Developmental Impairments in Children with Congenital Heart Defects:

A prospective case-cohort study

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ABSTRACT

With the advances in congenital cardiac surgery and medical management in recent decades, mortality rates for congenital heart defects (CHD) have declined remarkably. As the number of CHD survivors has increased, there is a growing focus on developmental impairments. Developmental impairments within a variety of developmental domains have been reported in school-age children with CHD. Less is known about the occurrence and persistence of developmental impairments in early childhood in children with CHD.

The aim of this dissertation was therefore to study developmental impairments during the first three years of life in children with CHD. For this purpose, data from the Norwegian Mother and Child Cohort Study (MoBa), conducted by the Norwegian Institute of Public Health, was linked with a nationwide medical CHD registry. Children with different severity of CHD were compared with children without CHD on developmental impairments in the motor, communication, and social domains. All information on child development was reported by mothers in MoBa questionnaires.

For the age span under study we found important differences between children with CHD and the controls. In early infancy two groups stood out as being particularly at risk for developmental impairments: Children with severe CHD showed higher odds for impairments in gross and fine motor skills. Children with CHD and comorbidity showed developmental impairments across gross motor, fine motor, and social domains. At age 18 months the same two groups differed from controls in levels of symptoms of communication impairments and social impairments. The largest differences from controls were found in children with CHD and comorbidity. At 3 years of age children with severe CHD had higher odds of both gross motor and communication impairments compared with controls. Children with mild and moderate CHD had higher odds of gross motor impairments but did not otherwise differ from controls. Predictors of impairments identified in children with severe CHD were: previous developmental impairments, smaller head circumference at birth, small for gestational age, and maternal distress.

These findings are important for our understanding of early development in children with CHD. They underline the importance of early attentiveness to developmental impairments and the importance of considering patient-specific conditions at birth for providing individualized, targeted therapeutic strategies that may improve developmental outcomes in children with CHD.

LIST OF PAPERS

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1. BACKGROUND

1.1. Congenital Heart Defects

1.1.1 Definition and prevalence

The human heart is an astonishing and fascinating organ. In the developing embryo the heart is the first organ to become fully functional. The heart starts to beat in the 22-day-old embryo and by day 24, blood is already circulating. It provides the circulatory system necessary for the embryogenesis and subsequent fetal development. There is a complex sequence of events that result in a well-formed heart at birth. This involves the forming of the four heart chambers and the great vessels. Disruption of any portion of the process may result in a congenital heart defect (CHD) (Moorman, Brown, & Anderson, 2009).

A commonly used definition of CHD is "a gross structural abnormality of the heart or intrathoracic great vessels that is actually or potentially of functional significance" (Mitchell, Korones, & Berendes, 1971, p. 324).

Congenital heart defects (CHD) are the most common congenital malformations. The prevalence of CHD in different studies varies from 4/1,000 to 50/1,000 live births (Hoffman & Kaplan, 2002). The variation in prevalence depends mainly on the number of trivial lesions included. In a review of 62 studies since 1955, Hoffman and Kaplan concluded that there is no evidence for differences in prevalence in different countries or time (Hoffman & Kaplan, 2002). Excluding trivial lesions, most studies reported between 5/1,000 and 10/1,000 live birth prevalence of CHD (Hoffman & Kaplan, 2002).

A number of differing classification systems exist for CHD. The most common classification is the division between cyanotic defects, where the child appears bluish due to abnormal mixing of blood, and other defects. The most common group of defects is called left-to-right shunts, which overload the lung circuit and may cause heart failure. However, Hoffman and Kaplan (2002) suggested that it is useful to grade CHD into groups according to severity (Hoffman & Kaplan, 2002).

This first severity group is *severe congenital heart disease*, which includes most of the patients who present severely ill in the newborn period or early infancy. They will need expert cardiologic care and surgical interventions. Defects such as transposition of the great arteries (TGA), tetralogy of Fallot, hypoplastic left heart syndrome (HLHS), and large ventricle septal defect (VSD) can be found in this group. The severity does not consistently

correspond to the complexity of the lesion. That is, simple defects may account for severe symptoms and require extensive treatment. This group accounts for 2.5 to 3 per every 1,000 live births.

The second group is *moderate congenital heart disease.* These patients need expert care to a lesser extent than those in the severe group. The number of surgical operations can often be minimized and sometimes replaced by interventional catheterization. Mild or moderate aortic stenosis, moderate pulmonary stenosis, or large atrial septal defects (ASD) are included in this group. The prevalence is estimated at 3 per 1,000 live births.

The last and largest group is *mild congenital heart disease*. The majority of these patients can be managed without specialized cardiologic care and many have defects that either close spontaneously or never cause medical problems. Small VSD, small ASD, small patent ductus arteriosus, and mild pulmonary stenosis are part of this group. The prevalence of this group depends on the number of small VSDs included (Hoffman & Kaplan, 2002).

1.1.2 Treatment of CHD: The history of declining mortality rates

Before pediatric cardiac surgery began in 1939 the majority of children with severe CHD died during infancy or early childhood. Robert Gross started the history of surgical treatment of CHD when he first closed a patent ductus arteriosus (PDA) in 1939 (Gross & Hubbard, 1984). The first procedures were performed outside the heart. Procedures inside the heart began with open-heart surgery with cardiopulmonary bypass in 1958 (Kirklin & Barrat-Boyes, 1993). However, operative mortality was initially high. Infants were in general not operated with a high degree of success until about 1970. From 1980 to 2000 surgical repair and palliation of most defects reached the high standards we know today (Hoffman, Kaplan, & Liberthson, 2004).

Parallel to technological development and general improvements in health care, diagnostic and treatment strategies have changed considerably over the last decades. Diagnostic methods in general have changed from invasive methods (cardiac catheterization) to non-invasive methods (e.g., echocardiography, magnetic resonance imaging). Therapeutic management has changed from palliative to reparative surgery offered to children with complex conditions at a younger age. Therapeutic catheter interventions have become an alternative to surgery for several conditions. These advances and the developing discipline of cardiologic intensive care have led to a remarkable decline in mortality rates for virtually all forms of congenital heart defects (CHD) (Billett, Majeed,

Gatzoulis, & Cowie, 2008). In a study by Eskedal and colleagues early mortality rates (the first 30 days after the initial operation) were shown to be substantially reduced in children with severe CHD (from 18.6% in 1990-1994 to 2.9% in 1995-1999) and in less severe CHD (from 6.2% to 1.9%) (Eskedal et al., 2005) in a Norwegian cohort. The improved outcome was maintained during the following 5 years. These findings are in line with reports from other countries (Gibbs, Monro, Cunningham, & Rickards, 2004; Stark et al., 2000).

1.2. Developmental morbidity in children with CHD

As the number of CHD survivors has increased, there has been a growing focus on developmental morbidity. There is a controversy regarding the prevalence and persistence of neurodevelopmental sequelae in children with CHD. There are few prospective follow-up studies and few studies looking at associations between predictors and later outcomes (Snookes et al., 2010). The available evidence in the literature suggests that developmental problems are common in children with severe types of CHD and less common in children with mild or moderate types of CHD. The occurrence varies between different studies depending on the type of lesion, complexity of surgery, age at examination and type of outcome (Wernovsky, 2006).

Previous studies on developmental outcomes in children with CHD mostly investigated disabilities in the domains of intelligence, motor skills, executive functions, and academic achievement. Most researchers concluded that IQ scores are within the normal range for the majority of children with CHD (Miatton, De Wolf, Francois, Thiery, & Vingerhoets, 2006). The morbidities found in children with CHD who require cardiac surgery as either neonates or infants are typically a higher incidence of academic difficulties, fine and gross motor delay, problems with visual-motor integration and executive planning, speech delays, inattention, and hyperactivity (Wernovsky, 2006). However, these findings were mostly reported in school-age children (Bellinger et al., 2003; Hövels-Gürich et al., 2002; Hövels-Gürich et al., 2006; Hövels-Gürich et al., 2008; Bellinger et al., 2003; Holm, Fredriksen, Fosdahl, Olstad, & Vollestad, 2007; Miatton, De Wolf, Francois, Thiery, & Vingerhoets, 2007). Less is known about the occurrence and persistence of developmental impairments in infancy and toddlerhood in children with CHD. Detecting developmental impairments early is challenging but creates the opportunity to provide benefits of early interventions. Early detection of impairments could also

contribute to our theoretical understanding of the mechanisms behind developmental impairments in children with CHD.

In the following I will define the concepts of motor, social, and communication development and review the literature available on these outcomes, focusing on infants and children up to school age with CHD.

1.2.1. Motor development

A motor skill can be defined as a "learned, goal-oriented, voluntary movement task or action of one or more of the body parts" (Gallahue & Ozmun, 2006). Prime learning and growth comes by and through movement. Every transition period (e.g., from crawling to standing without support to walking) reflects new ways for infants and toddlers to interact with their environments and to gather information and interrelate with others (Kopp, 2010). Therefore, motor development is a crucial component of understanding child development. It is common to divide the muscular aspects of movement into gross and fine motor skills. For gross motor skills the large muscles are at use to perform a task, and for fine motor skills several small muscles are at use to perform a task with precision (Gallahue & Ozmun, 2006). For example, reaching for an object involves 14 muscles. In early infancy gross motor development involves, for example, holding up the head from around age 3 months, rolling over around age 2 months, sitting up around age 6-7 months. By the age of 11 months most children can stand alone and are able to walk with support. After this most children start to walk alone. Around the age of 18 months children start to run. They learn to kick and catch a ball, jump, etc. As infants and toddlers grow, they learn to perform these tasks with greater skill (Gallahue & Ozmun, 2006). The definition of motor impairment or "delay" is often based on the notion of what 90% of children in a normative sample are able to do.

According to the available literature, motor difficulties are often found to be among the most prevalent morbidities in children with CHD (Miatton et al., 2006; Snookes et al., 2010). There are several important follow-up studies on motor development in early infancy and preschool age. Hovels-Gürich and colleagues from Aachen University of Technology published a series of follow-up studies in children who underwent cardiac surgery in infancy. They found fine motor dysfunction in 22.1% and gross motor dysfunction in 23.4% in a sample of 77 children age 3-9 years (mean age 5.4) after the neonatal arterial switch operation (Hövels-Gürich, Seghaye, Dabritz, Messmer, & von Bernuth, 1997). Another

influential study is the Boston Circulatory Arrest Study by Bellinger and colleagues (Bellinger et al., 1999). Gross and fine motor delay was reported to be prevalent in toddlers (from age 1 year) (Bellinger, Rappaport, Wypij, Wernovsky, & Newburger, 1997). A group of 158 children with D-transposition of the great arteries was reported to have mean gross and fine motor scores corresponding to the 9th and 4th percentiles for age respectively at follow up at age 4 (Bellinger et al., 1999). Another study, which is part of a series of published reports from Montreal Children's Hospital, reported fine and/or gross motor deficits in 42% of 131 children at 12 to 18 months after surgery in children who underwent cardiac surgery requiring cardiopulmonary bypass before the age of 2 (Limperopoulos et al., 2002). In the follow-up 5 years after initial surgery (N= 94), mean gross and fine motor quotients were still shifted downward, and gross and fine motor delays (defined as 1.5 standard deviations below the normative mean) were prevalent in 49.4% and 39% respectively (Majnemer et al., 2006).

Several studies on motor development in children with CHD used the Psychomotor Developmental Index (PDI) from Bayley Scales of Infant Development (BSID). A prospective cohort study of 29 infants who underwent Norwood operations for palliation of hypoplastic left heart syndrome (HLHS) reported motor scores in the mildly delayed range (75.2 ± 14.5) on the BSID at age 1 year (Visconti et al., 2006). Evaluated on the same scale, a group of 244 infants who underwent surgery before 6 months was rated within the same range (77.0 ± 18.0) at 1 year follow-up (Gaynor et al., 2006). The same results were reported in another sample of 50 infants with HLHS (77.1± 21.0) (Goldberg et al., 2007). In another prospective study of 35 children operated for CHD follow-up scores at 1 year on the same scale were higher than reported in the other studies but still shifted downwards compared to norms (89 ± 20) (Robertson et al., 2004). In a follow-up study, children who underwent surgery before 6 weeks of age were assessed at 18-24 months using the BSID. At age 18-24 months (n= 41) the scores were in the lower normative range on the PDI (89 ± 13) (Alton et al., 2007). Finally, a sample of 17 children with TGA was evaluated at age 3 years using the BSID, and the reported motor scores were within the normal range (101.1 ± 17.5) (Toet et al., 2005).

To conclude, most studies on motor development in preschool-age children reported motor impairments in 22-50% (depending on the applied cutoff, type of motor impairment, and measure used). The studies using BSID reported means in the mildly delayed range.

1.2.2. Communication development

Communication is a broad construct that includes any act, intentional or unintentional, that influences another person (Prizant, Wetherby, & Roberts, 2000). Communication is therefore closely related to social-cognitive, socioemotional, and motor development. The transformation in newborns who communicate through vocalization and body language into 3-year-olds who communicate through multiword utterances is complex and amazing. An important component of communication skills or competence is the ability to use linguistic skills to communicate (Hoff, 2006). It relates both to the understanding that language can be used in order to communicate and the skill at producing connected discourse in conversation and storytelling. The are several subcomponents of language: *phonology* comprises the sounds and sound system of language, the *lexicon* consists of words and their associated knowledge, *morphology* is the system of combining units of meaning into words, and *syntax* is the system of combining words into sentences (Hoff, 2006). The development of these components starts from early infancy and goes through several predictable milestones. For example, in a typical child at 6 months babbling appears, between 15-18 months a 200-word vocabulary is reached, between 18-24 months words are combined, and around 36 months narrative skills develop (Hoff, 2006). However, language acquisition involves wide individual variation. For some children, language acquisition does not proceed in a straightforward fashion. In fact, disorders of language rank among the most prevalent developmental disabilities in children (Heim & Benasich 2006). Symptoms of language impairment can appear early on and include limited amount of speech, limited range of vocabulary, use of short sentences (expressive impairments), unintelligible speech (phonological impairments), and/or difficulties understanding words or sentences (receptive impairments) (American Psychiatric Association, 2000).

Some studies have been conducted on communication development in preschool-age children with CHD. The Boston Circulatory Arrest Study reported a delay of two to four months in communicative development in children age 16-30 months with TGA (Bellinger et al., 1997). The same research group documented communication skills below expectations in a large prospective study of children with severe types of CHD at 4 years of age (Bellinger et al., 1999; Bellinger et al., 2003). As part of the study, a subsample of 76 4-year-old children was assessed and compared to a control group on narrative discourse attainment (Hemphill, Uccello, Winner, Chang, & Bellinger, 2002). Interestingly, the results

suggested that the elaboration of events and contextual information, the expression of subjective evaluation and causality, and clarity and explicitness of information reporting may constitute special challenges for this population. Although the children with CHD displayed the same components in their narratives as typically developing children do, their performance differed in frequency, diversity, and adequacy, suggesting that there is a delay in narrative skills in children with CHD (Hemphill et al., 2002).

However, between the age of 3-4.6 years Hövels-Gürich and colleagues reported language scores to be within the normal range in all of 31 children with TGA, but the language scores were significantly reduced compared to controls (Hövels-Gürich et al., 2001). A group of 51 children with HLHS or functional single ventricle lesions tested between the ages of 34 and 96 months were reported to score within the normal range on communication on both the Wechsler Intelligence Test and Vineland Test (Goldberg et al., 2000).

In conclusion, the few previous studies on early communication impairments are contradictory. It remains unclear whether preschool children with CHD are at higher risk of communication impairments.

1.2.3. Social development

There are a wide variety of definitions of social skills or competence. Despite the lack of one single definition of social competence, there are essential features that are generally agreed on as characterizing competent social development in early childhood. Primarily, these include the abilities to interact with others effectively and to develop positive relationships (Fabes, Gaertner, & Popp, 2006). From the first days of life, infants demonstrate awareness of their environment and evidence of learning (Stern, 1985). Social interactions start already during infancy and primarily involve contact with parents, siblings, or adult caregivers. Infants begin social smiling around 2-3 months (Crockenberg & Leerkes, 2000). “The discovery of intersubjectivity” first described by Stern (Stern, 1985) appears between 7 and 9 months and involves behaviors that indicate that infants now understand that thoughts and desires are shareable with others. During toddlerhood and early childhood the children’s social world expands to include peer interactions. Over the course of early childhood, children should become increasingly able to initiate and maintain social relationships, become skilled at coordinating and communicating their actions and feelings with those of others, and evidence more complex levels of play (e.g., pretend play)

(Fabes et al., 2006). This means that the children are able to show positive behaviors towards others, such as helping and sharing. Childhood social experiences and peer relations are associated with a range of short and long-term outcomes, such as social and behavioral problems, school adaptation, and psychopathology (Buhs & Ladd, 2001; Coie, Terry, Lenox, Lochman, & Hyman, 1995). Thus, how children cope with and adapt to the increasing demands for socially competent behavior may be critical to subsequent adjustment and development.

The few studies available on social skills and impairment in children with CHD show conflicting results. In preschool children with CHD the findings range from poor social skills (Limperopoulos et al., 2001) to average and even above average social skills.(Goldberg et al., 2000; Hulser, Dubowy, Knobl, Meyer, & Scholmerich, 2007) For example, Limperopoulos and colleagues (Limperopoulos et al., 2001) found poor social skills at age 1-3 years in 53% of children with severe CHD. On the other hand, Goldberg and colleagues reported adequate socialization skills in preschool children with severe CHD (Goldberg et al., 2000). Hovels-Gürich and colleagues reported social functioning in a group of children with severe CHD at age 3-4 years to be the same as population norms (Hövels-Gürich et al., 2001). It thus remains unclear whether social development is affected in children with CHD.

