses, could do more to raise awareness of mental health. One female participant said that teachers should also have mental health training so that they might recognise when pupils are having problems. A male participant thought that it was important for schools to raise awareness of mental health issues, including having people who had had problems in the past visiting schools and giving talks.

Children with complex mental and physical health conditions and their parents did not have additional comments regarding health education and promotion.

### **11.5 Mental health conditions and the role of school**

School was a very important topic to all young people with ADHD and their parents. Parents mostly discussed the problems their children had at school, difficulties in concentration, hyperactivity during lessons or in breaks, as well as social issues and discrimination. In this study we will only discuss the results relating to the role of school.

Some children in Germany and Czech Republic talked about having an assistant who helped them concentrate during class.

*"So I had a qualified social education worker. This is a woman who helped me with math for example. I had private lessons with her, so I was able to concentrate better." (ID41, G, M, child)*

The presence of the assistant in a class had a positive impact on children's school performance. One parent in Germany said it was very difficult to get an assistant. Even if it was paid for by the government, the headmaster did not agree with the presence of an assistant in class. Another participant in Germany said that they stopped using the service because her son started to feel ashamed because of having the assistant in front of other children.

Most participants in Germany complained about the lack of understanding and even insensitive remarks from teachers in regular schools, which could impact their mental condition. Parents often felt let down by teachers and in some cases even decided to change school, because the situation became unbearable for the child. In one case, a mother in Germany talked about one teacher asking her to give her child some medication, so that he will be "easier to handle" in class. Many of the parents in most countries talked about how

important the right school was for their children's mental health. They talked about spending countless hours looking for schools, talking to teachers and staff, and trying to find the best environment for their children, who had special needs in their opinion.

*"We spend about 180 hours in finding the right school. Those 180 hours were too few in my opinion, because we did not manage to talk with all the staff. We should have had done it, because it is very important that they can have a good relationship with everybody." (G, F, parent)*

Parents in Germany told us how difficult and stressful school can be for their children. Common experiences were anxiety, depression and in some rare cases even suicide thoughts.

*"You need to help the child, if he cries and is afraid to go to school for two years, this is what you notice that he cannot absorb anything, because of the stress and he could not absorb anything during the lessons." (G, M, parent)*

In Germany, three participants visit a special school for children with ADHD. They all emphasized the necessity for such an institution, where people paid a lot of attention to the needs of the children, especially for those with a severe condition like ADHD. The benefits of such school include: fewer children per classroom, a special training for the teachers, fewer strict rules, two dogs, school counsellors and psychologists, who are always available. In Spain, there was one participant who had some special attention

*"They have to take him out of the class, he has been sometimes one full month without entering the classroom (...) all have had the courage to organize themselves and give support and dedication only to him." (ID 57, S, F, parent)*

Parents from the UK felt strongly that teachers should have more training to understand and deal with children who have ADHD. One mother and father, talking about their 18-year-old son, felt that they had to '*let him fail at school...let him get detentions...be excluded to provide evidence that his behaviour is bad at home and at school.*' The 'evidence' was needed to convince the consultant that their son had ADHD. Parents also complained that teachers often misunderstood (and punished) their child's behaviour as 'naughty' rather than related to ADHD.

One parent of a child with ADHD from the Czech Republic said that a teacher helped her by giving her son medication for ADHD when he was at school. The teacher was also aware of some of the side effects of the tablets and did not examine the child when he did not feel well.

## **11.6 Physical health conditions and the role of school**

Some children with complex physical health conditions and their parents talked about school in relation to social relationships, school performance and self-esteem. These topics are beyond the aim of this report and will not be presented in detail here.

Some children with epilepsy in the Czech Republic and Germany talked about stigmatization and bullying in school because of their conditions.

*"I had bum bag after the first seizure for a while and they insulted me in school because of that. They said I was pregnant or a girl or something. And they kicked my bag." (G, M, child)*

This was not a very common experience in the five countries. Most of the children experienced a lot of support from their school friends. Most participants were very open about their experiences school. Those who had bad experiences only told the teachers about their condition.

Some children commented that they had had some issues at school because of their condition. One girl from the Czech Republic said that her teachers did not like that her alarm clock, reminding her to take her pills, always rang during the lesson. She later realized that she might postpone the time to the break between classes, so she no longer has this issue. Another girl in the Czech Republic recalled that she had a seizure while she was examined orally because of the increased stress. She was surprised by the reaction of her teacher, who left her lying on the floor and started examining another student. He did not talk about it with her during or after the class.

*"Well, I was being examined and the teacher put a pressure on me: "Write it on the blackboard, say the right answer; say how it should be." I didn't know the answer and he still wanted to hear it. I started it lean on the desks around and he did not get I was feeling sick. I fell down on the floor. And as I told you, I can hear everything when I have the seizure but I cannot answer in any way. So I heard what the teacher said: "So, what we're gonna do now, I guess we will continue. Come and finish the formula (to another girl in the class)." When I woke up, stayed on the floor for a while because I felt sick and then I returned to my desk because I didn't understand the teacher, what was that? I asked my class teacher if it is possible somehow be freed from the examinations. I didn't feel well with the teacher, who examined me. Some situations are not pleasant. My class teacher called my mum and she picked me up from school." (ID67, CZ, F, child)*

On the basis of her negative experience she visited her GP to get a medical certificate allowing her to be exempt from oral examinations at school. The GP served here as a counsellor for the participant. Another mother from the Czech Republic was unsure if the teacher could give her son with TBI a diazepam suppository if he had an epileptic seizure because she knew that they could not give medication to pupils.