1.3. Mechanisms

In spite of the somewhat tenuous results with respect to the prevalence and persistence of early developmental impairments in children with CHD, there seems to be general agreement that these children represent an “at risk” group for developmental morbidity. However, it remains unclear why children with CHD are at risk and how their medical condition is affecting their development. In earlier years, researchers attributed neurodevelopmental sequelae in children with CHD to surgical procedures. However, it soon became clear that the etiology had to be multifactorial. The nature of CHD is too diverse and complex to relate developmental impairments to isolated parameters. When they are reviewed, the medical and surgical factors relating to developmental outcomes are often divided into: *preoperative, intraoperative and postoperative contributors* (Massaro, El-Dib, Glass, & Aly, 2008; Wernovsky, 2006; Miatton et al., 2006). Some researchers view the factors as either fixed (patient specific) or modifiable (Ballweg, Wernovsky, & Gaynor, 2007). Psychological models such as “the vulnerable child syndrome” have also been

applied to understand developmental impairments in children with CHD. In the following, I will try to give an overview of possible mechanisms linking CHD to developmental impairments.

1.3.1. Preoperative factors

Brain abnormalities: In early gestation the central nervous system and the cardiovascular systems form nearly simultaneously. Therefore, it is not surprising that structural brain abnormalities co-exist in children with structural abnormalities of the heart (Shillingford & Wernovsky, 2009). Observations of *reduced brain volumes*, *white matter injury*, and *incomplete closure of cerebral operculae* in fetuses with severe CHD suggest delayed in utero structural brain development (Limperopoulos et al., 2010).

The operculum comprises an area of the brain that is thought to be related to motor and language. Abnormalities in this area have been linked to motor and communication impairment (Chen et al., 1995). Thus, abnormalities in brain functions might contribute to a higher risk of developmental impairments in children with CHD. Head circumference at birth is a marker for brain development. Importantly, preoperative microcephaly has been shown to be associated with poor neurodevelopmental outcomes at 1 year after surgery in children with CHD (Limperopoulos et al., 2002). Injury to the white matter (periventricular leucomalacia) (often seen in premature infants) has increasingly been recognized in full term infants with CHD (Mahle et al., 2002). It has been suggested that decreased flow to the brain pre-operatively is associated with lesions in the white matter (Licht et al., 2004). For example, preoperative MRI examinations have revealed periventricular leucomalacia in 16% of patients, but the study found new lesions or worsening of preoperative lesions in 67% after operation (Mahle et al., 2002). In premature children periventricular leucomalacia was found to be associated with developmental impairments (Chen, Huang, Chung, Huang, & Yang, 2004; Monset-Couchard, de Bethmann, & Kastler, 2002). It is therefore plausible that congenital cerebral abnormalities represent important factors contributing to the etiology of developmental impairments in children with CHD.

Genetics: It is known that 5-8% of congenital heart defects result from chromosome abnormalities, most commonly Down Syndrome and 22q11.2 deletion (e.g., DiGeorge or velo-cardio-facial syndrome) (Miatton et al., 2006). Not all studies on developmental impairments excluded or reported whether their sample included children with genetic syndromes, and not all syndromes are detected at an early age. Genetic syndromes might

therefore be an important contributor to developmental impairments found in children with CHD.

Specific genotypes have also been suggested to be important factors in explaining development in children with CHD. For example, Apolipoprotein E is known to be of importance to the regulation of cholesterol metabolism, and is thought to affect neurological recovery following a variety of injuries to the central nervous system (Shillingford & Wernovsky, 2009). When determining the APOE genotype of children with CHD aged 6 months or less, results of a study showed a significant effect of the APOE e2 allele to predict lower psychomotor development at 1 year of age after cardiac surgery (Gaynor et al., 2003). Thus it is possible that genetic polymorphism may explain some of the variation in developmental outcomes in children with CHD.

Other preoperative factors: When reviewing the studies on neurodevelopmental outcomes in children with CHD it has been noted that birth weight or gestational age are only sporadically mentioned. Because these factors are associated with cognitive deficits, it was suggested that they should be used as exclusion criteria or studied as possible confounding factors (Miatton et al., 2006). In some studies *lower birth weight* and *younger gestational age* were shown to predict poorer neurodevelopmental outcomes along with several other patient-specific factors such as *gender, ethnicity*, and *Apgar score* in children with CHD (Gaynor et al., 2007). Parental factors such as *socioeconomic status* (SES) were also shown to be important in predicting IQ scores in children with CHD (Forbess et al., 2002).

S*everity of the heart defect* has been suggested to be an important preoperative factor to consider (Miatton et al., 2006). Given the great variability in severity of CHD, it is not reasonable to expect mild CHD to have as severe developmental consequences as severe CHD has. This factor is obviously interrelated with other risk factors. Most studies on development were conducted with children with one single type of heart defect, resulting in small sample sizes and results that are difficult to generalize to other heart defects (Visconti et al., 2006).

Finally, *pre-operative treatment factors* are important in understanding how development could be affected by the cardiac defect. The unstable cardiac status of the newborn with CHD often makes it necessary with urgent treatment. However, certain heart defects are repaired later in life. Some children are hospitalized and receive, for instance, intravenous infusions of medication (e.g., prostaglandin), and some require intubation. Others receive invasive interventions, such as balloon septostomy. All of these pre-operative

interventions carry risk to the central nervous system, potentially causing developmental impairments (Shillingford & Wernovsky, 2009).

1.3.2. Intraoperative factors

Variation in intraoperative support, such as the conduct of cardiopulmonary bypass, is viewed as one of the few modifiable medical risk factors and has therefore been the subject of extensive research (Shillingford & Wernovsky, 2009). However, many of these different support techniques have not been shown to have effect on developmental outcomes. For example, *alpha-stat* or *PH-stat* management was not consistently related to either improved or impaired neurodevelopmental outcomes at 1 to 4 years of age (Bellinger et al., 2001). On the other hand, very *prolonged periods of uninterrupted circulatory arrest* may have adverse neurological outcomes. A threshold length of 40 minutes or more for deep hypothermic circulatory arrest duration was demonstrated for language and IQ outcomes (Wypij et al., 2003). Several studies concluded that low-flow cardiopulmonary bypass is a superior strategy compared to circulatory arrest, because the latter does not impair cerebral perfusion (Scallan, 2004). However, findings are inconsistent, and it has been suggested that the effects of circulatory arrest are most likely modified by other preoperative and postoperative factors related to the patient (Shillingford & Wernovsky, 2009; Gaynor et al., 2007). The use of *hemodilution* (an increase in the volume of plasma, resulting in a reduced concentration of red blood cells in blood) during cardiopulmonary bypass is another potential risk factor that might cause brain injury and increase the risk of adverse neurological outcomes. It has been demonstrated that lower hematocrit levels are associated with deficits in motor functions (Jonas et al., 2003). The list of intraoperative factors potentially affecting the developmental outcome in children with CHD is long. Ongoing research is continuing to look into the optimum levels of different support techniques during operations in order to potentially reduce the risk for children operated for CHD.

1.3.3. Postoperative factors

The first days following cardiac surgery is a particularly vulnerable time for infants, especially following cardiopulmonary bypass. *Low cardiac output* (the blood being pumped by the heart) is known to occur in 10-25% of neonates and infants following cardiac surgery (Hoffman et al., 2003). This poses a risk, as the central nervous system and the brain may be

especially vulnerable at this time to insults of decreased delivery of oxygen (Shillingford & Wernovsky, 2009).

Longer stay in the hospital and the intensive care unit after operation has also been associated with worse developmental outcomes (Newburger et al., 2003; Gaynor et al., 2006). Longer stay is associated with reintubation, hypertension (high blood pressure), arrhythmia (abnormal electrical activity in the heart), sepsis (blood infection), and several other potential risk factors to the nervous system.

1.3.4. Psychological factors

Developmental impairments in children with CHD cannot be understood without considering the neurological mechanisms described above. However, psychological models should also be used to complement the picture in understanding child development in children with CHD. Important psychological models suggest that child development should be understood as a complex and dynamic process involving how the child and caregivers interact (e.g., the transactional model (Sameroff & Chandler, 1975). There are several reasons why the interaction between a child with CHD and its caregiver might be affected.

Hospitalization and surgery limit many of the normal stimuli known to be important for optimal growth and development, such as normal touch and stimulation from parents, feeding, and nurturance (Mussato, 2009). Hospitalization affects the routines that help organize young children's day-to-day life (beds are used for both sleeping and playing; lights may be on all night, etc). It may also interrupt infants' developing attachments with their caregivers, which are important for interaction and subsequent development (Minde, 2000).

The *vulnerable child syndrome* originally described by Green and Solnit (1964) is defined as a reaction characterized by disturbance in psychosocial development, often occurring in children whose parents expect them to die prematurely. It has been described in several populations of children with chronic illness. It is a normal response to overprotect and lower expectancies regarding the performance of children with complex conditions. Yet, when overdone, this could have a negative influence on the children's development and eventually on their quality of life. According to the theory of the vulnerable child syndrome, parents may respond to the diagnosis of cardiac disease in a newborn by distancing themselves from the infant, or demonstrating diminished attachment to the baby as a way of protecting themselves from the pain and loss they fear. This has important implications for

bonding and later parent-infant interactions. In support of this, infants with congenital heart disease and their mothers were shown to demonstrate less positive affect and engagement during interaction than a non-cardiac group when assessed both prior to and 6 months after corrective surgery (Gardner, Freeman, Black, & Angelini, 1996). Moreover, the temperament of infants with cardiac disease was described by mothers as more withdrawn, more intense, and as having lower thresholds to stimulation than healthy infants (Marino & Lipshitz, 1991). These characteristics may impact parental involvement with the child and could have a negative influence on development.

Short summary:
Taken together, both empirical research and a variety of biological, medical, and psychological mechanisms suggest that children with CHD are at risk of developmental impairments. Yet, several important domains can be identified where research is still scarce. In particular, the earliest developmental phases of social and communication skills have remained understudied, and the few existing studies are contradictory. Moreover, the influence of the severity of CHD, birth-related confounders, co-morbidity, and psychological factors has not systematically been examined. Finally, the impact of early signs of developmental impairments on later impairments is not well documented.

2. OBJECTIVES

2.1 Paper I

The objective of paper I was to assess whether the motor and social development of children with varying severity of CHD differs from that of children without CHD at age 6 months.

2.2 Paper II

The objective of paper II was to compare symptoms of communication and social impairments in 18 months old children with different severity of CHD with those of controls.

2.3 Paper III

The objectives of paper III was to examine the occurrence of motor, social and communication impairments in 3-year-old children with varying severity of congenital heart defects (CHD) and to identify predictors associated with developmental impairments in children with severe CHD.

3. METHODS

3.1. Design

The study design had a prospective case-cohort design, linking a nationwide CHD registry administrated at the Department of Pediatrics, Pediatric Cardiology Unit, at Oslo University Hospital, Norway to the Norwegian Mother and Child Cohort Study (MoBa) and the Medical Birth Registry of Norway (MBRN). The MoBa study follows more than 90,000 mothers and their babies from pregnancy to early childhood. Infants with CHD in the MoBa cohort were identified by matching the personal identification number in the two databases.

Case identification: To identify the patients with CHD in the MoBa study, an anonymous data file from Oslo University Hospital containing only the list of personal identification numbers of children born between 1999 and 2008 was sent to the MBRN. The MBRN performed a case-match between the list from the CHD registry and the list of participants in the MoBa and identified the cases that were present in both registries. The complete list of matched numbers was sent back to Oslo University Hospital, where senior cardiologists (Dr. H. Holmstrøm and Dr. L. Eskedal) and PhD candidates (R. Brandlistuen and K. Stene-Larsen) extracted CHD data, systemized the information from the patients' records, and coded the cardiac diagnoses for the matched cases (see further description under *classification of the CHD,* section 3.3.1 below). Medical information was manually updated and co-morbidity carefully registered for every case based on medical records. Operative variables were revised in collaboration with cardiac surgeon Dr. H. Lindberg. The final data file was sent back to the MBRN, where the extracted CHD file was merged to the MoBa data. An anonymous data file containing both MoBa data and CHD data was then sent to our research team. All stages in the process described above were approved by the Norwegian Ethics Committee and by the Norwegian data inspectorate.

The MoBa study is conducted by the Norwegian Institute of Public Health and follows mothers and their child from early pregnancy into childhood (Magnus et al., 2006). With the target population of all women who give birth in Norway, this national cohort study presents a broad basis for studying health development. Recruitment started in 1999 and ended in 2008. The participation rate at first assessment was 42.7% (Magnus et al., 2006). Response rates among mothers who consented to join the study were 95% during pregnancy, whereas after birth they were 87% at 6 months, 77% at 18 months, and 62% at 3 years (Magnus et al., 2006) (Magnus P, 2007). Informed consent was obtained from each participant before the study.

The MBRN has collected information since 1967 on all births with a gestational age of at least 16 weeks (Irgens, 2000). It is owned by the State Health Inspectorate. The registry includes information on the pregnancy and delivery based on the antenatal forms and data recorded at the maternity departments (Irgens, 2000).

The CHD registry includes information on all live born children with significant CHD in Norway. The CHD register was started in 1990 (Eskedal, 2008) and was designed to serve essential functions in the department of pediatric cardiology, with detailed data from every examination, procedure, and contact with patients entered into the database on a daily basis. Relevant data on extra-cardiac anomalies and non-cardiac diseases are also registered. The quality of the data is ensured by continuous daily use of the registry and the limited number of cardiologists with authorization to enter data. The exception to this rule is that a few specially assigned nurses have entered all procedure-related codes extracted from the hospital records in order to complement the register.

3.2. Participants

Paper I

The MoBa study releases an updated version of the data files once in every calendar year. Paper I was based on version 3 of the quality assured data files of MoBa released in 2008. A first match identified 304 infants with CHD as being members in both data sources. By the age of 6 months, 18 children had died, and 19 children were no longer participating in the study. After exclusion of 31 children with syndromes or chromosomal defects (e.g., Down syndrome, deletion of chromosomal region 22q11), our case group totaled 236 children with CHD.

Paper II

Paper II was based on version 4 (2009) of the quality assured data files of MoBa. A case-match at 18 months identified 213 infants with CHD who were present in both data sources. 54 children had been lost between 6 and 18 months due to attrition (n=53) and death (n=1). After excluding 15 children with syndromes or chromosomal defects (e.g., Down syndrome, deletion of chromosomal region 22q11), our case group totaled 198 children.

Paper III

Paper III was based on version 5 (2010) of the quality assured data files of MoBa. A case-match at child age 3 years identified 293 children with CHD who were present in both data sources and had a mild, moderate, or severe CHD, representing 0.66% of the MoBa cohort. Of these, 77 children were lost due to attrition, among which 28% had severe heart defects. A z-test of two proportions showed that the severity of the heart defects did not differ between children lost to attrition and children continuing to participate ($Z = 0.836$, $P = 0.20$). Exclusion criteria were: syndromes or chromosomal defects (e.g., Down syndrome, deletion of chromosomal region 22q11) and significant comorbid medical conditions (e.g., extracardiac malformations, cancer, severe asthma) ($N = 41$). The final case group consisted of 175 children.

3.3. Measures

3.3.1. Classification of the CHD

Before the classification of CHD could begin, extensive work had to be performed in order to systemize and quality ensure the data from the cardiac registry, including information from the medical records on syndromes and co-morbid medical diagnoses. For many of the patients, follow-up information on syndromes, etc. was available up to about 5 years after birth, ensuring information that exceeds the actual timing of developmental follow-up in MoBa. This information was used to reduce the likelihood that neurological syndromes detected during the preschool years would be included in the CHD groups.

Two senior pediatric cardiologists (Dr. H. Holmstrøm & Dr. L. Eskedal), blind to the developmental outcomes measured in the MoBa study, classified the cardiac defects according to severity and treatment-related aspects. The classification was based on

previously accepted methods (Hoffman & Kaplan, 2002). Treatment related aspects were included as an important factor in the severity grading for the following defects: Pulmonary stenosis is not perceived as a severe CHD if it is treated with balloon-dilatation successfully and without complications. Surgically treated pulmonary stenosis is perceived as a severe CHD. VSD without other additional heart defects, which are successfully and without complications operated or closed with catheter once, are classified as moderate severity.

In addition, the CHD registry contains healthy children with heart murmurs that needed to be separated from children with mild CHD. The healthy children in the registry were defined as: (1) all children with one normal heart examination, (2) children with serial examinations as part of investigation or follow-up of a significant additional problem, such as other malformations or cancer, (3) newborns that are examined once or several times as part of the neonatal readjustments, but not after 1 months age, (4) premature, including those with a large PDA that does not need follow up after the neonatal period (1 month). It was desirable to separate completely healthy children from those having a trivial or spontaneously resolving heart condition that needs follow-up for some time. A medical follow-up may have an impact on the parents' perception of the child's health. Consequently, the need for follow-up after the neonatal period and/or three or more controls excludes the child from the healthy group, and these children were considered to have a mild CHD.

The two cardiologists classified and agreed on the classification of all of the cardiac defects among all of the patients. The cardiac defects were classified as follows (for examples of CHD diagnoses, see Tables 1 and 2):

1. "Mild CHD": This group includes children who are generally asymptomatic and have no need for treatment.
2. "Moderate CHD": Children in this group may be symptomatic and require treatment and follow-up through childhood.
3. "Severe CHD" includes all complex and/or serious heart defects. Children in this group are generally symptomatic and sometimes critically ill. Early expert care is warranted. The children are in need of treatment by surgery and/or catheter, often repeatedly.
4. "CHD with comorbidity": This group consists of children diagnosed with one or more medical diseases in addition to CHD. These are children with

comorbidities such as diaphragmatic hernia, cleft palate, and intestinal malformations.

In papers II and III mild and moderate CHD were collapsed into one group. In paper III CHD with comorbidity was excluded, because it consisted of fewer than 20 cases.

Table 1. Types of congenital heart defects in the mild and moderate CHD group (based on the sample of paper III)

Type of congenital heart defect	Number of cases
Patent ductus arteriosus	21
Small atrial septal defect/Patent foramen ovale	17
Small ventricular septal defect	33
Other mild CHD	15
Atrial septal defect	6
Coarctation of the aorta	5
Valvular pulmonary stenosis	5
Ventricular septum defect	13
Total	115

Table 2. Types of congenital heart defects in the severe CHD group (based on the sample of paper III)

Type of congenital heart defect	Number of cases
Hypoplastic left heart syndrome	3
Other univentricular heart	4
Double outlet right ventricle	2
Pulmonary atresia with intact ventricular septum	2
Fallot (incl Pulmonary atresia with ventricular septal defect)	7
Common arterial trunc	2
Transposition of the great arteries	16
Atrioventricular septal defect	2
Pulmonary stenosis	5
Aortic stenosis	6
Coarctation of the aorta with interruption of the aortic arch	7
Total anomalous pulmonary venous drainage	1
Large ventricular septal defect	3
Total	60

As a complement to this severity grading, we present the mean Aristotle score for the children that were operated on for their heart defect. The Aristotle score is an internationally accepted complexity score that ranges from 1.5 to 14, where a higher score indicates a higher degree of complexity with respect to the heart defect and with respect to the surgical procedure (Lacour-Gayet et al., 2004). The children with severe CHD in this study were characterized as more severe compared with the average Aristotle score in treatment centers comparable in size to the Oslo University Hospital (Lacour-Gayet et al., 2004). The average Aristotle score in other patient samples is 6.7, and the mean Aristotle score in our sample of CHD at 18 and 36 months age was 9.

3.3.2. Motor, social, and communication development

Box 1 shows an overview of the measures of developmental outcomes at time point 6, 18 and 36 months.

Motor development. The items for the rating of fine and gross motor skills were derived from the Ages and Stages Questionnaire (ASQ) (Squires, Bricker, & Potter, 1997) at both 6 months and 3 years of age. ASQ is a parent-completed tool widely used in the United States by programs focusing on early detection and family support programs. The ASQ consists of a series of questionnaires spanning the developmental period of four months to five years of age. Each questionnaire contains a set of 30 questions representing five domains: Communication, Gross Motor, Fine Motor, Problem Solving and Personal-Social. The format of the ASQ is designed to enhance parental accuracy in rating their child's competence. Results comparing parental completion of the ASQ with professional assessments have generally indicated high agreement, with inter-observer reliability of 94% (Squires et al., 1997). Test-retest reliability, measured as percentage of agreement between classifications based on the questionnaires completed twice by 175 parents at 2-weeks intervals, was 94% (Squires et al., 1997). The general validity of ASQ has been reported to be good, with average 88% agreement between the questionnaires and standardized assessment. Specificity was high (average 86%), whereas sensitivity was lower (average 75%) (Squires et al., 1997). The ASQ was validated in a Norwegian sample (Richter & Janson, 2007) and found to be an effective diagnostic tool for detecting developmental delay and/or disturbances. The Ages and Stages scale is usually dichotomized by splitting the scale at 2 standard deviations to separate children at risk of developmental delay from

normally developing children (Squires et al., 1997). The cutoff point was set to 2 standard deviations after running ROC analyses ("relative" or receiver operating characteristic) to identify the cutoff point that limits underscreening and overscreening (Squires et al., 1997).

At age 6 months each of the two motor domains was represented by 3 items, and at age 3 years each of the two motor domains was represented by 2 items selected for the MoBa study. The selection aimed at representing the subscales with items that were most relevant for motor development at 6 months and 3 years of age. The selection was performed by specialists in clinical and developmental psychology on a consensus basis. At age 6 months the motor items were selected from the 6 months ASQ questionnaire. At age 3 years one question was chosen from motor skills at 36 months and one from 48 months in each domain. This modification was chosen to obtain a greater variation in answers. The items were scored using the response categories *yes, very often* (1), *yes, sometimes* (2), *not yet* (3), *don't know* (missing). For each developmental domain, a sum score was calculated. To identify children at risk for clinically significant fine or gross motor impairments, we set a cutoff at 2 standard deviations above the mean, as suggested by Squires et al. (Squires et al., 1997). To explore the reliability at 6 months, we applied a 2-parameter item response theory (IRT) model (Lord FM, 1980). The results of these analyses indicated adequate reliability for both scales, with factor loadings at 0.46 to 0.76 for the gross motor scale and 0.80 to 0.97 for the fine motor scale. Dichotomization of the variables at 2 standard deviations above the mean was supported by the results from the IRT analyses, showing good local reliability at and above 2 standard deviations above the mean on all three scales. In other words, the scale was good at discriminating between the children with the highest scores and the rest. At 3 years of age reliability was estimated calculating the polychoric correlation (correlation for ordered-category data) between the two items for each domain. The polychoric correlation between the fine motor items was 0.62 and between the gross motor items 0.83, suggesting good reliability.

Social development. At age 6 months the items for the rating of social skills were derived from three different developmental instruments relevant for children between 4 and 12 months of age: Bayley Scales of Infant Development (Bayley N., 1993), Non-Verbal Communication Checklist (NVCC) (Schjolberg, 2003), and the Ages and Stages Questionnaire (Squires et al., 1997). The social domain was represented by 5 items. Mothers were asked to find time to observe the child and rate the extent to which the child would typically show mastery of the skill, according to the response categories *yes, very often* (1), *yes, sometimes* (2), *not yet* (3), *don't know* (missing). A sum score was calculated, with a

score from 5 to 15 on the social scale. To explore the reliability, we applied a 2-parameter item response theory (IRT) model (Lord, 1980). The results of these analyses indicated adequate reliability, with factor loadings at 34 to .76 for the social scale. To identify the children with clinically significant developmental impairments, we set a cutoff at 2 standard deviations above the mean, as suggested by Squires et al (Squires et al., 1997). Dichotomization of the variables at 2 standard deviations above the mean was supported by the results from the IRT analyses showing good local reliability at and above 2 standard deviations above the mean.

At child age 18 months social skills were measured by means of items from the personal-social (4 items) subscale of the ASQ selected for the MoBa study (Squires et al., 1997). The selection of items aimed at representing the subscales with items that were most relevant for social development in 18-month-old children. The selection was performed by specialists in clinical and developmental psychology on a consensus basis. Mothers were asked to find time to observe the child and rate the extent to which the child would typically show mastery of the skill, using the response categories (1) *yes, very often*, (2) *yes, sometimes*, (3) *not yet* and (missing) *don't know*. A sum score was calculated ranging from 4 to 12, where a high score indicates symptoms of social impairments. To explore the reliability, we conducted confirmatory factor analyses using structural equation modeling. The results of these analyses indicated adequate reliability for both scales, with factor loadings ranging from 0.62 to 0.89 on the communication scale and 0.45 to 0.77 on the social scale.

At child age 3 years social impairment was measured by the prosocial subscale of the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997). SDQ was designed to measure psychological adjustment in children. It is suited for research as well as screening and for use in clinical settings. The original scale is composed of 25 questions covering five sub domains (prosocial, hyperactivity-inattention, emotional, conduct and peer). The subscale on prosocial behavior consists of 5 questions (all 5 are included in MoBa) that are answered on a 3-point Likert scale with the categories "*disagree*," "*partially agree*," and "*totally agree*." The scores were summarized and dichotomized at the 90th percentile. Ratings above this cutoff have been shown to be associated with a substantial increase in psychiatric risk, with odds ratios of 15 (rated by parents). The specificity and negative predictive value was high (95%), whereas the sensitivity and positive predictive value was lower (35%) (Goodman, 2001). Test-retest reliability and inter-rater reliability has generally been shown to be satisfactory. In our study Cronbach's alpha was .75.

Communication development. At child age 18 months communication skills were measured by means of items from the communication subscales (3 items) of the ASQ selected for the MoBa study (Squires et al., 1997). Mothers were asked to find time to observe the child and rate the extent to which the child would typically show mastery of the skill, using the response categories (1) *yes, very often*, (2) *yes, sometimes*, (3) *not yet* and (missing) *don't know*. A sum score was calculated ranging from 3 to 9 on the communication scale, where a high score indicates symptoms of communication impairments. To explore the reliability, we conducted confirmatory factor analyses using structural equation modeling. The results indicated adequate reliability, with factor loadings ranging from 0.62 to 0.89 on the communication scale.

At child age 3 years items for rating communication skills were selected from the ASQ (Squires et al., 1997). The original communication section of ASQ at 36 months consists of six questions. The last two are not included in the MoBa questionnaire. Instead, one question from communication skills at 18 months and one from 48 months are included in MoBa in order to capture a greater variation in the answers. Mothers were asked to find time to observe the child and rate the extent to which the child would typically show mastery of the skill using the response categories *yes, very often* (1), *yes, sometimes* (2), *not yet* (3), *don't know* (missing). To identify the children at risk for clinically significant communication impairments, we set a cutoff at 2 standard deviations above the mean, as suggested by Squires et al (Squires et al., 1997). The scale showed high reliability with ordinal theta (the recommended reliability test for Likert-type data with less than 6 response categories) (Gadermann, Guhn, & Zumbo, 2008) at $\Theta = 0.93$.

Grammar impairment was measured by Dale and colleagues' parent-based assessment of grammar abilities (Dale, Price, Bishop, & Plomin, 2003). The scale was used by Dale and colleagues in the Twins Early Development Study (TEDS). Mothers were asked which of the six alternative formulations best described how their child talks: (1) child is not yet talking, (2) child is talking, but you cannot understand him/her, (3) child is talking in one-word utterances, such as "milk" or "down," (4) child is talking in 2- to 3-word phrases, such as "me got ball" or "give doll," (5) child is talking in fairly complete sentences, such as "I got a doll" or "can I go outside?" (6) child is talking in long and complicated sentences, such as "when I went to the park, I went on the swings" or "I saw a man standing on the corner." To identify children suspected of grammar difficulties, the sample was divided into two groups: children who were rated as talking in fairly complete

sentences or long and complicated sentences (94%) (group 1), and children who were rated as talking in 2- to 3-word phrases or less (6%) (group 2).

Box 1. Measures of developmental outcomes at time point 6, 18 and 36 months

Time point	Motor development	Communication development	Social development
Age 6 months	*Ages and Stages Questionnaire (ASQ)* Gross motor: 3 items Fine motor: 3 items Appendix: Questionnaire 4, p 7, q 36. 1-3 and 9-11.		*Bayley Scales of Infant Development (BSID)* *Non-Verbal Communication Checklist (NVCC)* *ASQ* Social: 5 items Appendix: Questionnaire 4, p 7, q 36. 4-8.
Age 18 months		*ASQ* Communication: 3 items Appendix: Questionnaire 5, p 8, q 32. 1-3	*ASQ* Personal-social: 4 items Appendix: Questionnaire 5, p 8, q 32. 10-13
Age 36 months	*ASQ* Gross motor: 2 items Fine motor: 2 items Appendix: Questionnaire 6, p 4, q 17. 1-4.	*ASQ* Communication: 6 items Appendix: Questionnaire 6, p 5, q 21. 1-6. *Dale grammar rating* Grammar: 1 item Appendix: Questionnaire 6, p 4, q 18.	Strengths and Difficulties Questionnaire (SDQ) Prosocial: 5 items Appendix: Questionnaire 6, p 5, q 20. 1-5.

3.3.3. Background variables and predictors

Information regarding the child's sex, gestational age, birth weight, and head circumference was retrieved from the MBRN (Irgens, 2000). Head circumference at birth was used as a continuous variable adjusted for sex. The child's gestational age in weeks was determined

by means of ultrasound examination and operationalized as a continuous variable. Birth weight in grams was measured as a continuous variable.

Maternal education was retrieved from MoBa questionnaire at the 17th week of gestation and was measured by 6 levels of education. The levels were transformed into a continuous variable of the number of years of education including college and university studies. Maternal psychological distress (anxiety and depression) was assessed at child age 6 months by the SCL-5, a shortened version of the Hopkins Symptom Checklist (SCL-25) (Strand, Dalgard, Tambs, & Rognerud, 2003) in paper 1. This measure comprises 5 items, each with four optional answers: *not at all* (1), *a little* (2), *quite a bit* (3), *extremely* (4). A typical item on the SCL-5 is "Worrying too much about things." The index was scored as the mean of the item scores. This SCL-5 index has been shown to correlate strongly ($r > 0.90$) with the SCL-25 index (Strand et al., 2003). In this study, Cronbach's alpha was $\alpha = 0.82$. In paper 3 the mothers' psychological distress (anxiety and depression) was assessed at child age 6 months by an 8-item version (SCL-8) of the Hopkins Symptom Checklist (SCL-25) (Strand et al., 2003). A typical item on the SCL-8 is "Worrying too much about things." Cronbach's alpha was 0.83 in this study.

Surgical factors were retrieved from the CHD registry. Age at first operation was measured continuously in days. Cardiopulmonary bypass time (CPB) (in minutes) and cross clamp time (in minutes) were summarized across all operations conducted before the child was 3 years old.

3.4. Statistical Methods

3.4.1. Binary logistic regression

In papers I and III binary logistic regression was used to investigate the odds of having developmental impairments in the CHD groups as compared to the control group. Logistic regression analyses were carried out for the motor, communication, and social variables separately. Univariate analyses, including CHD group as categorical variable with the control group as reference category, were carried out to obtain crude odds ratios. Multivariate logistic regression analyses were then performed to adjust for plausible confounders. The CHD groups were compared with the control group on the plausible confounding variables using ANOVA and the Bonferroni post hoc test for continuous variables and the chi-square test for categorical variables. Control variables adjusted for in the multiple logistic analyses included the variables shown to differ significantly between

the CHD groups and the control group. Variables were entered simultaneously in the multivariate logistic regression.

In paper III a second step of logistic regression analyses was performed, including only children with severe CHD. To investigate associations between different risk factors and developmental impairments among the group of children with severe CHD, univariate logistic regression analyses were conducted entering potential predictors one by one.

The analyses were computed using SPSS 17.0.

3.4.2. Analyses of covariance (ANCOVA)

For paper II ANCOVA (SPSS GLM, option UNIVARIATE) was conducted to investigate the difference in mean scores on the developmental scales for the communication and social scales separately. The CHD groups were entered as a factor in the ANCOVA with the control group as the reference category. Variables entered as covariates were birth weight and gestational age. These analyses were computed using SPSS 17.0.

3.4.3. Reliability

Some remarks regarding the reliability estimates is warranted, as we used estimates that are less common than the standard Cronbach's alpha estimate. It has been shown that when the items on a scale are measured on categorical levels with less than 6 categories in addition to skewed distribution of scores, Cronbach's alpha underestimates the inter-item reliability (Gadermann et al., 2008). We therefore sought to measure reliability using other approaches.

For paper I we performed an item response theoretical (IRT) analysis (Lord, 1980). In IRT, the response categories for each item are viewed as discrete response categories. IRT is based on the concept that the probability of choosing one of these response categories after being presented the item is a function of the latent trait or ability (i.e., the latent variable in the present case would be the mother's comprehension of the child's ability). Reliability is consistency of measurement. Reliability within latent variables is the squared correlation of a measure and its latent variable (Bollen, 1989). The factor loadings were extracted to represent the reliability showing how the items loaded on the latent factor. IRT analysis also allows investigation of whether a scale is more reliable at certain points or if the scale has high general reliability. In other words, you can investigate if the scale is more

reliable in discriminating children with certain scores from the rest, or if the scale is equally reliable for all scores on the scale.

To explore the reliability in paper II, we conducted confirmatory factor analyses (CFI) using structural equation modeling (SEM) primarily because the CFI in SEM is able to compute factor loadings based on polychoric correlations. We reported the factor loadings as an indication of the consistency between the items and the latent factor.

In paper III we learned that the ordinal theta based on a polychoric correlations matrix could be used to estimate reliability (Ferketich, 1990; Gadermann et al., 2008; Zumbo, Gadermann, & Zeisser, 2007). The ordinal theta was calculated with the formula $\Theta = (p / (p - 1) * (1 - (1 / \lambda_1))$. The letter "p" in the formula is the number of items in the scale, and the symbol λ_1 denotes the largest eigenvalue derived from the factor analyses of the polychoric correlation matrix of the scale. The ordinal theta is a suitable reliability test for categorical scales; it is highly resistant to skewness and has been shown to provide accurate estimates for scales that use only 3 Likert-type categories (Zumbo et al., 2007). These analyses were calculated using Mplus version 4 in paper I and version 5.1 in papers II and III (Muthén & Muthén, 2007).