One boy in Germany did not like that his teacher was too sensitive about his condition (TBI). He felt that was annoying that the teachers disallowed him from participating in almost every activity, if it was possible that he could hurt himself, for example to go on school trips. He thinks, they do this not because they want to protect him, but only to protect themselves, because they do not want him to have an accident on "their watch". Another reason could be that they do not know what he can and cannot do on his own and do not want to have too much trouble to help him all the time.

*"They do not let me do everything, because they think, I could hurt myself. But they practically do not let me do anything. I was not allowed to come to the school trip, because they thought, I would not be able to handle everything by myself, to sleep there and other things." (ID40, G, M, child)*

His feeling of not being understood was also caused by the fact that his teachers rejected an offer from a patient organization about a cost-free training and information event about children with TBI. They feared an additional time burden and the possibility that because of the training they will need to have more responsibilities.

In Spain there is one mother who explains that the school does an individualized curricula adaptation according to the capacities and skills of the child.

*"What they have done is an internal curricula adaptation, she has to achieve what she has to learn, but they do an individualized evaluation, they make her improve and learn but at her level, they have to give her more time." (ID 85, S, F, parent)*

## 11.7 Improving services

*Health care provided in schools:*

- Participants from all countries felt that schools should improve the health care available to children in general.
- According to children in the Czech Republic teachers should have information on children's medication allergies and be able to provide basic help if needed.
- It was very often suggested that each school should have a school nurse whose task would be to examine the child, treat minor health problems and give some light medication, for example for headache or stomach pain, and provide first aid.
- One parent from the Czech Republic would appreciate if the GP would visit schools for their regular check-up and vaccinations so that she would not have to go with her child.
- Because of the positive experiences with paramedics in schools in Germany, children in Germany wished that teachers would do some extra medical training.
- Children in Czech Republic proposed having a special room in school, where someone would take care for children who are sick.

*Acute problems and accidents:*

- In addition, participants from all countries suggested that teachers should learn how to manage acute health issues and injuries.

*Health education and promotion:*

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- All participants agreed that there should be more education about health issues in school. For example, students should learn about first aid.
- Many young people in the UK and the Netherlands felt that there should be more information about GPs being able to help with mental health problems, and that this should be made available in schools, for example by posters in schools and talks in school assemblies.
- There should be more promotion of community activities that involve schools, neighbours' associations, health care services and so on. There should be a resume of these activities at a community level.
- General campaigns about certain health issue problems should be developed at school and out of the health care services.
- There need to be more information in schools about sexual health.

### *Complex health conditions and the role of school:*

- Having specially trained professionals at every school, who would also be paid adequately, would help to improve services for children with special needs (e.g., ADHD, TBI) in the opinion of some participants in the Czech Republic.

## Chapter 12 – Financial issues

Financial issues cover types of insurance, paying for private services, medication costs, alternative therapies, and vaccinations. Financial issues were not discussed by participants in all countries. Participants in the Netherlands did not talk about financial issues. In the UK they were discussed very briefly in terms of a lack of resources (e.g. psychological support) and waiting lists.

### 12.1 Financial issues

The Czech participants talked about finances in relation to primary care services. They appreciated that health care in the Czech Republic is covered by insurance, though some procedures must be paid for. One participant said that she was surprised how expensive the examination needed for a medical certificate was for a motor vehicle driver. Another participant said that he liked a patient participatory system that was valid for a few years in the Czech Republic when everyone had to pay a small fee when using health services (it was 30 CZK per examination, 100 CZK for using emergency services). In his opinion, in countries where health care is for free, quality of the provided care is lower and so some people rather use private health care where they have to pay for services. This participant was satisfied with the quality of provided care in the Czech Republic and he was surprised that the participatory fees were cancelled. In relation to private services, one child also mentioned that staff were much kinder than in the public sector, possibly because they were paid better.

A mother from the Czech Republic said that she appreciated that the whole family had the same family doctor. This had several advantages, including financial benefits. When her husband (or herself) was ill, the GP sometimes gave them a '*paragraph*' instead of a sick note. A '*paragraph*' is temporary parental leave. If the parent needs to take care of their sick child, they may take a few days off work. Employees still get 60 % of their daily income. In the case of sick notes, the employee is not paid for the first three days at home.

Participants from Germany said that health insurance companies were more willing to pay for children's health compared to that of adults, which was perceived as good. One issue that came up was related to homeopathy, which was controversial. German participants did not agree whether this kind of treatment was reasonable or not. The parents, who did not believe in it, thought it was unfair that health insurance companies paid for some homeopathic treatments because it did not have any effect, only higher premiums for everyone. Other parents liked paediatricians who tried homeopathic treatment first and then recommended antibiotics if that treatment had not worked.

Financial issues were also discussed in relation to vaccinations. One young participant from the Czech Republic recalled choosing between a HPV vaccination, which was free, and one

which was supposed to be better but not covered by the insurance: she chose the second option.

### **12.1.1 Mental health conditions**

Regarding primary health care for children, only parents of children with ADHD in the Czech Republic talked about financial issues. They mentioned that, before going to the GP with their child, they used medications bought in a pharmacy first. Only one of the parents talked a bit more about issues related to the pharmacy. She said she noted that, because of competition between pharmacies, pharmacies try to offer lower prices to their customers.