4. RESULTS

4.1. Summary of Paper I

The purpose of paper I was to assess whether the development of children with varying severity of CHD differed from that of children without CHD at age 6 months. By comparing infants with varying severity of CHD with a large control group from the same cohort, we indeed found differences in fine motor skills, gross motor skills, and social skills at age 6 months.

Two groups stood out as being particularly at risk for developmental impairments at this early age: Children with severe CHD showed almost four times higher odds for impairments in gross motor skills and two times higher odds for impairments in fine motor skills. Children with CHD and comorbidity showed developmental impairments across all developmental domains: a three times higher probability for gross motor impairments, more than five times higher probability for fine motor impairments, and more than three times higher probability for social impairments. In contrast, children with mild and moderate

CHD showed no significant increase in developmental impairments. In contrast to many earlier studies, our results were controlled for birth weight, gestational age, child sex, and maternal psychological distress.

4.2. Summary of Paper II

The purpose of paper II was to compare symptoms of communication and social impairments in 18-month-old children with different severity of CHD with those of controls. Eighteen-month-old children with CHD differed significantly from controls in levels of symptoms of communication impairments and social impairments. The largest differences from controls were found in children with CHD and comorbidity. Children with severe CHD also showed higher levels of both symptoms of communication and social impairments. Children with mild/moderate CHD showed a small difference only in symptoms of communication impairments. All analyses were adjusted for gestational age and birth weight.

4.3. Summary of Paper III

The primary objective of paper III was to investigate the occurrence of motor, social, and communication outcomes in children with varying severity of CHD at age 3 years. We identified higher odds of both gross motor and communication impairments especially for children with severe CHD compared with a control group. In this study the children with severe CHD also tended to have increased odds for grammar, fine motor, and social impairments, but these findings were not statistically significant. A new finding was that children with mild/moderate CHD showed higher odds for gross motor impairments, although not as high as for children with severe CHD. They were otherwise not different from the control group. When comparing the odds of having any developmental impairments between the groups, children with mild/moderate CHD were not different from controls, while children with severe CHD had two times higher odds of having any developmental impairment.

A secondary objective of this study was to identify predictors associated with developmental impairments in 3-year-old children with severe CHD. Predictors of impairments identified were: previous developmental impairments, smaller head circumference at birth, small for gestational age, maternal distress. None of the variables

related to surgery (age at first operation, cardiopulmonary bypass time, or cross clamp time) were associated with developmental impairments.

4.4. Conclusions:

In paper I we concluded that increased odds of motor impairments are present already in infancy in children with severe CHD and children with CHD and comorbidity. CHD with comorbidity increases the odds of social impairments.

In paper II we concluded that identification of differences in communication and social development between children with CHD and controls already at 18 months may be an important step in understanding the development of children with CHD. It may be necessary to broaden the scope of inquiry from neurodevelopmental domains to communication and social domains in order to provide children with CHD with the assistance that they require too achieve satisfactory development.

In paper III we concluded that children with severe CHD have increased odds of having any developmental impairments at the age of 3 compared with controls, particularly gross motor and communication impairments. Because early developmental impairments were associated with later developmental impairments in children with severe CHD, we emphasized the importance of early attentiveness to developmental impairments. We also underlined the importance of considering patient-specific conditions at birth for providing individualized, targeted therapeutic strategies that could hopefully improve developmental outcomes in children with CHD. In addition we suggested that parental support to reduce maternal distress could potentially benefit the long-term development of the child.

5. DISCUSSION

5.1. Interpretation of the findings

Whereas previous studies primarily focused on studying severe types of CHD or were conducted with children with one single type of severe heart defect, resulting in small sample sizes and results that are difficult to generalize to other heart defects (Visconti et al., 2006), in this study we included a wider range of severity in a population based sample. To our knowledge no other study has included mild, moderate, and severe CHD groups in the same study and comparing all of them to the same control group. Literature reviews

reported that developmental problems are common in children with severe types of CHD and less common in children with mild or moderate types of CHD based on findings from different studies usually on single, either mild, moderate, or severe CHD diagnoses (Wernovsky, 2006). In our study the CHD groups were compared on the same measures and to the same comparison group, and we can therefore be more certain that the "signature" of increasing symptoms with increasing severity of CHD (Wernovsky, 2006) is supported.

In view of the lack of follow-up studies on the early childhood period, especially on the domains of communication and social development in children with CHD, the current study contributed towards filling this gap and provided new insights regarding development across a wider spectrum of developmental domains in this important period of a child's life. Thus, an important finding of our study was that the increased odds of developmental impairments were present already at age 6 months. This finding is in line with other studies identifying developmental impairments in early infancy (Bellinger et al., 1997). However, our study is the first study to demonstrate that symptoms of developmental impairments at 6 and 18 months in children with CHD are related to later outcomes within the early childhood period. In light of the extensive literature on school-age children with CHD showing difficulties within a broad range of developmental domains (Hövels-Gürich et al., 2006; Bellinger et al., 2003; Hövels-Gürich et al., 2002; Hövels-Gürich et al., 2006; Hövels-Gürich et al., 2008; Bellinger et al., 2003) in addition to lower quality of life (Landolt, Buechel, & Latal, 2008) we feel confident that our study on infancy and early childhood complements the literature and underlines the importance of early detection. However, we cannot be sure whether the symptoms of impairments identified in this study are precursors of the later difficulties observed in other studies. In fact, early screening (and diagnosing) of developmental disorders and impairments is controversial. In recent years, there has been growing recognition of the importance of early detection of developmental problems (American Academy of Pediatrics, 2001). Yet, some researchers argue against screening for developmental impairments in the preschool age period, because some studies show low predictive value. These arguments are often used to justify a "wait and see" approach instead of early screening and intervention. On the other hand, it is also important to consider that the instability of developmental impairments could result from the problems changing character or manifestation across development. For example, a child showing early symptoms of language impairments might "catch up" in this domain by school age but still have other developmental or behavioral difficulties. This represents a great challenge in understanding child development. However, it also suggests that care should be taken in

assuming that many children "grow out" of their impairments. In order to solve these issues in the current study, the children would have had to be followed up into school age. Indeed, a few previous studies followed children from preschool age into school age and showed that early developmental problems were associated with outcomes at school age in children with CHD (Hövels-Gürich et al., 2008).

Whereas it is common to exclude children with syndromes and chromosomal defects when studying children with CHD, only few studies mention the possible confounding effect of other medical conditions often associated with CHD, such as diaphragmatic hernia and intestinal malformations. In some studies children with these associated conditions were excluded. But other studies do not mention children with comorbidity at all, meaning that children with CHD with comorbidity could be mixed with children with CHD without comorbidity, thereby biasing the results of the studies in a more negative direction. To our knowledge, no previous study examined children with CHD and comorbidity separately. In our study, children with CHD and comorbidity showed the highest odds of developmental impairments at 6 months and the highest levels of symptoms of developmental impairments at 18 months, with a large difference from the control group. Unfortunately, we were not able to include children with comorbidity at 36 months, because the group consisted of fewer than 20 cases. Still, our findings underline that children with CHD and comorbidity are at the highest risk of communication, social, and motor impairments. The size of the deviations from the controls in the study at 18 months suggests implications for the children's psychosocial functioning. However, the group of children with CHD and comorbidity was a very heterogeneous group consisting of several different comorbid medical conditions. The sample was too small to evaluate if any particular medical comorbid diagnoses were particularly at risk, and consequently we have to be careful in generalizing these findings to all children with comorbid medical conditions.

Although many studies exclude children below 2500 grams and week 37 of gestation, the mean birth weight and gestational age is still usually lower in case groups of CHD. Because these factors are often associated with developmental problems similar to what has been observed in children with CHD, it is important to adjust for these differences. In our study we demonstrated that developmental impairments were still present after adjusting for these confounders, suggesting that the effects on development are not merely a result of preterm birth or low gestational age in these children.

Maternal distress is a difficult factor to handle in the studies of children with CHD. First, it represents a potential confounder, for it is well known that mothers who are

depressed or anxious have a tendency to rate their children more negatively than healthy mothers do. Accordingly, in the first paper we adjusted for the effect of maternal distress. This reduced the odds of developmental impairments for children with CHD compared with controls, but significant differences remained. On the other hand, it is possible that maternal distress is not a confounding variable but in fact an important explanatory factor of why children with CHD display more developmental problems. Maternal distress in mothers of severely ill children could lead to overprotection, lower expectations, and less engagement with respect to the child (Gardner et al., 1996). Mothers of infants with a severe disease may also show weaker attachment to the baby as a way of protecting themselves from the pain and loss they fear (Upham & Medoff-Cooper, 2005). According to the theory of the vulnerable child syndrome, this could have a long-term negative influence on child development (Green & Solnit, 1964) In this sense, rather than being a confounder, maternal distress could be an important mediator partly explaining why children with severe CHD show early signs of developmental impairments. Thus in paper III we included maternal distress at 6 months as a predictor and found a prospective association with developmental impairments at age 3 years for children with severe CHD. If the reporting bias were the only explanation, the mothers should have rated their children as being more at risk in all developmental domains and not only in the motor and communication areas.

Because developmental impairments are evident in children with severe CHD, we sought to identify predictors of developmental impairments in this group only. We wanted to explore whether patient specific characteristics or surgical variables were associated with developmental impairments at age 3 years. We found that developmental impairments were predicted by earlier developmental impairments and maternal distress at child age 6 months, smaller head circumference at birth, and being small for gestational age. As head circumference at birth is a marker for brain development, our findings support the notion that neurological deficits might be present already at birth. This is in line with Limperopoulos and colleagues' finding that preoperative microcephaly is associated with poor neurodevelopmental outcomes one year after surgery (Limperopoulos et al., 2002). We showed that this association still holds at age 3. The finding that being small for gestational age at birth (SGA) is a (nearly) significant predictor also supports the suggestion made by Gaynor and colleagues (Gaynor et al., 2007) that developmental impairments are more related to patient-specific factors than to surgical events and procedures. The lack of association between surgical factors and developmental impairments was also reported by several other recent studies (Fuller et al., 2009; Tabbutt et al., 2008). This could suggest that

the current era of surgery for children with CHD is doing well. However, even though patient-specific factors appear to be stronger predictors of neurodevelopmental outcomes, some factors related to surgery are still reported to be significantly associated with neurodevelopmental outcomes (Gaynor et al., 2007); this demonstrates the complexity involved in understanding predictors of development in children with CHD.

5.2. Methodological considerations

The results presented in this dissertation should be interpreted in the context of a number of limitations and methodological considerations. In this section I review different aspects of the design and statistical analyses that may impact the generalizability of our findings.

First, the participation rate in MoBa is rather low, at 42.7% (Magnus et al., 2006), which raises an important question as to how representative the participants of this study are. However, analyses have shown that even though the MoBa study does not yield exact prevalence estimates due to self-selection biases, the associations between exposure and outcome seem to be reliable and valid (Nilsen et al., 2009). Similar findings were reported from a national birth cohort study in Denmark, where the participation rate was even lower (30%); still, odds ratios on selected associations were not biased (Nohr, Frydenberg, Henriksen, & Olsen, 2006).

Second, when dividing the group of children with CHD into mild, moderate, and severe CHD (and in addition, papers I and II included a separate group of CHD with comorbidity), the group sizes became relatively small and uneven. This reduces the power to detect differences between the CHD groups and the control group, and therefore we are at risk of making type II errors (to maintain the null hypothesis when it is actually wrong). Consequently, the significant differences obtained with the small sample size in the current study indicates that these are robust differences that could likely occur in larger samples, but the non-significant findings shown for some of the outcome variables could be a result of lack of power to detect them. In paper III the issue of lack of power is especially important when considering the results of the analyses of predictors of developmental impairments in the severe CHD group. The measure of "any developmental impairment" was used in order to maximize the number of children in the impaired group instead of performing separate analyses on motor and communication impairments, but still the power to detect differences was rather low (depending on the predictor). To avoid type II errors we therefore interpreted the p-value with care, noticing that borderline significant results should not be ignored. Still,

we might have made type II errors due to lack of power when concluding that certain predictors were not significant.

In papers I and II the outcome variables were dichotomized at a common cut-off value to define children at risk for impairments. This was done although the methodological literature shows that dichotomization of quantitative measures often lead to negative consequences, such as loss of effect size and power, as well as spurious statistical significance and overestimation of effect size (MacCallum, Zhang, Preacher, & Rucker, 2002). Moreover, dichotomization could lead to underestimating the extent of variation in outcomes between groups (Altman & Royston, 2006; Altman & Royston, 2006). Individuals close to but on opposite sides of the cut points are characterized as being very different (normal vs. impaired) rather than very similar. MacCallum and colleagues (2002) argued that the loss of effect size would be altered only marginally by skewness, heteroscedasticity, or nonlinearity. They suggested that in cases of extreme skewness, heteroscedasticity, or nonlinearity, it would be advisable to transform the variables or use nonlinear regression (Maccallum et al., 2002). However, according to MacCallum and colleagues there are two situations where dichotomization could be justified. One is where taxometric analyses provide clear support for two distinct types or taxons within the sample. The other involves the occasions when the distribution of a continuous variable is extremely highly skewed. In paper I the variables were extremely highly skewed and dichotomization of the variables at 2 standard deviations above the mean was supported by the results from the IRT analyses showing good local reliability at and above 2 standard deviations above the mean on all three scales. In other words, both the distribution of the variables and the IRT analyses suggested that dichotomization was appropriate. However, in paper II the variables were less skewed, and there was much more variation in the outcome variables, and we therefore decided to follow the advice of MacCallum and log transform the scores and treat them continuously rather than dichotomizing them. In paper III the same distribution was seen in the outcome variables as in paper I, and accordingly, we performed dichotomization.

It is important to consider the issue of construct validity when interpreting the results from this study. Construct validity concerns two related levels: (1) the explication of theoretical constructs, and (2) the operationalization of those theoretical constructs. As the constructs of motor, communication, and social development are reasonably valid theoretical constructs, the limitation in this study is related to the operationalization of these constructs. The MoBa study includes short versions of scales mainly to reduce the burden for the respondents and in order to include a large number of scales in the questionnaires

with limited space. Unfortunately, the short versions used were not validated, and thus we do not know whether the short scales measure the construct that they are supposed to measure. Moreover, we do not know whether the validated cutoffs for the full scales (2 standard deviations and 90th percentile) are valid also for the short scales. As the MoBa study proceeds, clinical sub-studies testing children for autism, ADHD, language disorders, and more will be performed, and the short scales in the MoBa study will be validated against clinical examinations and diagnoses. This is crucial in order to determine the construct validity of these measures.

Finally, the generalizability of the results of this study across methods is limited by relying only on maternal ratings. Additional clinical full scale assessments and clinical testing of the child's development would have been desirable to establish valid clinical diagnoses or developmental profiles. However, because of the large size and the broad scope of the MoBa study, clinical assessments were not feasible. Multiple raters such as including the father or the kindergarten teacher would have been feasible within the frame of the MoBa study and desirable in order to determine the across method generalizability of these measures. Unfortunately, fathers were only included in the MoBa study at the 17th week of gestation. Kindergarten teachers will be included in a sub-study at the 5-year MoBa follow-up (starting in 2010). At the same time, studies have shown that mothers are good raters of their child's development, as they have firsthand experience with their child's usual behavior and are able to observe them in a wide variety of settings (Squires et al., 1997). Moreover, it is reassuring that the findings of this study are in accordance with the results of studies on children with CHD using clinical examinations (Bellinger et al., 1999) and multiple raters (Hövels-Gürich et al., 2008).

6. IMPLICATIONS AND FUTURE DIRECTIONS

The findings of this study emphasize the importance of early attentiveness to developmental impairments especially for children with severe CHD and CHD with comorbidity. Children with severe CHD have now been extensively studied and reported to be at risk for several developmental impairments particularly within the domains of motor and communication development. The impairments can be detected from a very early age even with simple, short screening measures. Early motor and communication impairments could have a

serious impact on later development and put children with CHD at risk for several subsequent problems. This would imply the advisability of a more active screening strategy in pediatric clinics from early infancy to ensure early referral and treatment of children showing early impairments. From a clinical point of view, our results suggest that children with CHD and comorbidity may need special attention. However, the interpretations of our findings are limited by the small and heterogeneous group of CHD and comorbidity included. Future research should investigate larger and more homogenous groups of children with CHD and comorbid conditions.

A positive implication of our findings is the reassuring message to parents of children with mild and moderate CHD that these groups of CHD do not seem to be at risk for developmental impairments in early childhood. Also, our findings imply that although children with severe CHD are at higher risk of developmental impairments, a large portion of this group are not reported to have more symptoms of impairments. It is hoped that this could reduce some of the parent's worries and encourage positive expectancies towards their child's development.

For the children with impairments, our findings on early predictors underline the importance of considering patient-specific conditions at birth for providing individualized, targeted therapeutic strategies that could hopefully improve developmental outcomes in children with CHD. In addition, parental support to reduce maternal distress could potentially benefit the long-term development of the child.

Several questions remain for future research to address. First, it remains unclear whether the early symptoms of impairments indicate lasting impairments in these areas of development or if they merely suggest temporary developmental delays, with the children catching up when they grow older. Further follow-up studies into later childhood are required. Second, more studies looking at predictors of developmental outcomes taking into account medical, biological, and psychological factors are warranted. This is important both in order to better understand the underlying mechanisms linking CHD with developmental impairments and in order to modify factors that potentially put children with CHD at risk for developmental impairments. Longitudinal studies in larger samples of children with CHD are necessary in order to perform multivariate analyses on predictors of separate developmental outcomes. Finally, studies on the effects of early intervention and treatment in children with CHD are needed to better understand the potential benefits of early interventions in this group.