Financial issues may have an impact on the behaviour of patients and their parents with respect to health care. One of the parents from the Czech Republic said that she would appreciate her husband coming with her and her children to the GP but that her husband would lose money at work if he went to the doctor with her during working hours:

*"When we had our first child we always went together to the examinations (...). But then he had to go to work, so it wasn't, we just did not have time for that, he would have to take a vacation. Nowadays, at work they actually have more money if he doesn't go to the doctor. So it forced us that we rather get 3000,- than go to the doctor together, right.*

#### ***How does it work exactly at his work?***

*Well, when he doesn't go to the doctor, he doesn't go anywhere, he has a work pass or something, simply when they don't go anywhere, they get 3000,- more on their pay check once in a half year. If he went to a paediatrician, the work would pay for it. And if he does not use this option for 3 months or half a year, he gets 3000." (ID37, CZ, F, parent)*

Another participant from the Czech Republic felt that it was important to attend regular check-ups at the dentist with her child because the care was very expensive when something went wrong. Another Czech participant said that she would not pay for most of the obligatory vaccinations but, if an insurance company paid for them, she would let her child be vaccinated.

Finances were also mentioned in relation to health and decision-making. A girl with ADHD from the Czech Republic said that she only got the first of two HPV vaccines because only the first HPV vaccination was covered by insurance. The mother chose not to pay for the second dose.

Participants from Germany and Spain were concerned about the financial costs and burden related to their children who had ADHD. Long appointments with a doctor and therapy visits – sometimes multiple times a week – were time consuming as well as costly.

*"And all the drives to the therapies, speech therapist, with the taxi or the bus, or to the doctors all the time. This all costs money." (G, parent)*

#### ***"And all this means money?"***

*Quite a lot, a lot, very much*

***And you, well, you are quite flexible because you are self-employed; maybe you have to do more sacrifice in timetable or changing it***

*And also my husband, working a lot of extra hours, a lot during the weekends, and also we get some help from the family, but mostly us*

***Is it expensive?***

*Very expensive, the value I am not sure... the value of money is that for us it is a lot of effort, it takes a lot of hard work, it is hard, but if you have a problem ... if you want some peace, you think well 100 euros more, where I have already spent 500 euros ... but it is very expensive... there are some therapies that you have to go twice a week or once, and each session it is sixty euros or seventy... or that week you also have the consultation with the specialist and it is 100 or 150 euros...." (ID53, S, F, parent)*

A mother from the Czech Republic suggested that an ADHD diagnosis might have an impact on insurance claims and pay-outs. She described how her daughter was injured at school before she got the diagnosis. After some discussions at school, where teachers said that the injury was the fault of her daughter, the mother received compensation from the insurance company. However, the mother believed that, had her daughter already had an ADHD diagnosis , the insurance company would have used it as a reason not to pay for the insured event.

### **12.1.2 Physical health conditions**

In the Czech Republic, some parents and children mentioned several financial issues. First, the costs of medication were mentioned by one mother of a child with epilepsy, who said:

*"It is really complicated because you have one type of medication. You have one type of medication and you have it, for example, in a 4 milligram pill. And you pay for the whole thing. And you have it in 8 milligram pills and you don't pay anything. But no one tells you that. (...) You can find it out on social networks, where there are support groups and you talk to each other and you find it out. Luckily, in our case, a pharmacist told us that instead of paying 800 for 10 pills, we should buy stronger medication, take just one half of it and we won't pay anything. So, I wouldn't pay 3000 in the pharmacy but 8000, right. (...) The financial side is really a burden, not only in our case but everywhere." (ID68, CZ, F, parent)*

Another issue related to care allowance. A mother of a child with a brain injury was disappointed that she did not get any financial support for her son. The people who were making the decision said that the boy was well oriented so did not meet the requirement needed for support. This mother commented that the people who were deciding about the support said he was oriented because he knew it was Thursday, but they did not understand that the boy did not remember where the school was, was easily lost because he could not orient himself anymore, and has to be led everywhere after the injury. These were criteria that were excluded from the assessment. A mother of a child with epilepsy said that

she recently applied for care allowance because she had to take care of her daughter with poorly controlled epilepsy. However, it takes too long to be informed about the decision.

Another issue that was discussed was assistive technologies and tools. A mother of a child with epilepsy said that she needed a wheelchair for her daughter. The mother said that it was quite problematic and she did not know if she would get support because if the assessors looked only at her epilepsy they may not recognize how serious it was and that she had other issues too (injured leg etc.). In this case, the insurance company would not provide the support, the family would have to pay for it, and another option would be asking a charity.

Another issue was related to spa care that was follow-up treatment for children after a brain injury in the Czech Republic. "Spa treatment" may be prescribed by a physician, usually to patients after accidents, surgeries or with a chronic disease as a form of outpatient care. If the treatment is prescribed, an insurance company covers the costs. The treatment involves various procedures such as heat therapy, hydrotherapy, electrotherapy, or baths and takes several weeks. If spa care was recommended by a health care professional, the insurance company pays for several weeks of rehabilitation in a spa. One of the mothers of a child with TBI said that she applied for spa treatment for her son every year after the injury and they always accompanied him. Unfortunately, the insurance company paid for the parent's stay only until the child was under 6 years. The mother does not know what to do next year because the insurance company will pay for her son's stay in the spa but not for hers. The spa rehabilitation is very effective according to her but her son is dependent on her since the injury but she is not able to finance her stay from own money.

The same mother is also in a lawsuit with an insurance company because they did not pay for permanent consequences of the injury. That is very tiring for her.

Other costs that were mentioned were related to the commuting to the specialists.

Children in Germany were critical about the health system in general, which they perceived as unjust. They would have liked insurance companies to pay for more services such as medication and transport in an ambulance. One parent told us that she had some financial problems because of her child's asthma and because of health care costs for her children in general. Therefore, she sometimes did not buy the necessary medication for her children, because she could not afford it. She wished that insurance companies would take care of the costs. She felt that it was unjust that people who could not afford it, had to pay for expensive medication for their children.

*"We think sometimes, should I pay for it or not, especially because you need to buy nose drops for every child." (G, F, parent)*

## 12.2 Improving services

### *Financial issues:*

- One child from the Czech Republic said that some of her friends complained that their doctors told them that it is not necessary to get vaccination for HPV, even if they asked for it. If a vaccination is not provided by a doctor, it will not be paid by insurance.
- Care allowance takes too long to get, the process should be faster according to a participant in the Czech Republic.

## Chapter 13 – Discussion and conclusion

In this chapter, key issues are discussed as well as the strengths and limitations of the study. Furthermore, we end the report with a conclusion and recommendations

### 13.1 Discussion of findings

This report presents the results of a qualitative study of children's and parents' experiences of primary health care for children. It demonstrates the complexity of children's and parents' experiences with primary health care for children. We identified a range of issues that are important for children and parents: accessing primary care services; physical environment; relationships with health care professionals; role of schools in providing health care; autonomy; continuity of care; financial issues and medical records. These dimensions of care are in line with results of other studies of adults' experiences of primary care (Baker et al., 2006; Cheraghi-Shoi et al., 2008; Coulter 2005; Davey et al, 2013; Gerard et al., 2008; Guthrie & Wyke, 2006; Mohammed et al., 2016; Rubin et al., 2006; Salisbury et al., 2009; Wensing et al., 2002) as well as studies focussing on children's and young people's experiences of primary care or other health services (Ahuja & Williams, 2010; Curtis et al., 2004; Schalkers et al., 2014).

The decision-making process parents described before approaching medical services was similar to that described by Hugenholtz et al. (2009). When parents notice abnormal behaviour or abnormal physical symptoms, they try to think of an explanation for these. They then apply their usual repertoire of care, observe and examine their child and give medicine if necessary. When parents feel they are losing control of the situation, they reach a turning point and start to think about getting professional help. Children also visit primary health care services for preventive health examinations and vaccinations.

Communication and relationships with health care professionals plays a pivotal role for children and parents in terms of what is good about it and what they felt needs to be improved. Communication and relationships were reported as a key quality component across various settings and conditions (Ahuja & Williams, 2010; Curtis et al., 2004; Jager et al., 2014; Schaeuble et al., 2010; Schalkers et al., 2014). In line with Freake et al. (2007) and Robinson et al. (2010), our participants think it is important that health care professionals explain things clearly, give information and advice; listen to them; are kind, caring, sympathetic and understanding; competent, experienced and qualified; do not patronize; and are non-judgemental. Better communication between patients and health care professionals is suggested to translate into better outcomes (Griffin et al., 2004).

Furthermore, participants stressed the importance of building a trusting relationship with their health care professional. In order to be able to build such a relationship, participants stressed that the importance of seeing the same professional every time, which is in line what Freake et al. (2007) described. Meeting with the same health care professional helps young people to have relaxed conversations, feel at ease and build a relationship. This is

related to continuity of care, which is another issue that was of importance to children and parents.

Many participants perceived a lack of continuity of care. This resulted in distress, especially for children as they met new people each time and had to repeat their story to different health care professionals as a result. A lack of coordination in primary care systems was perceived by several participants. This can have serious consequences for children; particularly for a child with complex long-term conditions. Our data showed that children with complex long-term condition do not often visit their primary health care professionals for problems related to their condition. They visit their specialists in secondary care. However, many parents underlined the importance of the primary health care professional being aware of their child's health condition. Poor communication among different health care professionals was often raised by participants. Ahuja & Williams (2010) found that this resulted in the child having to wait for a long time to get appropriate support and care. Parents felt frustrated, helpless and misled (Ahuja & Williams, 2010). Communication between health care professionals was mostly based on medical reports that parents had to bring to the GP themselves. Parents suggested that shared medical records would help. These could be helpful in sharing the medical history of a child. However, parents have some concerns about confidentiality.

Children and young people felt that they should be involved in managing their own care. They varied in how much parental involvement they desired and if they prefer to visit a primary health care professional alone or with their parents. Many of them prefer to have care providers who talk directly to them. For successful participation of children in the healthcare, it is important that children's contributions are taken into account and acted upon (Schalkers et al., 2014). However, decisions are often made in cooperation with parents. Parents noted that they often make a decision based on the information provided by the health care professionals bearing in mind what is the best for their child.

Responsibility for own health was often discussed in relation to vaccinations. Many children and parents think they are responsible for their own health and that they should decide whether to get a vaccination or not. Freedom of choice was stressed. In order to make the choice, parents and children felt they did not have enough information. Improving parental information about vaccinations schedules and about the pros and cons of vaccines was suggested by parents as well as in the literature (Mills et al., 2005).

The physical environment of the primary care facility was also important for participants. A bright and colourful setting contributes to a pleasant atmosphere, which is in agreement with previous research (Schalkers et al., 2014). Furthermore, age-appropriate activities and resources in waiting areas are valued positively which was in line with a study of Curtis et al. (2004).