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I

II

III

Running head: Developmental Impairments in Children with CHD

Occurrence and Predictors of Developmental Impairments in 3-Year-Old Children with Congenital Heart Defects

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ABSTRACT

Objective: To examine the occurrence of developmental impairments in 3-year-old children with varying severity of congenital heart defects (CHD) and to identify predictors associated with developmental impairment in children with severe CHD.

Methods: We linked prospective data collected at birth, 6,18, and 36 months from the Norwegian Mother and Child Cohort Study (MoBa), conducted by the Norwegian Institute of Public Health, with a nationwide medical CHD registry and identified 175 3-year-olds with CHD in a cohort of 44,044 children. Children with mild/moderate (n=115) and severe (n=60) CHD were compared with children without CHD (43,929) on motor, communication, and social impairments as reported by mothers in MoBa questionnaires. Predictors of developmental impairment were analyzed for the group with severe CHD.

Results: Children with severe CHD had more than 3 times higher odds of communication and gross motor impairments compared with controls, and had 2 times higher odds of any developmental impairment compared with controls. Children with mild and moderate CHD had more than 2 times higher odds of gross motor impairment but did not otherwise differ from controls. Predictors of impairment identified were: previous developmental impairments, smaller head circumference at birth, small for gestational age, maternal distress.

Conclusion: Children with severe CHD have increased odds of developmental impairments at age 3 years. Early developmental impairments are associated with later developmental impairments, suggesting lasting impairments and not merely temporary delay. Patient-specific conditions at birth should be considered and maternal support provided to potentially improve outcomes in children with CHD.

Index terms: motor development, communication development, social development

Congenital heart defects are the most common birth defects, occurring in 6-8 per 1000 live births.[1] Advances in medical and surgical management have led to improved survival in the last decade(s).[2] Whereas reduction of short-term morbidity and mortality are important goals, more recent research has deemed developmental outcomes equally important.

There is a controversy regarding the prevalence and persistence of neurodevelopmental sequelae in children with CHD. There are few prospective follow-up studies and few studies looking at associations between predictors and later outcomes.[3] The available evidence in the literature suggests that developmental problems are common in children with severe types of CHD and less common in children with mild or moderate types of CHD. The occurrence varies between different studies depending on the type of lesion, complexity of surgical operation, age at outcome, type of outcome, etc. Across studies, children with isolated CHD present with normal intellectual capacities but tend to show motor and language dysfunctions. Motor difficulties are often found to be among the most prevalent morbidities.[4,5] Indeed, gross and fine motor impairment is reported to be prevalent already at the age of 6 months [6] and in toddlers (from 1 year of age), persisting to the age of school entry.[7,8] Studies on early communication impairment often report the occurrence of impairment in a variety of linguistic tasks, including expressive, receptive, and speech tasks.[9-11] The few studies available on social impairment show conflicting results. In preschool children with CHD the findings range from poor social skills[11,12] to average and even above average social skills.[13,14]

Developmental impairments in children with severe CHD were previously attributed largely to operative procedures without considering other potential risk factors. More recent studies suggest that factors other than operative management strategies may be more important determinants of developmental outcomes. Preexisting brain abnormalities,[15] the severity of the

defect, and the age at repair are considered to be important risk factors. Number of operations and length of stay in cardiac intensive care unit are important.[16] Patient-specific factors such as low birth weight, socioeconomic status, parental distress, and presence of genetic syndromes are also reported to be more important predictors than operative management strategies.[17]

The primary objective of this study was to investigate the occurrence of different developmental outcomes in children with CHD at 3 years of age. Based on previous findings we expected children with severe CHD to be at higher risk of developmental impairments than children with milder forms of CHD and children without CHD. If children with severe CHD were at higher risk of developmental impairment, the secondary objective of the study was to identify predictors associated with developmental impairments in 3-year-old children with severe CHD. To our knowledge this is the first study to investigate whether developmental impairments detected as early as 6 months of age in children with CHD are associated with developmental impairment at age 3 years.

METHODS

Study Design and Participants

Our study has a case-cohort design and is part of an ongoing study following children with CHD from birth to 3 years. We identified all children with CHD within a large prospective epidemiological study, the Norwegian Mother and Child Cohort Study (MoBa) (www.fhi.no/morogbarn). Children without CHD served as a comparison group (43,929) from the same age cohort. The MoBa study is conducted by the Norwegian Institute of Public Health and follows mothers and their child from early pregnancy into childhood.[18] Recruitment started in 1999 and ended in 2008. The participation rate at first assessment was 42.7%.[18] Response

rates among mothers who agreed to join the study were 95% during pregnancy, whereas after birth they were 87% at 6 months, 77% at 18 months, and 62% at 3 years.[18,19] Informed consent was obtained from each participant before the study.

The present study was based on version 5 (2010) of the quality assured data files of MoBa. The Regional Committee for Medical Research and the Norwegian Data Inspectorate approved the study. In addition to the information from MoBa, we used information on the child's status at birth from the Medical Birth Registry of Norway (MBRN).[20] Clinical information on the diagnosis and treatment of children with CHD was available through a nationwide CHD registry administrated by the Department of Pediatrics, Pediatric Cardiology Unit, at Oslo University Hospital, Norway, which serves as a national tertiary center for these children.[2] The CHD registry includes information on all live born children with significant CHD in Norway. All examinations, diagnoses, procedures, and contacts with patients with CHD are entered into the database with assigned dates. To ensure the quality of the registry, only senior pediatric cardiologists enter data.

Infants with CHD in the MoBa cohort were identified by matching the personal identification number in the two databases. A case-match at child age 3 years identified 293 children with CHD who were present in both data sources and had a mild, moderate, or severe CHD, representing 0.66% of the MoBa cohort. Of these, 77 children were lost due to attrition, among which 28% had severe heart defects. A z-test of two proportions showed that the severity of the heart defects did not differ between children lost to attrition and children continuing to participate ($Z = 0.836$, $P = 0.20$). Exclusion criteria were: syndromes or chromosomal defects (e.g., Down syndrome, deletion of chromosomal region 22q11) and

significant comorbid medical conditions (e.g., extracardiac malformations, cancer, severe asthma) (N = 41).

Two senior pediatric cardiologists blind to the developmental outcomes measured in the MoBa study classified the cardiac defects according to severity and treatment-related aspects. The classification was based on previously accepted methods.[1] Both cardiologists classified all the cardiac defects and agreed on the classification of all of the patients. The cardiac defects were classified as follows:

1. "Mild/moderate CHD" (n = 115). The children with mild CHD were generally asymptomatic and had defects that were left untreated and that usually resolved spontaneously. The children with moderate CHD could be symptomatic and required follow-up through childhood. The most common heart defects in this group are left to right shunts, pulmonary valve stenosis, and noncritical coarctation of the aorta.
2. "Severe CHD" (n = 60). These children were usually clearly symptomatic and sometimes severely ill in the newborn period or early infancy, and they all required treatment. The most common heart defect in this group is transposition of the great arteries (TGA).

Table 1 shows a description of the participants.

Measures

Outcome variables. At child age 3 years mothers rated their child's mastery of skills within five developmental domains. *Communication impairment:* Items for rating communication skills were taken from the Ages and Stages Questionnaire (ASQ).[21] The ASQ is

validated in a Norwegian sample and was found to be an effective diagnostic tool for detecting developmental impairments or disturbances.[22] The communication scale consisted of 6 items. Mothers were asked to find time to observe the child and rate the extent to which the child would typically show mastery of the skill using the response categories *yes, very often* (1), *yes, sometimes* (2), *not yet* (3), *don't know* (missing). In order to identify the children at risk for clinically significant communication impairment, we set a cutoff at 2 SDs above the mean, as suggested by Squires et al.[21] The scale showed high reliability with ordinal theta (the recommended reliability test for Likert-type data with less than 6 response categories) [23] at Θ = .93.

Grammar impairment was measured by Dale and colleagues' parent-based assessment of grammar abilities.[24] Mothers were asked which of the six alternative formulations best described how their child talks: (1) child is not yet talking, (2) child is talking, but you cannot understand him/her, (3) child is talking in one-word utterances, such as "milk" or "down," (4) child is talking in 2- to 3-word phrases, such as "me got ball" or "give doll," (5) child is talking in fairly complete sentences, such as "I got a doll" or "can I go outside?" (6) child is talking in long and complicated sentences, such as "when I went to the park, I went on the swings" or "I saw a man standing on the corner." To identify children suspected of grammar difficulties, the sample was divided into two groups: children who were rated as talking in fairly complete sentences or long and complicated sentences (94%) (group 1), and children who were rated as talking in 2- to 3-word phrases or less (6%) (group 2).

Fine and gross motor impairment items were derived from the Ages and Stages Questionnaire (ASQ).[21] Each of the two motor domains was represented by 2 items and scored using the response categories *yes, very often* (1), *yes, sometimes* (2), *not yet* (3), *don't know* (missing). The gross motor items were: "Can your child kick a ball by swinging his/her leg

forward without holding onto anything for support?" and "Can your child catch a large ball with both hands?" The fine motor items were: "When drawing, does your child hold a pencil, crayon, or pen between his/her fingers and thumb like an adult does?" and "Can your child undo one or more buttons?" To identify children at risk for clinically significant fine or gross motor impairment, we set a cutoff at 2 standard deviations above the mean, as suggested by Squires et al.[21] The polychoric correlation between the fine motor items was .62 and between the gross motor items .83.

Prosocial impairment was measured by the prosocial subscale of the Strengths and Difficulties Questionnaire (SDQ).[25] The subscale consists of 5 questions that are answered on a 3-point Likert scale with the categories "*disagree*," "*partially agree*," and "*totally agree*." The scores were summarized and dichotomized at the 90th percentile. High SDQ scores (> 90% of the population) have been shown to be associated with a substantial increase in psychiatric risk, with odds ratios of 15 (rated by parents). The specificity and negative predictive value was high (95%), whereas the sensitivity and positive predictive value was lower (35%).[26] In our study Cronbach's alpha was .75.

Any developmental impairment was calculated as present if the child was rated above the cutoff on one or more of the developmental measures.

Control variables and predictors. Information regarding the child's sex, gestational age, birth weight, and head circumference was retrieved from the MBRN.[20] Head circumference at birth was used as a continuous variable adjusted for sex. The child's gestational age in weeks was determined by means of ultrasound examination and operationalized as a continuous variable. Birth weight in grams was measured as a continuous variable.

Maternal education was retrieved from MoBa questionnaire at the 17th week of gestation and was measured by 6 levels of education. The levels were transformed into a continuous

variable of the number of years of education – including college and university studies. The mothers' psychological distress (anxiety and depression) was assessed at child age 6 months by an 8-item version (SCL-8) of the Hopkins Symptom Checklist (SCL-25).[27] A typical item on the SCL-8 is "Worrying too much about things." Cronbach`s alpha was 0.83 in this study.

All surgical factors were retrieved from the BERTE registry. Age at first operation was measured continuously in days. Cardiopulmonary bypass time (CPB) (in minutes) and cross clamp time (in minutes) were summarized across all operations conducted before the child was 3 years old.

Early measures of motor, social, and communication impairment were constructed from the 6 months and 18 months MoBa questionnaires and used as described in previous publications.[6,11] At 6 months the variable was dichotomized at 2 SDs. At 18 months the variable was used continuously.

Statistical Analyses

Statistical analyses were divided into two steps. In the first step, the entire sample was included. To investigate the odds of having communication, grammatical, social, or motor impairments in the CHD groups as compared to the control group, logistic regression analyses were carried out for all the outcome variables separately. Univariate analyses, including CHD groups as a categorical variable with the control group as reference category, were carried out to obtain crude odds ratios (ORs). Multivariate logistic analyses were then performed to adjust for plausible confounders. The CHD groups were compared with the control group on the plausible confounding variables using ANOVA and the Bonferroni post hoc test for continuous variables and the chi-square test for categorical variables. Control variables adjusted for in the

multiple logistic analyses included the variables shown to differ significantly between the CHD groups and the control group: gestational age and birth weight (see Table 1).

In a second step, only children with severe CHD were examined. To investigate associations between different risk factors and developmental impairments among the group of children with severe CHD, univariate logistic regression analyses were conducted entering potential risk factors one by one. The analyses were computed using SPSS 17.0.

Ordinal theta was calculated with the formula $\Theta = (p / (p - 1) * (1 - (1 / \lambda 1))$. The letter "p" in the formula is the number of items in the scale, and the symbol $\lambda 1$ denotes the largest eigenvalue derived from the exploratory factor analyses of the polychoric correlation matrix. These analyses were computed in Mplus version 4.[28]

RESULTS

Differences in Developmental Impairments

Table 2 shows the adjusted ORs for all CHD groups compared with the controls on all of the developmental outcomes.

The severe CHD group had more than 3 times higher odds of communication impairment after adjusting for gestational week and birth weight, whereas the mild/moderate CHD group did not differ significantly from the controls. In the adjusted analysis of grammatical impairment and pro-social impairment, we found that none of the CHD groups had significantly increased odds compared with the control group. For the adjusted analyses of gross motor impairment both the severe CHD group (more than 3 times higher odds) and the mild/moderate group (more than 2 times higher odds) differed significantly from the control group. None of the groups differed significantly from the control group on fine motor development.

In the adjusted analyses of any developmental impairment, the children with severe CHD had 2 times higher odds for any developmental impairment than the control group. A total of 16 (27%) of the 60 children with severe CHD had one or more developmental impairments (11 on one domain, 3 on two domains, 1 on three domains, and 1 on all domains). The mild/moderate CHD group was not significantly different from the controls.

Predictors of Developmental Impairment in Children with Severe CHD

Table 3 shows the odds ratios of the predictors of developmental impairments in children with severe CHD. For child characteristics, birth head circumference (p= .03) and being small for gestational age at birth (SGA) (borderline significant at p=.07) were associated with developmental impairments at 3 years of age. Sex, gestational age, and birth weight were not significantly associated with developmental impairments. None of the variables related to surgery (age at first operation, cardiopulmonary bypass time, or cross clamp time) was associated with developmental impairments. Of maternal characteristics, maternal distress at 6 months was associated with developmental impairments (borderline significant at p = .09), whereas maternal education was not. Finally, with regard to previous developmental impairments, motor impairments at child age 6 months (p=.04), symptoms of communication impairment at 18 months (p=02), and symptoms of social impairments at 18 months (borderline significantly associated at p=.06) were significantly associated with developmental impairments at 36 months.

DISCUSSION

The primary objective of this study was to investigate the occurrence of different developmental outcomes in children with varying severity of CHD at 3 years of age. As

expected, we identified higher odds of both gross motor and communication impairments especially for children with severe CHD compared with a control group. This is in line with previous findings that motor[5,29] and communication impairments[9,10] are the most prevalent morbidities in children with severe CHD. In this study the children with severe CHD also tended to have increased odds for grammar, fine motor, and social impairments, but these findings were not statistically significant. A new finding was that children with mild/moderate CHD showed higher odds for gross motor impairment, although not as high as for the severe group, but they were otherwise not different from the control group. This is in accordance with our previous findings that the occurrence of developmental impairments in children with CHD increases with the severity of the CHD.[6] When comparing having any developmental impairment between the groups, children with mild/moderate CHD were not different from controls, whereas the severe CHD group had two times higher odds of having any developmental impairment.

Because children with severe CHD were at higher risk of developmental impairment, a secondary objective of this study was to identify predictors associated with developmental impairments in 3-year-old children with severe CHD. Increasing evidence suggests that neurological deficits may be evident in infants with CHD prior to surgical intervention.[30] Observations of reduced brain volumes and incomplete closure of cerebral operculae in fetuses with severe CHD suggest delayed in utero structural brain development.[31] The operculum comprises an area of the brain that includes motor and language. Abnormalities in this area have been linked to motor and communication impairment.[32] Thus, abnormalities in brain functions might contribute to a higher risk of developmental impairment in children with CHD. Head circumference at birth is a marker for brain development. Our finding that smaller head circumference at birth is associated with later developmental impairment is in line with

Limperopoulos and colleagues' finding that preoperative microcephaly is associated with poor neurodevelopmental outcomes at 1 year after surgery.[15] We were able to extend that finding by showing that this association is still present at age 3. This supports the theory that abnormalities in brain functions in children with CHD could be one of the factors that contribute to the higher prevalence of developmental impairment in children with severe CHD. The finding that being small for gestational age at birth (SGA) is a (nearly) significant predictor also supports the suggestion made by Gaynor and colleagues[17] that developmental impairments are more related to patient-specific factors than to surgical events and procedures. The lack of association between surgical factors and developmental impairment has also been reported by several other recent studies.[33,34] This could suggest that the current era of surgery for children with CHD is doing well. However, even though patient-specific factors appear to be stronger predictors of neurodevelopmental outcomes, some factors related to surgery are still reported to be significantly associated with neurodevelopmental outcomes[17]; this demonstrates the complexity involved in understanding predictors of development in children with CHD.

The association between maternal distress and developmental outcomes further supports the necessity of using a multifactor approach to understand development in children with CHD. Maternal distress in mothers of severely ill children could lead to overprotection, lower expectations, and less engagement with respect to the child.[35] Mothers of infants with a severe disease may also show weaker attachment to the baby as a way of protecting themselves from the pain and loss they fear.[36] According to the theory of the vulnerable child syndrome, this could have a long-term negative influence on child development.[37] At the same time, it is possible that the association is due to a negative reporting bias, where distressed mothers overestimate problems with the child's development. However, if the reporting bias were the

only explanation, the mothers should have rated their children as being more at risk in all developmental domains and not only in the motor and communication areas.