Other themes that we identified in our study were access to primary health care services, the role of school, and financial issues. Our findings do not present a universally poor picture; many children and parents were satisfied with the primary health care services for

children. But nor do they present a universally good one. Whilst some of the needs of the children, young people and their families are complex and beyond the influence of an individual health professional, other concerns are clearly within a health care professional's ability to improve.

### **13.2 Strengths and limitations**

This study is the first of its kind to explore primary health care services in the Czech Republic, Germany, the Netherlands, Spain and the United Kingdom. Our findings suggest similarities and differences between these countries, and areas for improvement.. The qualitative study is intended to be exploratory rather than conclusive. Each dataset was analysed by the primary researcher and in Spain also by one of the research assistants (CRP). Primary researchers benefitted from familiarity with healthcare context, language and culture. All researchers were trained in the DIPEX methodology that was used in the study. The researchers were independent of primary health care services, which may help participants' willingness to give critical feedback (Freake et al., 2007). The country specific analyses were shared and discussed in monthly Skype meetings, several face-to-face workshops and meetings. Due to difficulties in recruiting participants ( particularly children with TBI and their parents) and different budgets in each local setting, researchers did not conduct a similar number of interviews/focus groups in each country. As a result, the size of some subsamples was relatively small. In total, the Czech Republic conducted 23 in-depth interviews and 2 focus groups; Germany conducted 2 in-depth interviews, 3 focus groups and did a secondary analysis of 23 in-depth interviews; the Netherlands conducted 25 in-depth interviews and analysed 11 interviews that were conducted in an earlier project; Spain conducted 19 in-depth interviews and 2 focus groups; and the UK conducted 11 in-depth interviews, 2 focus group interviews and did a secondary analysis of 6 in-depth interviews. Each country-specific study also varied in terms of how the data were collected. In some countries the data were collected by experienced senior researchers and in others by junior research assistants. We are not comparing like for like. However, we have very rich data across the three subgroups and data from children as well as parents. While some data were collected by experienced researchers and others by research assistants, each dataset was analysed by an experienced researcher. As with any qualitative work, the results are not necessarily generalizable to other groups of children and parents (Maxwell, 1996). Our sample represents individuals willing to share their experiences. Whether these individuals also represent the voices of those unable or unwilling to share their experiences remains to be determined. Furthermore, participants in the Czech Republic and Spain had predominantly a high level of education (i.e., university); participants in the Czech Republic and the Netherlands came predominantly from a specific region – this could have impacted our findings.

### **13.3 Conclusions and recommendations**

This report sits within the wider work of Work Package 1 and Work Package 2, which seeks to identify the current core models of primary care for children and first-contact services across Europe, and to outline safe and efficient interfaces of models of primary health care with secondary, social and complex care, respectively. This report is significant for being the

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first study of its kind to identify areas of concern to children, young people and their families in terms of primary health care services for children in five European countries. This report provides an overview of the experiences of "healthy" children, children with complex mental health conditions (ADHD), children with a complex physical health conditions (TBI, epilepsy, rare disease), and their parents with primary care services for children in the Czech Republic, Germany, the Netherlands, Spain and the United Kingdom.

Our findings show that the following issues are important to children, young people and their families: accessing primary care services; physical environment of the primary care facility; relationships with health care professionals; role of schools; autonomy; continuity of care; financial issues and medical records. Careful interpretation and analysis of patients' subjective experiences highlighted what is working well in primary care services for children, what needs to be changed, and how to go about making improvements.

This work is particularly important when thinking about a child's experience of primary health care because of their lack of autonomy and the lack of power they have to effect change or influence how care is delivered to them. It is vital to assess the patient's experience of the health care service, which in turn provides important evidence about the best way to run and provide services. Eliciting the views of children, young people and their parents is essential in the appraisal of health systems. This is essential for the MOCHA project: without the input of young people it is difficult to ensure the suitability of primary care systems to meet the needs of children and young people. We recommend that the MOCHA project take the issues raised by children and parents into consideration when discussing what is important to children and their parents in terms of primary care services and secondary care interfaces.

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## **Appendix 1: Topics to be explored in the interviews**

### **Access**

Access to health care refers to the ease with which an individual can obtain needed medical services. Financial, social, cultural barriers, travel time, waiting time, accessibility for disabled (e.g. elevator)

### **Thoughts and feelings before the consultation**

Waiting room, receptionist, atmosphere, opening hours, out of hours services, making appointments.

### **Communication**

Responding to emotions, what makes a good GP, trust, feelings about GP, information providing, shared decision making, understanding (patient has the feeling that the doctor understands him and the doctor has to speak in a way that it will be clear for the patient).

Children with complex needs: Experiences with GPs' reaction to complaints not related to their condition (e.g. headache)

### **Responsibility for your own health**

Shared decision making, child's adherence and compliance.

### **Privacy/confidentiality**

Preferences to visit the doctor by themselves or with parents, accessibility to medical records.

### **Coordination between GP/professionals/organizations of examinations**

Seeing the same doctor/different GPs every time, transition.

Children with complex needs: Mental health care/social care collaborating with primary care, transition from hospital or rehabilitations to primary care; role of the primary care in getting diagnosis

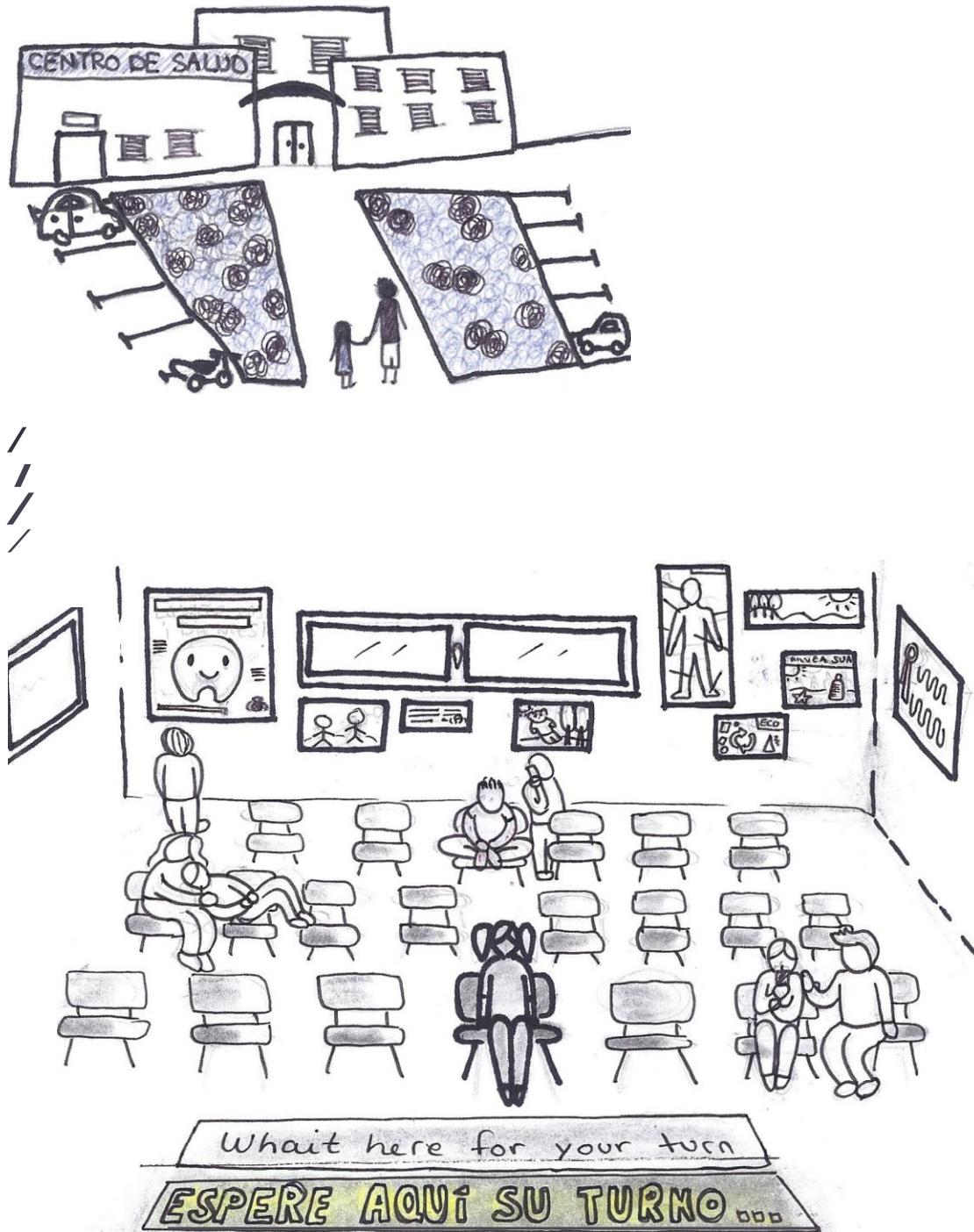
### **Improving primary health care services for children**

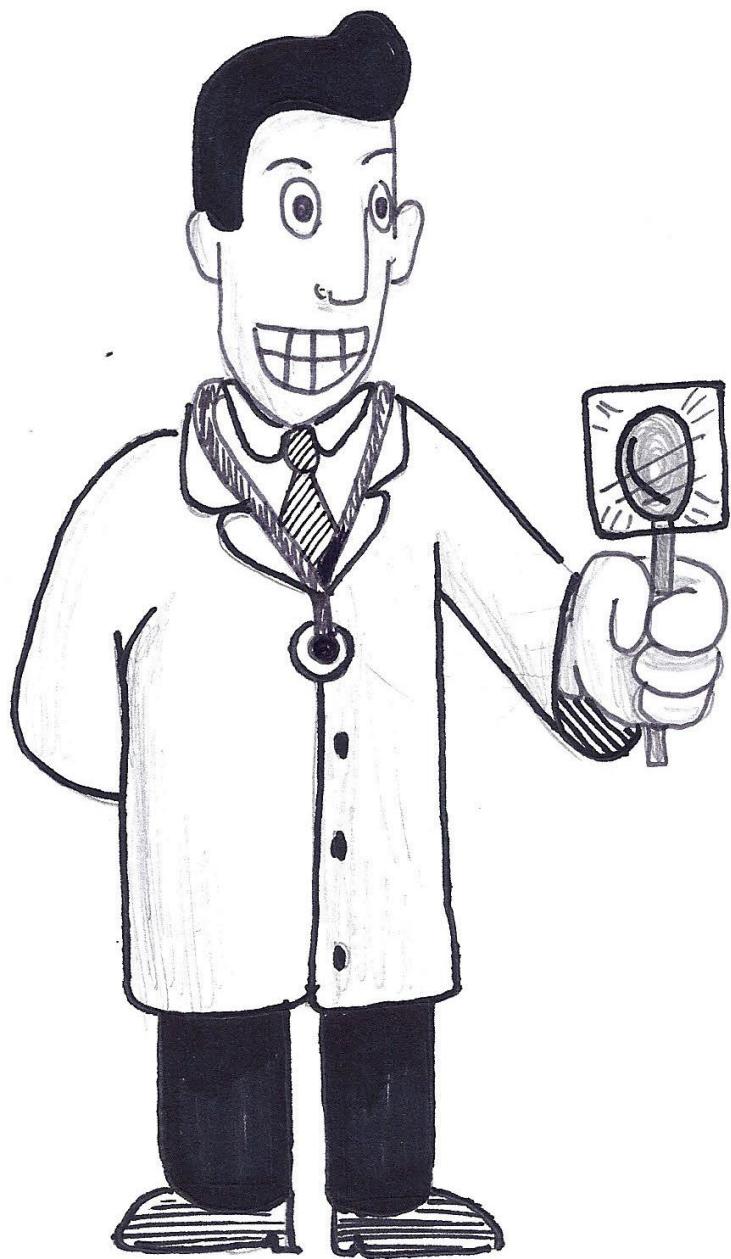
What makes better doctors, services, waiting rooms etc.