Several limitations of this study need to be addressed. First, the participation in MoBa is rather low, at 42,7%[18], which raises an important question as to how representative the participants of this study are. However, analyses have shown that even though the MoBa study does not yield exact prevalence estimates due to self-selection biases, the associations between exposure and outcome seem to be reliable and valid.[38] In our study 27% of the severe CHD group had one or more developmental impairment. This is in the lower range of numbers reported in other studies.[10] Second, our results rely on short scales and subscales of parent-report screening measures. Additional clinical full scale assessments and clinical testing of the child's development would have been desirable to establish valid clinical diagnosis or developmental profiles. However, because of the large size and the broad scope of the MoBa study, clinical assessments were not feasible. Also, studies have shown that mothers are good raters of their child's development, as they have firsthand experience with their child's usual behavior.[21] Finally, the analyses of predictors of developmental impairments in children with severe CHD were limited by the small number of cases. Because of that we may have underestimated the effect of important predictors due to lack of statistical power.

In conclusion, the current results show that children with severe CHD have increased odds of having any developmental impairment at the age of 3 compared with controls, particularly gross motor and communication impairments. Early developmental impairments were associated with later developmental impairments in children with severe CHD, suggesting lasting impairments and not merely temporary delay. This emphasizes the importance of early attentiveness to developmental impairments. Other early predictors found in this study were smaller head circumference at birth, SGA, and maternal distress. This underlines the

importance of considering patient-specific conditions at birth for providing individualized, targeted therapeutic strategies to improve developmental outcomes in children with CHD. In addition, parental support to reduce maternal distress could potentially benefit the long-term development of the child.

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Table 1. Characteristics of the CHD Groups Compared with the Control Group

	Control group (n = 43,929)	Mild/moderate CHD (n = 115)	Severe CHD (n = 60)	P value[†]
Sex (%)				
Boys/girls	51.1 / 48.9	50.4 / 49.6	58.3/ 41.7	0.53
Birth weight (g)				
M ± SD	3581 ± 584	3506 ± 811	3331 ± 759*	.002
Gestational age (weeks)				
M ± SD	39.4±1.9	38.9 ± 2.7	38.6 ± 2.4*	<.0001
Maternal education (years)				
M ± SD	14.7 ± 2.5	14.5 ± 2.6	14.7 ± 2.6	ns
Surgery for CHD (%)	-	15.9	93.3	
Catheterized (repair) (%)	-	11.3	25.0	
Aristotle score‡ M ± SD	-	5.8 ± 1.13	9 ± 2.38	

[†] P values apply to comparison testing between the groups by means of the chi-square test for categorical variables and ANOVA for continuous variables.

* differ from controls $p < .05$ Bonferroni Post hoc test.

‡ Aristotle score is a score of the complexity of the surgical procedure in congenital heart surgery.[39]

Table 2. Logistic Regression Analyses of Developmental Outcomes in Children with CHD Compared with Control Group

	Control (n= 43,929)	Mild/Moderate CHD (n= 115)		Severe CHD (n= 60)	
	OR[†]	OR[†]	(95 % CI)	OR[†]	(95% CI)
Communication impairment	1	1.92	(.84 - 4.40)	3.15*	(1.25 - 7.91)
Grammar impairment	1	1.93	(.97-3.84)	1.58	(.57-4.38)
Prosocial impairment	1	.85	(.40-1.83)	1.45	(.62-3.38)
Gross motor impairment	1	2.34*	(1.13-4.82)	3.30*	(1.41-7.72)
Fine motor impairment	1	1.72	(.75-3.92)	2.17	(.79-6.02)
Any developmental impairment	1	1.20	(.80 – 2.11)	2.09*	(1.15-3.77)

* Significant difference from controls $p < .05$.

[†]Adjusted for gestational age and birth weight.

Table 3. Univariate Logistic Regression Analyses of Associations Between Risk Factors and Developmental Impairments in Children with Severe CHD (N = 60)

Risk factors	Range (mean) / N (%)	P values	OR*	95% CI
Child characteristics				
Sex (boys)	35 (58.3)	.12	2.74	.76-9.82
Gestational age in weeks	30-41 (38.6)	.29	.79	.51-1.22
Birth weight in grams	1251-4990 (3331)	.42	.83	.53-1.30
Small for gestational age (SGA)	7 (11.7)	.07	4.56	.89-23.2
Birth head circumference (cm) †	29-38 (34.7)	.03	.44	.21-.93
Surgical variables				
Age at first operation (days)	1-986 (81.9)	.16	1.54	.85-2.77
Cardiopulmonary bypass time (min)	32-281 (102.2)	.18	.58	.26-1.28
Cross-clamp time (min)	2-146 (49.4)	.15	.57	.26-1.22
Maternal characteristics				
Maternal education (years)	9-18 (14.7)	.64	1.15	.65-2.03
Maternal distress at 6 months (z-scores)	-.77-5.29 (.58)	.09	1.43	.94-2.16
Previous developmental impairments				
Motor impairment at 6 months	15 (25)	.04	3.61	1.01-12.92
Symptoms of communication impairment at 18 months (z-scores)	-.86-2.79 (.34)	.02	2.06	1.15-3.69
Symptoms of social impairment at 18 months (z-scores)	-.53-5.53 (.17)	.06	1.61	.98-2.66

* All continuous predictors were standardized into Z-scores before they were included in the logistic regression analyses.

† Standardized head circumference at birth, adjusted for sex.

APPENDIX I

Questionnaire 4
6 months postpartum

den norske **Mor & barn undersøkelsen**

Questionnaire 4 - When your child is around 6 months old

This questionnaire comes in two parts. The first part is about your child, while the other part is about yourself. It will help if you have your child's health card to hand before you start answering the questions so that you can use the information contained in it when completing this questionnaire. If you find a question difficult to answer, you can skip it and go onto the next question.

If you have had twins or triplets, complete one questionnaire for each child.

The questionnaire will be processed by a computer. *It is therefore important that you follow these instructions when completing it:*

- Use a blue or black ballpoint pen.
- In the small check boxes, enter *a cross* to indicate what you think is the most appropriate answer like this: ☒
  If you make a mistake you can delete the cross by filling in the box completely like this: ■
- Write numbers in the large green boxes.
  It is important that you only write in the white area of each box like this:
  Number: 0 1 2 3 4 5 6 7 8 9
- In the case of numbered boxes with more than one square, enter a one-digit number in the right box. *Example: 5 is entered as follows* 5
- Date boxes are split into 3 sections, with the first one for the day of the month, the second one for the month and the last one for the year.
  So, enter the date as follows: 6 (Day) 5 (Month) 2005 (Year)
- Specific information concerning, *for example, medication* should be written on the lines provided. *Please write clearly!*

As soon as you have completed the questionnaire, return it to us in the enclosed stamped addressed envelope.

Specify the day, month and year when the questionnaire was completed ☐☐ Day ☐☐ Month ☐☐☐☐ Year *(write the year in full, e.g. 2005)*

About your child's birth

1. Is your child a boy or girl?

☐ Boy

☐ Girl

2. How big was your child when he/she was born?

Birth weight: ☐☐☐☐ g

Length: ☐☐,☐ cm

3. In which week of your pregnancy did you give birth?

☐☐ week

4. How long was your child in hospital after the birth?

Number of days ☐☐ or weeks ☐☐

5. Was your child transferred to another department or hospital after the birth?

☐ No

☐ Yes

If yes, specify _____

6. Was your child delivered by caesarean section?

☐ No

☐ Yes

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7. If yes, was the caesarean section planned?

- ☐ No
- ☐ Yes

If yes, why?

- ☐ Breech presentation
- ☐ Previous caesarean
- ☐ Pregnancy complication or mother taken ill
- ☐ Poor growth or other factor relating to the foetus
- ☐ Own preference
- ☐ Other

8. Were there any complications during the birth?

- ☐ No
- ☐ Yes

If so, describe:_____

9. Were you admitted or transferred to another department or other hospital due to complications in connection with the birth? *(Applies both before and after the birth.)*

- ☐ No
- ☐ Yes

10. If yes, where?

Department:
_____

Hospital: _____

11. How many days were you in hospital in connection with the birth?

Before the birth ☐☐ Number of days

After the birth ☐☐ Number of days

12. Did the birth go as you had expected?

- ☐ Yes, as expected
- ☐ No, it went better
- ☐ Neither/nor
- ☐ No, it was worse
- ☐ Don't know

13. How true do you think the following descriptions are of the birth? *(Enter a cross in a box for each item.)*

	Fairly true	Partially true	Not true
I felt safe and in good hands	☐	☐	☐
I was in a lot of pain	☐	☐	☐
I received too few pain-killing drugs	☐	☐	☐

14. Was anyone from your close family present at the birth?

- ☐ Yes, child's father
- ☐ Yes, someone else
- ☐ No

About your child

Nutrition

15. What did you give your child to drink during the first week of life?
(You can enter a cross in more than one box.)

- ☐ Breast milk
- ☐ Water
- ☐ Sugar water
- ☐ Formula
- ☐ Other, specify: _____
- ☐ Don't know/don't remember

16. What has your child been given to drink during the first 6 months of his/her life?
(Enter a cross for each month you gave your child the relevant drink.)

	Child's age in months						
	0	1	2	3	4	5	6
Breast milk	☐	☐	☐	☐	☐	☐	☐
Standard Collett formula	☐	☐	☐	☐	☐	☐	☐
Collett formula with Omega 3	☐	☐	☐	☐	☐	☐	☐
Standard NAN formula	☐	☐	☐	☐	☐	☐	☐
Nan HA1 formula	☐	☐	☐	☐	☐	☐	☐
Other milk, specify: _____	☐	☐	☐	☐	☐	☐	☐
Water	☐	☐	☐	☐	☐	☐	☐
Squash/Juice	☐	☐	☐	☐	☐	☐	☐

17. How often do you give your child the following to drink at the moment? *(Enter a cross in a box for each item.)*

	Never/ seldom	1-3 times a week	4-6 times a week	At least once a day
1. Breast milk	☐	☐	☐	☐
2. Breast milk supplement	☐	☐	☐	☐
3. Normal sweet milk, any type	☐	☐	☐	☐
4. sour milk (yogurt, buttermilk, etc.)	☐	☐	☐	☐
5. Organic milk products (milk, yogurt)	☐	☐	☐	☐
6. Boiled water	☐	☐	☐	☐

Cont.

	Never/ seldom	1-3 times a week	4-6 times a week	At least once a day
7. Tap water	☐	☐	☐	☐
8. Bottled water	☐	☐	☐	☐
9. Bottled baby cordial	☐	☐	☐	☐
10. Other type of cordial, sweetened	☐	☐	☐	☐
11. Cordial, artificially sweetened	☐	☐	☐	☐
12. Juice	☐	☐	☐	☐
13. Other, specify: _____	☐	☐	☐	☐

18. How often does your child eat the following food at the moment, and how old was your child when you started giving him/her this food?

	How often do you give this to your child? Never/ seldom	1-3 times a week	4-6 times a week	At least once a day	How old was your child when you gave him/her this foodfor the first time?
Instant porridge					
1. Rice porridge, maize porridge	☐	☐	☐	☐	☐ months
2. Oatmeal porridge, different types	☐	☐	☐	☐	☐ months
3. Wheat porridge, all types, rusk porridge	☐	☐	☐	☐	☐ months
Home-made porridge using:					
4. Wheat flour (rough/fine), rusk, semolina, oats	☐	☐	☐	☐	☐ months
5. Iron-enriched wheat flour	☐	☐	☐	☐	☐ months
6. Helios baby flour	☐	☐	☐	☐	☐ months
7. Millet	☐	☐	☐	☐	☐ months
Processed dinner in a jar:					
8. Vegetables	☐	☐	☐	☐	☐ months
9. Vegetables and meat	☐	☐	☐	☐	☐ months
Home-made dinner:					
10. Potato/vegetable puree	☐	☐	☐	☐	☐ months
11. Meat and vegetables/potatoes	☐	☐	☐	☐	☐ months
12. Fish and vegetables/potatoes	☐	☐	☐	☐	☐ months
13. Other type of home-made dinner	☐	☐	☐	☐	☐ months
Snack/dessert:					
14. Home-made fruit puree	☐	☐	☐	☐	☐ months
15. Fruit/berry puree in a jar	☐	☐	☐	☐	☐ months
16. Rusks/biscuits/bread	☐	☐	☐	☐	☐ months
17. Other, specify: _____	☐	☐	☐	☐	☐ months

19. Do you think or do you know that your child has a reaction to milk/dairy products?

☐ No
☐ Yes

20. If yes, which products?

☐ Whole milk
☐ Low-fat milk/skimmed milk
☐ Cream/whipped cream/ice cream
☐ Yogurt/sour milk
☐ Breast milk when mother is drinking milk
☐ Other

21. Do you give your child cod liver oil, vitamins, iron or any other dietary supplement?

☐ No ☐ Yes

22. If you give your child cod liver oil, vitamins, iron or another dietary supplement, specify how much you give your child each time and how often. How old was your child in months and weeks when you gave him/her the product for the first time?

Name of product	How many teaspoons each time?	How often do you give your child this?	How old was your child when you started giving the product?
1. Cod liver oil	☐ teaspoons	☐ daily ☐ sometimes	☐ months and ☐ weeks
2. Biovit	☐ teaspoons	☐ daily ☐ sometimes	☐ months and ☐ weeks
3. Sanasol	☐ teaspoons	☐ daily ☐ sometimes	☐ months and ☐ weeks
4. Nycoplus Multi-Vitamin mixture for children	☐ teaspoons	☐ daily ☐ sometimes	☐ months and ☐ weeks
5. Fluoride		☐ daily ☐ sometimes	☐ months and ☐ weeks
6. Iron supplement, specify: _____		☐ daily ☐ sometimes	☐ months and ☐ weeks
7. Other dietary supplement, specify: _____		☐ daily ☐ sometimes	☐ months and ☐ weeks

Growth, health and use of medication

You will find the information to help you answer the following questions on your child's health card.

23. How many times have you been to the mother and child health centre with your child?

☐ Never
☐ 1-2 times
☐ 3-5 times
☐ 6-10 times
☐ more than 10 times

24. Has your child been given the vaccinations recommended by the health centre?

☐ Yes
☐ No, don't want vaccination
☐ No, your child has been often ill
☐ No, vaccinations postponed for practical reasons
☐ Don't know

25. Referring to your child's health card, enter a cross for the vaccinations which your child has received and whether the vaccinations had any side-effect. *(Enter a cross in a box for each item.)*

Vaccinations	Has your child received the vaccination?		Was there any side-effect after the vaccination?		Was there any side-effect resulting in contact with a doctor?		Was there any side-effect resulting in hospital admission?	
	No	Yes	No	Yes	No	Yes	No	Yes
1. DTP (Infanrix)	☐	☐	☐	☐	☐	☐	☐	☐
2. DT (diphtheria/tetanus)	☐	☐	☐	☐	☐	☐	☐	☐
3. Polio – Hib (Act-Hib polio)	☐	☐	☐	☐	☐	☐	☐	☐
4. Hepatitis B (Engerix-B)	☐	☐	☐	☐	☐	☐	☐	☐
5. BCG (tuberculosis)	☐	☐	☐	☐	☐	☐	☐	☐
6. Pneumococcus (Prevenar)	☐	☐	☐	☐	☐	☐	☐	☐
7. Other vaccination:_____	☐	☐	☐	☐	☐	☐	☐	☐

26. Referring to your child's health card, enter below your child's weight, length and head circumference when he/she was around 6 weeks, 3 months and 6 months.

+	Date of examination: Day	Month	Year	Length	Head circumference	Weight
Approx. 6 weeks				, cm	, cm	g
Approx. 3 months				, cm	, cm	g
5-6 months				, cm	, cm	g

The following questions concern any illnesses or health problems your child has had. We will first ask you about more longterm problems, then about illnesses and problems of a more acute nature.