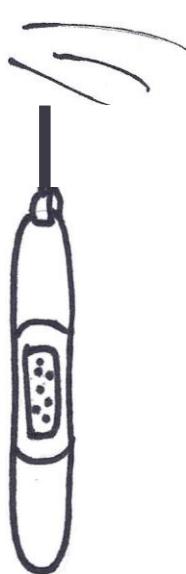
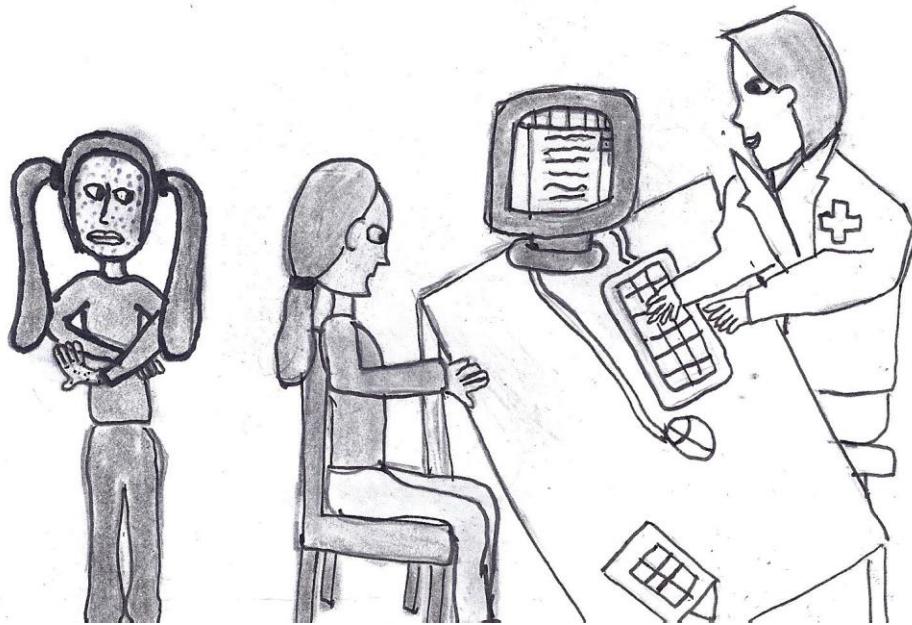
### **School psychologist / nurse / teacher**

Use the same topics as we did for GP for example.

## Appendix 2: Pictures used in the interviews



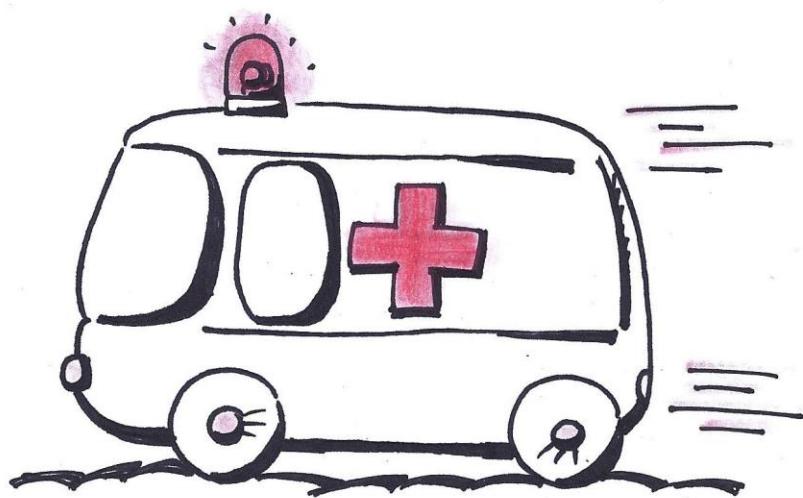
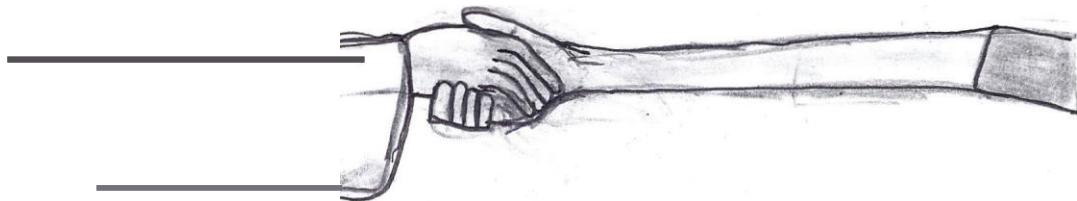