27. Does your child have or has he/she had any of the following health problems? If yes, has the mother and child health centre or someone else referred your child for further specialist investigation? *(Enter a cross in a box for each item.)*

+	Has(had) your child problems? No	Yes	Has your child been referred for a specialist investigation? No	Yes, referred from health centre	Yes, referred by someone else
1. Hip disorder/dislocated hip	☐	☐	☐	☐	☐
2. Impaired hearing	☐	☐	☐	☐	☐
3. Impaired vision	☐	☐	☐	☐	☐
4. Delayed motor development (movement development)	☐	☐	☐	☐	☐
5. Too little weight gain	☐	☐	☐	☐	☐
6. Too much weight gain	☐	☐	☐	☐	☐
7. Abnormal head circumference	☐	☐	☐	☐	☐
8. Heart defect	☐	☐	☐	☐	☐
9. Testicles not descended into scrotum	☐	☐	☐	☐	☐
10. Asthma	☐	☐	☐	☐	☐ +
11. Atopic eczema (childhood eczema)	☐	☐	☐	☐	☐
12. Hives	☐	☐	☐	☐	☐
13. Food allergy/intolerance	☐	☐	☐	☐	☐
14. Delayed psychomotor development (several functions)	☐	☐	☐	☐	☐
15. (Other) malformations: _____	☐	☐	☐	☐	☐
16. Other:_____	☐	☐	☐	☐	☐

28. If your child was referred for a specialist investigation, what did this investigation show?

☐ Everything was fine +
☐ Still some doubts/further investigations needed
☐ Don't know
☐ Given the following diagnosis: _____

_____

_____

29. Is you child suspected of having a syndrome or chromosomal defect?

☐ No
☐ Yes, a syndrome
☐ Yes, a chromosomal defect
☐ If yes, specify the name or describe the problem:_____

_____

_____

30. Has your child been treated for a hip problem (hip dysplasia)?

☐ No
☐ Yes, treated with a cushion
☐ Yes, treated with a plaster cast
☐ Yes, treated with braces +

If yes, how long did the treatment go on for? ☐ months

31. Has your child had the following illness/health problem? If yes, did you go to a doctor or hospital about it? *(Enter a cross in a box for each item.)*

	Has your child had health problems?		Number of times doctor/clinic	Did you go to a doctor/clinic?		Has your child been admitted to hospital for this?	
	No	Yes		No	Yes	No	Yes
1. Common cold	☐	☐		☐	☐	☐	☐
2. Throat infection	☐	☐		☐	☐	☐	☐
3. Ear infection	☐	☐		☐	☐	☐	☐
4. Pseudocroup	☐	☐		☐	☐	☐	☐
5. Bronchitis/RS virus/pneumonia	☐	☐		☐	☐	☐	☐
6. Gastric flu/diarrhoea	☐	☐		☐	☐	☐	☐
7. Urinary tract infection	☐	☐		☐	☐	☐	☐
8. Conjunctivitis	☐	☐		☐	☐	☐	☐
9. Febrile convulsions	☐	☐		☐	☐	☐	☐
10. Other convulsions (without any fever)	☐	☐		☐	☐	☐	☐
11. Colic	☐	☐		☐	☐	☐	☐
12. Nappy rash	☐	☐		☐	☐	☐	☐
13. Other, describe _____	☐	☐		☐	☐	☐	☐

32. Have your child ever been given any medication?

☐ No
☐ Yes

33. If yes, give the name of the medicines and when they were given. *(Include all types of medication, as well as natural medicines, taken both on a regular and occasional basis.)*

Name of medicine *(e.g. Apocilin, Paracetamol)*	How old was your child when you gave the medicine? <1 Month	1-2 months	3-4 months	5-6 months	Number of days given in total
_____	☐	☐	☐	☐	
_____	☐	☐	☐	☐	
_____	☐	☐	☐	☐	
_____	☐	☐	☐	☐	

34. Has your child been examined at or admitted to hospital (since returning home from hospital after birth)?

☐ No

☐ Yes, specify: _____

35. Has your child been operated on or does he/she have a condition requiring an operation?

☐ No

☐ Yes, specify:

_____

Development, childcare and life style

36. The following questions concern your child's development. If you haven't actually observed your child, spend a little time looking at what he/she can actually do. *(Enter a cross in a box for each question.)*

	Yes often	Yes, but seldom	No, not yet	Don't know
1. When your child is lying on his/her back, does he/she play by grabbing hold of his/her feet?	☐	☐	☐	☐
2. When your child is lying on his/her tummy, does he/she raise his/her upper body off the ground with straight arms?	☐	☐	☐	☐
3. Does your child roll over from his/her back onto his/her tummy?	☐	☐	☐	☐
4. When you "chat" to your child, does he/she try to "chat" back to you?	☐	☐	☐	☐
5. Does your child babble and make sounds when he/she is lying on his/her own?	☐	☐	☐	☐
6. Can you tell how your child is just by listening to the sounds he/she is making *(e.g. contented, hungry, angry,in pain)?*	☐	☐	☐	☐
7. Do you get a smile from your child when you just smile at him/her *(without touching or tickling him/her and without holding up a toy)?*	☐	☐	☐	☐
8. When you call your child, does he/she turn towards you one of the first times you say his/her name?	☐	☐	☐	☐
9. Does your child grab hold of a toy you give him/her and then put it in his/her mouth or hold it?	☐	☐	☐	☐
10. When your child is sitting on your lap, does he/she stretch out for a toy or something else on the table in front of you?	☐	☐	☐	☐
11. Does your child hold onto a toy with both hands when he/she is examining it?	☐	☐	☐	☐

37. Where is your child cared for during the day?

☐ At home with mother/father/other family member
☐ At home with an unqualified childminder
☐ At a childminder's/family creche
☐ In an outdoor nursery
☐ In a nursery

38. How many other children are there usually along with your child during the day?

☐☐ children

39. Does your child go to baby swimming?

☐ No
☐ Yes

If yes, indicate the number of times during the last 2 months ☐☐

40. How often is your child outside? *(Enter just one cross.)*

☐ Seldom
☐ Often, but less than 1 hour a day
☐ 1-3 hours a day
☐ More than 3 hours a day

41. Does your child use a dummy/pacifier?

☐ Seldom or never
☐ Only when he/she goes to sleep
☐ Often
☐ Most of the time

42. How many hours in total does your child sleep per 24 hours?

☐ Less than 8 hours
☐ 8 - 10 hours
☐ 11 - 13 hours
☐ 13 - 14 hours
☐ More than 14 hours

43. How do you put your child down when he/she is going to sleep? *(Enter a cross in a box for each item.)*

	On back	On side	On tummy
After the birth	☐	☐	☐
At 2 months	☐	☐	☐
At 4 months	☐	☐	☐
At 6 months	☐	☐	☐

44. Does your child share a bed with his/her mother/father (at least half the night)? *(Enter a cross in a box for each item.)*

	No	sometimes	Often
After the birth	☐	☐	☐
At 2 months	☐	☐	☐
At 4 months	☐	☐	☐
At 6 months	☐	☐	☐

45. Enter a cross to indicate whether you agree or disagree with the following statements about your child's mood and temperament. Think about how he/she usually is. *(Enter a cross in a box for each item.)*

	Totally disagree	Disagree	Slightly disagree	Neither agree or disagree	Slightly agree	Agree	Totally agree
1. Your child whimpers and cries a lot	☐	☐	☐	☐	☐	☐	☐
2. Your child is usually easy to pacify when he/she is crying	☐	☐	☐	☐	☐	☐	☐
3. It doesn't take much for your child to become upset and start crying	☐	☐	☐	☐	☐	☐	☐
4. When your child is crying, he/she usually screams angrily and loudly	☐	☐	☐	☐	☐	☐	☐
5. Your child is very easy to deal with	☐	☐	☐	☐	☐	☐	☐
6. Your child demands an awful lot of attention	☐	☐	☐	☐	☐	☐	☐
7. When your child is left alone, he/she usually plays contentedly on his/her own	☐	☐	☐	☐	☐	☐	☐
8. Your child is so demanding that he/she would pose a major problem for most parents	☐	☐	☐	☐	☐	☐	☐
9. Your child smiles and laughs often	☐	☐	☐	☐	☐	☐	☐
10. Your child is easy to put down and goes to sleep quickly	☐	☐	☐	☐	☐	☐	☐

46. Currently how often does your child usually wake up during the night? *(Enter just one cross.)*

- ☐ 3 or more times every night
- ☐ Once or twice every night
- ☐ A few times a week
- ☐ Seldom or never

Comments

About yourself

The last time you completed a questionnaire was around week 30 of your pregnancy. The questions we are asking you now are mainly about the period after this up until your child was 6 months old.

Health and use of medication

47. Did you go to your doctor/midwife/health visitor for your own health problems during the first month after the birth?

☐ No
☐ Yes ☐☐ times

48. If yes, what was the reason for this?

☐ Perninealwound/stitches
☐ Caesarean section wound
☐ Mastitis
☐ Sore nipples
☐ Breastfeeding problems
☐ Other, specify: _____

49. When you think back to the time just after the birth, did you feel depressed during that period?

☐ No
☐ Yes, specify how long: ☐☐ weeks

50. Apart from being in hospital for the birth, have you been admitted to hospital since you completed the previous questionnaire?

☐ No
☐ Yes, specify hospital: _____

51. Do you have a chronic/long-term illness which has started since you completed the previous questionnaire?

☐ No
☐ Yes, specify: _____

52. Overall, how would you describe your physical health at the moment?

☐ Very good
☐ Good
☐ Poor
☐ Very poor

53. Have you had any of the following problems/illnesses since you completed the previous questionnaire? If yes, are you taking or have you taken medication for these problems? *(This includes every type of medication, including natural medicines, taken on both a regular and occasional basis.) (Enter a cross in a box for each item.)*

Have you suffered from?				If you have taken medication				
Illness / problem	No	Yes, last part of during pregnancy	Yes, after the birth	Name of medication taken	Last part of this pregnancy	After the birth 0-3 mth	After the birth 4-6 mth	Number of days taken in total
1. Sugar in urine	☐	☐	☐	_____	☐	☐	☐	☐☐☐
2. Protein in urine	☐	☐	☐	_____	☐	☐	☐	☐☐☐
3. High blood pressure . .	☐	☐	☐	_____	☐	☐	☐	☐☐☐
4. Swelling (oedema)	☐	☐	☐	_____	☐	☐	☐	☐☐☐
5. Cystitis	☐	☐	☐	_____	☐	☐	☐	☐☐☐
6. Sluggish bowels/constipation	☐	☐	☐	_____	☐	☐	☐	☐☐☐
7. Diarrhoea/vomiting	☐	☐	☐	_____	☐	☐	☐	☐☐☐
8. Heartburn/acidity	☐	☐	☐	_____	☐	☐	☐	☐☐☐
9. Common cold/influenza	☐	☐	☐	_____	☐	☐	☐	☐☐☐
10. Sore throat/sinusitis/earinfection	☐	☐	☐	_____	☐	☐	☐	☐☐☐

cont. next page

Have you suffered from?				If you have taken medication				
Illness / problem	No	Yes, last part of during pregnancy	Yes, after the birth	Name of medication taken	Last part of this pregnancy	After the birth 0-3 mth	After the birth 4-6 mth	Number of days taken in total
11. Pneumonia/bronchitis . .	☐	☐	☐	_____	☐	☐	☐	
12. Asthma	☐	☐	☐	_____	☐	☐	☐	
13. Hay fever/other allergy.	☐	☐	☐	_____	☐	☐	☐	
14. Headache/other pains .	☐	☐	☐	_____	☐	☐	☐	
15. Vaginitis	☐	☐	☐	_____	☐	☐	☐	
16. Mental health problems	☐	☐	☐	_____	☐	☐	☐	
17. Mastitis.	☐	☐	☐	_____	☐	☐	☐	
18. Fever	☐	☐	☐	_____	☐	☐	☐	
19. Other, specify: _____	☐	☐	☐	_____	☐	☐	☐	

54. Have you taken medicines other than those mentioned in Question 52? *(For instance, sleeping tablets, sedatives or analgesics.)*

☐ No ☐ Yes

55. If yes, give the name of the medicines and when you took them. *(Include all types of medication, as well as natural medicines, taken both on a regular and occasional basis.)*

Name of medicine (e.g. Valium, Rohypnol, Paracetamol)	Last part of pregnancy: Taken medication	Last part of pregnancy: Number of days	0-3 months after the birth: Taken medication	0-3 months after the birth: Number of days	4-6 months after the birth: Taken medication	4-6 months after the birth: Number of days
_____	☐		☐		☐	
_____	☐		☐		☐	
_____	☐		☐		☐	

56. Do you take or have you taken cod liver oil, vitamins or other dietary supplements since the previous questionnaire?

☐ No ☐ Yes

57. If yes, which product, when did you take it and how often? *(One line for each product.)*

Name of product	When did you take the product? Last part of pregnancy	0-3 months after the birth	4-6 months after the birth	How often? Taken daily	Taken sometimes
_____	☐	☐	☐	☐	☐
_____	☐	☐	☐	☐	☐
_____	☐	☐	☐	☐	☐

58. Have you experienced any pain in your back or pelvis since you completed the previous questionnaire?

☐ No
☐ Yes

59. If yes, enter a cross to indicate where you have experienced pain, when and how much.

Where was the pain?	Last part of pregnancy: Some pain	Last part of pregnancy: Major pain	0-3 months after the birth: Some pain	0-3 months after the birth: Major pain	4-6 months after the birth: Some pain	4-6 months after the birth: Major pain
Small of the back	☐	☐	☐	☐	☐	☐
One of the pelvic/sacroiliac joints at the back	☐	☐	☐	☐	☐	☐
Both pelvic/sacroiliac joints at the back	☐	☐	☐	☐	☐	☐
Over the coccygeal bone	☐	☐	☐	☐	☐	☐
In the buttocks	☐	☐	☐	☐	☐	☐
Over the pubic bone	☐	☐	☐	☐	☐	☐
Groin	☐	☐	☐	☐	☐	☐
Other back pains	☐	☐	☐	☐	☐	☐

60. Currently, do you wake up at night because of pelvic pain?

☐ No, never
☐ Yes, but only sometimes
☐ Yes, often

61. Do you have such problems walking at the moment due to pelvic pain that you have to use a stick or crutches?

☐ No, never
☐ Yes, but not every day
☐ Yes, every day

62. Have you *ever* received treatment for pelvic pain?

☐ No
☐ Yes

63. If yes, enter a cross to indicate the type of treatment and when it was.

	Before this pregnancy	During this pregnancy	After this birth
Physiotherapy	☐	☐	☐
Chiropractic	☐	☐	☐
Medication	☐	☐	☐
Other, specify: _____	☐	☐	☐

64, How long was it before you resumed sexual intercourse after the birth?

☐☐ weeks

☐ Have not had sexual intercourse

65. Do you have any of the following problems at the moment; if so, how often and to what extent? *(Enter a cross in a box for each item.)*

Problem	How often do you have these problems? Never	1-4 times a month	1-6 times a week	Once a day	More than Once a day	How much at a time? Drops	Large amounts
Incontinence when coughing, sneezing or laughing	☐	☐	☐	☐	☐	☐	☐
Incontinence during physical activity (running/jumping)	☐	☐	☐	☐	☐	☐	☐
Incontinence with a strong need to urinate	☐	☐	☐	☐	☐	☐	☐
Problems retaining faeces	☐	☐	☐	☐	☐	☐	☐
Problems with flatulence	☐	☐	☐	☐	☐	☐	☐

66. How many times did you go for an ultrasound scan during your pregnancy?

☐☐ times

67. Was everything OK with the ultrasound scan(s)?

☐ Yes
☐ No

68. If no, what was the problem?

☐ The baby was not growing enough.
☐ Suspected malformation,describe:

_____

☐ Other, specify: _____

69. How much did you weigh at the end of your pregnancy and how much do you weigh now?

At end of pregnancy ☐☐☐,☐ kg

Now ☐☐☐,☐ kg

+

70. Were you completely or partly on sick leave after week 30 of your pregnancy? *(Don't include maternity leave)*

- ☐ No
- ☐ Yes,partly on sick leave
- ☐ Yes,completely on sick leave

+

71. If you were on sick leave after week 30 of your pregnancy, complete the table below with a line for each time you were on sick leave. Give the reason and enter a cross indicating which weeks of your pregnancy you were on sick leave. Specify how many days and what percentage of the period you were on sick leave each time.

Reason for sick leave:	Was on sick leave during pregnancy weeks 30-33	34-37	38+	Number of days	% sick leave
Example: pelvic girdle pains	☐	☒	☐	10	50
	☐	☐	☐		
	☐	☐	☐		
	☐	☐	☐		

Finances – lifestyle

72. Would your current financial situation allow you to cope with an unexpected bill of NOK 10,000 for a dental visit or a repair, for a instance?

- ☐ No
- ☐ Yes
- ☐ Don't know

73. Have you found it difficult sometimes during the last six month to cope with running expemces for food, transport, rent etc.?

- ☐ No, never
- ☐ Yes, but infrequently
- ☐ Yes, sometimes
- ☐ Yes, often

74. Are there pets in the child's home?

- ☐ No
- ☐ Yes

+

75. If yes, which type(s)? *(You can enter a cross in more than one box.)*

- ☐ Dog
- ☐ Cat
- ☐ Guinea pig, rabbit, mouse, rat, etc.
- ☐ Budgie, other type of bird
- ☐ Other type of animal:

_____

76. Do you have heating based on electrical heating cables under the floor in rooms where you child is? (Do <u>not</u> include waterborne heating)

- ☐ No
- ☐ Yes

77. If yes, in which rooms? *(You can enter a cross in more than one box.)*

- ☐ Living room
- ☐ Kitchen
- ☐ Child's room
- ☐ Bedroom
- ☐ Hall
- ☐ Bathroom
- ☐ Other rooms

78. How often do you exercise these muscle groups at home or at the gym at present? *(Enter a cross in a box for each item.)*

	Never	1-3 times times a month	Once a week	Twice a week	Three times or more a week
Stomach muscles	☐	☐	☐	☐	☐
Back muscles	☐	☐	☐	☐	☐
Pelvic floor muscles (muscles around the vagina, urethra, rectum)	☐	☐	☐	☐	☐

79. How often are you physically active at present? *(Enter a cross in a box for each item.)*

	Never	1-3 times a month	Once a week	Twice a week	Three times or more a week
1 Didn't smoke	☐	☐	☐	☐	☐
2 Brisk walking	☐	☐	☐	☐	☐
3 Running/jogging/orienteering	☐	☐	☐	☐	☐
4 Cycling	☐	☐	☐	☐	☐
5 Training studio/weight training	☐	☐	☐	☐	☐
6 Special gymnastics/aerobics for pregnant women	☐	☐	☐	☐	☐
7 Aerobics/gymnastics/dancing without running and jumping	☐	☐	☐	☐	☐
8 Aerobics/gymnastics/dancing with running and jumping	☐	☐	☐	☐	☐
9 Dancing (swing, rock, folk)	☐	☐	☐	☐	☐
10 Skiing	☐	☐	☐	☐	☐
11 Ball sport	☐	☐	☐	☐	☐
12 Swimming	☐	☐	☐	☐	☐
13 Riding	☐	☐	☐	☐	☐
14 Other	☐	☐	☐	☐	☐

80. Currently how often are you physically active (during your spare time or at work) that you get out of breath or sweat?