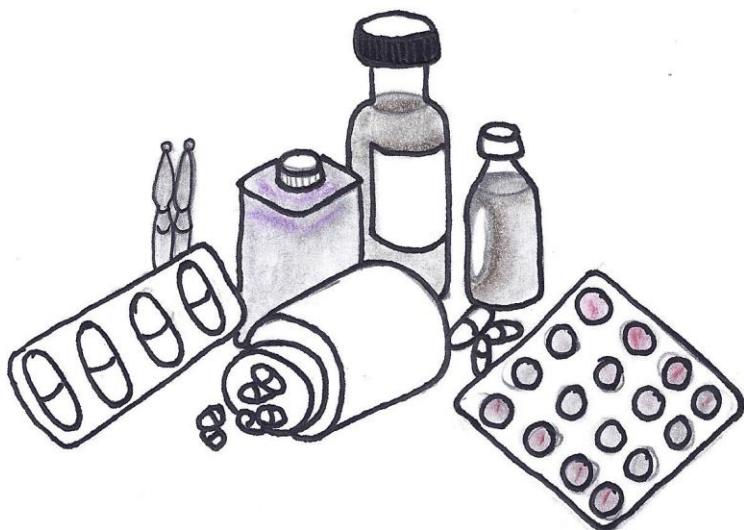
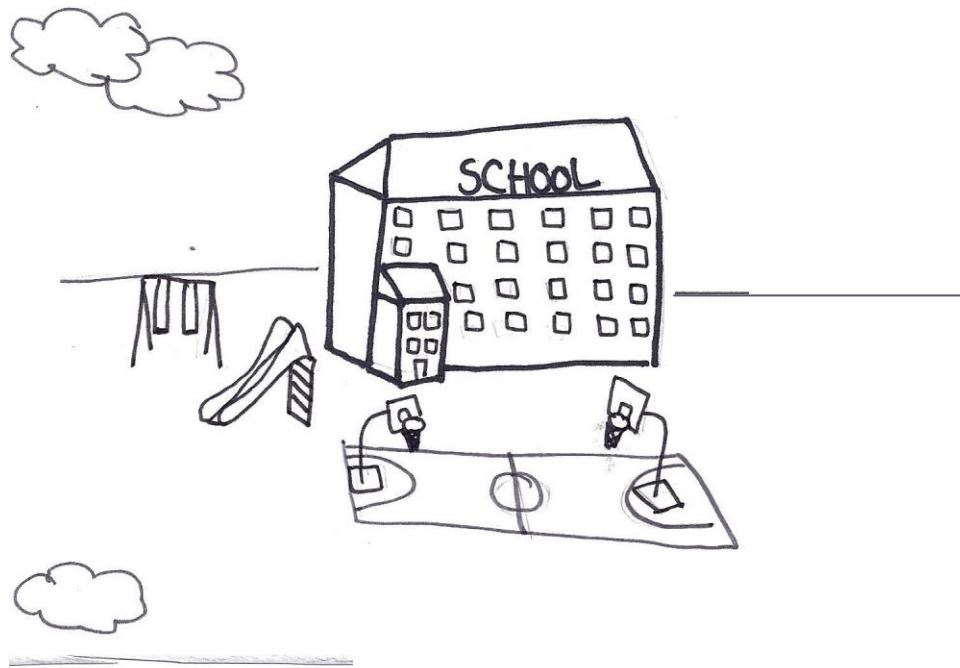
Patient experiences of primary care in 5 DIPEx countries



Patient experiences of primary care in 5 DIPEx countries



Patient experiences of primary care in 5 DIPEx countries

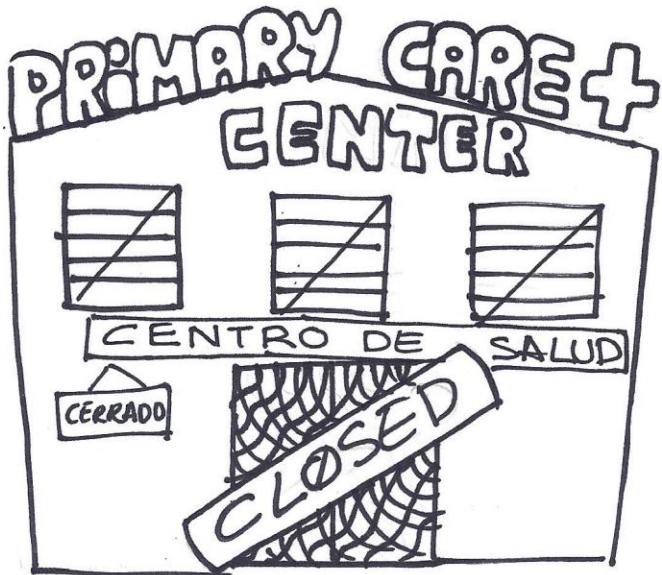


Patient experiences of primary care in 5 DIPEx countries



Patient experiences of primary care in 5 DIPEX countries





### **Appendix 3: Statements used in interviews with children**

Making an appointment with the doctor is very difficult.

I have to wait for a long time in the waiting room and I get bored.

I always visit the same doctor and nurse.

I am not afraid to ask the nurse or doctor a question.

I am always asked about what I think and feel listened to.

They ask my parents more questions and explain more to them than to me.

## **Appendix 4: Writing a letter used in interviews with children**

Dear chief executive, what I really like about the primary care center is.....

And I would immediately change/improve if I were the boss.....

These are my ideas to change/improve.....

I would just like to tell or ask for.....