	Spare time	At work
Never	☐	☐
Less than once a week	☐	☐
Once a week	☐	☐
Twice a week	☐	☐
3-4 times a week	☐	☐
5 times or more a week	☐	☐

81. What were your and your partner/husband's smoking habits during the last 3 months of your pregnancy and in the period after the birth? *(Enter a cross in a box for each period.)*

	Yourself			Your partner/husband		
	Last 3 mths during pregnancy	0-3 mths after birth	4-6 mths after birth	Last 3 mths during pregnancy	0-3 mths after birth	4-6 mths after birth
Didn't smoke	☐	☐	☐	☐	☐	☐
Smoked sometimes	☐	☐	☐	☐	☐	☐
Smoked every day	☐	☐	☐	☐	☐	☐
If every day, number of cigarettes per day	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐
If sometimes, number of cigarettes per week	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐

82. Is your child ever present in a room where someone smokes?

- ☐ No
- ☐ Yes, sometimes
- ☐ Yes, several times a week
- ☐ Yes, every day

If every day, number of hours ☐☐

83. Did you take any of the following substances during the last 3 months of your pregnancy and after the birth? *(Enter a cross in a box for each item.)*

	No	Yes, last 3 month of pregnancy	Yes after birth
Hanish	☐	☐	☐
Amphetamines	☐	☐	☐
Ecstasy	☐	☐	☐
Cocaine	☐	☐	☐
Heroin	☐	☐	☐
Other, specify: _____	☐	☐	☐

84. Have you taken any of the following substances during the last 3 months of your pregnancy and after the birth? *(Enter a cross in a box for each item.)*

	No	Yes, last 3 months of pregnancy	Yes, after birth
Anabolic steroids	☐	☐	☐
Testosterone preparations	☐	☐	☐
Growth hormone (e.g. genotropin/somatropin)	☐	☐	☐

85. How often did you drink alcohol during the last 3 months of your pregnancy and how often do you drink now? *(Enter a cross in a box for each period.)*

	Last 3 months of pregnancy	After the birth	
		0-3 months	4-6 months
Roughly 6-7 times a week	☐	☐	☐
Roughly 4-5 times a week	☐	☐	☐
Roughly 2-3 times a week	☐	☐	☐
Roughly once a week	☐	☐	☐
Roughly 1-3 times a month	☐	☐	☐
Less often than once a month	☐	☐	☐
Never	☐	☐	☐

Alcohol units
In order compare different types of alcohol, we ask for the number of alcohol units (= 1.5 cl of pure alcohol). In practice, this means the following:

1 glass (1/3 litre) of beer	= 1 alcohol unit
1 wine glass of red or white wine	= 1 alcohol unit
1 sherryglass of sherry	= 1 alcohol unit
1 brandy glass of spirits or liquer	= 1 alcohol unit
1 bottle of alcopop/cider	= 1 alcohol unit

86. How many units of alcohol do you usually drink when you consume alcohol (complete both for the last 3 months of your pregnancy and afterwords)? *(See explanation about alcohol units.) (Enter a cross in a box for each period.)*

Number of alcohol units	Last 3 months of pregnancy	After the birth	
		0-3 months	4-6 months
10 or more	☐	☐	☐
7-9	☐	☐	☐
5-6	☐	☐	☐
3-4	☐	☐	☐
1-2	☐	☐	☐
Less than 1	☐	☐	☐

A little more about yourself and how you are keeping now

87. Do you have a boyfriend/ husband/partner?

☐ Yes
☐ No

88. If yes, to what extent do you agree with the following descriptions? *(Enter just one cross in a box for each item.)*

	Totally agree	Agree	Slightly agree	Slightly disagree	Disagree	Totally disagree
My husband/partner and I have a close relationship	☐	☐	☐	☐	☐	☐
My partner and I have problems in our relationship	☐	☐	☐	☐	☐	☐
I am very happy in my relationship	☐	☐	☐	☐	☐	☐
My partner is usually understanding	☐	☐	☐	☐	☐	☐
I often think about ending our relationship	☐	☐	☐	☐	☐	☐
I am satisfied with my relationship with my partner	☐	☐	☐	☐	☐	☐
We often disagree about important decisions	☐	☐	☐	☐	☐	☐
I have been lucky in my choice of partner	☐	☐	☐	☐	☐	☐
We agree on how children should be raised	☐	☐	☐	☐	☐	☐
I think my partner is satisfied with our relationship	☐	☐	☐	☐	☐	☐

89. In your daily life, how often do you *(Enter just one cross in a box for each item.)*

	Seldom never	Fairly seldom	A few times	Often	Very often
Feel pleased about something	☐	☐	☐	☐	☐
Feel happy	☐	☐	☐	☐	☐
Feel joyful, as though everything is going your way	☐	☐	☐	☐	☐
Feel that you will scream at someone or hit something	☐	☐	☐	☐	☐
Feel angry, irritated or annoyed	☐	☐	☐	☐	☐
Feel mad at somebody	☐	☐	☐	☐	☐

90. Indicate with a cross whether you agree or disagree with the following statements.
(Enter just one cross in a box for each item.)

	Totally disagree	Disagree	Slightly disagree	Neither agree or disagree	Slightly agree	Agree	Totally agree
My life is largely what I wanted it to be	☐	☐	☐	☐	☐	☐	☐
My life is very good	☐	☐	☐	☐	☐	☐	☐
I am satisfied with my life	☐	☐	☐	☐	☐	☐	☐
I have achieved so far what is important for me in my life	☐	☐	☐	☐	☐	☐	☐
If I could start all over, there is very little I would do differently	☐	☐	☐	☐	☐	☐	☐

91. Have you experienced any of the following situations since the previous questionnaire? If yes, how painful or difficult was this for you? *(Enter a cross in a box for each item.)*

			If yes		
	No	Yes	Not so bad	Painful/ difficult	Very painful/ difficult
Have you had problems at work or where you study?	☐	☐	☐	☐	☐
Have you had financial problems?	☐	☐	☐	☐	☐
Have you been divorced, separated or ended your relationship with your partner?	☐	☐	☐	☐	☐
Have you had problems or conflicts with family, friends or neighbours?	☐	☐	☐	☐	☐
Have you been seriously worried that there is something wrong with your child?	☐	☐	☐	☐	☐
Have you been seriously ill or injured?	☐	☐	☐	☐	☐
Has anyone close to you been seriously ill or injured?	☐	☐	☐	☐	☐
Have you been involved in a serious accident, fire or robbery?	☐	☐	☐	☐	☐
Have you lost someone close to you?	☐	☐	☐	☐	☐
Have you been pressurized into having sexual intercourse?	☐	☐	☐	☐	☐
Other	☐	☐	☐	☐	☐

92. Have you experienced any of the following feelings during the last week? *(Enter just one cross in a box for each item.)*

	Yes, almost all the time	Yes, now and then	Not very often	No, never
Really reproached yourself when something went wrong	☐	☐	☐	☐
Have been anxious or worried for no reason	☐	☐	☐	☐
Have been afraid or panicked for no reason	☐	☐	☐	☐
Have been so unhappy that you've had problems sleeping	☐	☐	☐	☐
Felt down or unhappy	☐	☐	☐	☐
Have been so unhappy that you've cried	☐	☐	☐	☐

93. How do you feel about yourself? *(Enter just one cross in a box for each item.)*

	Totally agree	Agree	Disagree	Totally disagree
I have a positive attitude towards myself	☐	☐	☐	☐
I feel completely useless at times	☐	☐	☐	☐
I feel that I do not have much to be proud about	☐	☐	☐	☐
I feel that I am a valuable person, as good as anyone else	☐	☐	☐	☐

94. Have you been bothered by any of the following feelings during the past 2 weeks? *(Enter just one cross in a box for each item.)*

	Not bothered	A little bothered	Quite bothered	Very bothered
Feeling fearful	☐	☐	☐	☐
Nervousness or shakiness inside	☐	☐	☐	☐
Feeling hopeless about the future	☐	☐	☐	☐
Feeling blue	☐	☐	☐	☐
Worrying too much about things	☐	☐	☐	☐
Feeling everything is an effort	☐	☐	☐	☐
Feeling tense or keyed up	☐	☐	☐	☐
Suddenly scared for no reason	☐	☐	☐	☐

Thank you very much for your help!

Insert the completed questionnaire in the stamped addressed envelope.

APPENDIX II

Questionnaire 5
18 months postpartum

den norske **Mor & barn undersøkelsen**

Questionnaire 4 - When your child is around 6 months old

This questionnaire comes in two parts. The first part is about your child, while the other part is about yourself. It will help if you have your child's health card to hand before you start answering the questions so that you can use the information contained in it when completing this questionnaire. If you find a question difficult to answer, you can skip it and go onto the next question.

If you have had twins or triplets, complete one questionnaire for each child.

The questionnaire will be processed by a computer. *It is therefore important that you follow these instructions when completing it:*

- Use a blue or black ballpoint pen.
- In the small check boxes, enter *a cross* to indicate what you think is the most appropriate answer like this: ☒
  If you make a mistake you can delete the cross by filling in the box completely like this: ■
- Write numbers in the large green boxes.
  It is important that you only write in the white area of each box like this:
  Number: 0 1 2 3 4 5 6 7 8 9
- In the case of numbered boxes with more than one square, enter a one-digit number in the right box. *Example: 5 is entered as follows* 5
- Date boxes are split into 3 sections, with the first one for the day of the month, the second one for the month and the last one for the year.
  So, enter the date as follows: 6 (Day) 5 (Month) 2005 (Year)
- Specific information concerning, *for example, medication* should be written on the lines provided. *Please write clearly!*

As soon as you have completed the questionnaire, return it to us in the enclosed stamped addressed envelope.

Specify the day, month and year when the questionnaire was completed ☐☐ Day ☐☐ Month ☐☐☐☐ Year *(write the year in full, e.g. 2005)*

About your child's birth

1. Is your child a boy or girl?

☐ Boy

☐ Girl

2. How big was your child when he/she was born?

Birth weight: ☐☐☐☐ g

Length: ☐☐,☐ cm

3. In which week of your pregnancy did you give birth?

☐☐ week

4. How long was your child in hospital after the birth?

Number of days ☐☐ or weeks ☐☐

5. Was your child transferred to another department or hospital after the birth?

☐ No

☐ Yes

If yes, specify _____

6. Was your child delivered by caesarean section?

☐ No

☐ Yes

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7. If yes, was the caesarean section planned?

- ☐ No
- ☐ Yes

If yes, why?

- ☐ Breech presentation
- ☐ Previous caesarean
- ☐ Pregnancy complication or mother taken ill
- ☐ Poor growth or other factor relating to the foetus
- ☐ Own preference
- ☐ Other

8. Were there any complications during the birth?

- ☐ No
- ☐ Yes

If so, describe:_____

9. Were you admitted or transferred to another department or other hospital due to complications in connection with the birth? *(Applies both before and after the birth.)*

- ☐ No
- ☐ Yes

10. If yes, where?

Department:
_____

Hospital: _____

11. How many days were you in hospital in connection with the birth?

Before the birth ☐☐ Number of days

After the birth ☐☐ Number of days

12. Did the birth go as you had expected?

- ☐ Yes, as expected
- ☐ No, it went better
- ☐ Neither/nor
- ☐ No, it was worse
- ☐ Don't know

13. How true do you think the following descriptions are of the birth? *(Enter a cross in a box for each item.)*

	Fairly true	Partially true	Not true
I felt safe and in good hands	☐	☐	☐
I was in a lot of pain	☐	☐	☐
I received too few pain-killing drugs	☐	☐	☐

14. Was anyone from your close family present at the birth?

- ☐ Yes, child's father
- ☐ Yes, someone else
- ☐ No

About your child

Nutrition

15. What did you give your child to drink during the first week of life?
(You can enter a cross in more than one box.)

- ☐ Breast milk
- ☐ Water
- ☐ Sugar water
- ☐ Formula
- ☐ Other, specify: _____
- ☐ Don't know/don't remember

16. What has your child been given to drink during the first 6 months of his/her life?
(Enter a cross for each month you gave your child the relevant drink.)

	Child's age in months						
	0	1	2	3	4	5	6
Breast milk	☐	☐	☐	☐	☐	☐	☐
Standard Collett formula	☐	☐	☐	☐	☐	☐	☐
Collett formula with Omega 3	☐	☐	☐	☐	☐	☐	☐
Standard NAN formula	☐	☐	☐	☐	☐	☐	☐
Nan HA1 formula	☐	☐	☐	☐	☐	☐	☐
Other milk, specify: _____	☐	☐	☐	☐	☐	☐	☐
Water	☐	☐	☐	☐	☐	☐	☐
Squash/Juice	☐	☐	☐	☐	☐	☐	☐

17. How often do you give your child the following to drink at the moment? *(Enter a cross in a box for each item.)*

	Never/ seldom	1-3 times a week	4-6 times a week	At least once a day
1. Breast milk	☐	☐	☐	☐
2. Breast milk supplement	☐	☐	☐	☐
3. Normal sweet milk, any type	☐	☐	☐	☐
4. sour milk (yogurt, buttermilk, etc.)	☐	☐	☐	☐
5. Organic milk products (milk, yogurt)	☐	☐	☐	☐
6. Boiled water	☐	☐	☐	☐

Cont.

	Never/ seldom	1-3 times a week	4-6 times a week	At least once a day
7. Tap water	☐	☐	☐	☐
8. Bottled water	☐	☐	☐	☐
9. Bottled baby cordial	☐	☐	☐	☐
10. Other type of cordial, sweetened	☐	☐	☐	☐
11. Cordial, artificially sweetened	☐	☐	☐	☐
12. Juice	☐	☐	☐	☐
13. Other, specify: _____	☐	☐	☐	☐

18. How often does your child eat the following food at the moment, and how old was your child when you started giving him/her this food?

	How often do you give this to your child? Never/ seldom	1-3 times a week	4-6 times a week	At least once a day	How old was your child when you gave him/her this foodfor the first time?
Instant porridge					
1. Rice porridge, maize porridge	☐	☐	☐	☐	☐ months
2. Oatmeal porridge, different types	☐	☐	☐	☐	☐ months
3. Wheat porridge, all types, rusk porridge	☐	☐	☐	☐	☐ months
Home-made porridge using:					
4. Wheat flour (rough/fine), rusk, semolina, oats	☐	☐	☐	☐	☐ months
5. Iron-enriched wheat flour	☐	☐	☐	☐	☐ months
6. Helios baby flour	☐	☐	☐	☐	☐ months
7. Millet	☐	☐	☐	☐	☐ months
Processed dinner in a jar:					
8. Vegetables	☐	☐	☐	☐	☐ months
9. Vegetables and meat	☐	☐	☐	☐	☐ months
Home-made dinner:					
10. Potato/vegetable puree	☐	☐	☐	☐	☐ months
11. Meat and vegetables/potatoes	☐	☐	☐	☐	☐ months
12. Fish and vegetables/potatoes	☐	☐	☐	☐	☐ months
13. Other type of home-made dinner	☐	☐	☐	☐	☐ months
Snack/dessert:					
14. Home-made fruit puree	☐	☐	☐	☐	☐ months
15. Fruit/berry puree in a jar	☐	☐	☐	☐	☐ months
16. Rusks/biscuits/bread	☐	☐	☐	☐	☐ months
17. Other, specify: _____	☐	☐	☐	☐	☐ months

19. Do you think or do you know that your child has a reaction to milk/dairy products?

☐ No
☐ Yes

20. If yes, which products?

☐ Whole milk
☐ Low-fat milk/skimmed milk
☐ Cream/whipped cream/ice cream
☐ Yogurt/sour milk
☐ Breast milk when mother is drinking milk
☐ Other

21. Do you give your child cod liver oil, vitamins, iron or any other dietary supplement?

☐ No ☐ Yes

22. If you give your child cod liver oil, vitamins, iron or another dietary supplement, specify how much you give your child each time and how often. How old was your child in months and weeks when you gave him/her the product for the first time?

Name of product	How many teaspoons each time?	How often do you give your child this?	How old was your child when you started giving the product?
1. Cod liver oil	☐ teaspoons	☐ daily ☐ sometimes	☐ months and ☐ weeks
2. Biovit	☐ teaspoons	☐ daily ☐ sometimes	☐ months and ☐ weeks
3. Sanasol	☐ teaspoons	☐ daily ☐ sometimes	☐ months and ☐ weeks
4. Nycoplus Multi-Vitamin mixture for children	☐ teaspoons	☐ daily ☐ sometimes	☐ months and ☐ weeks
5. Fluoride		☐ daily ☐ sometimes	☐ months and ☐ weeks
6. Iron supplement, specify: _____		☐ daily ☐ sometimes	☐ months and ☐ weeks
7. Other dietary supplement, specify: _____		☐ daily ☐ sometimes	☐ months and ☐ weeks

Growth, health and use of medication

You will find the information to help you answer the following questions on your child's health card.

23. How many times have you been to the mother and child health centre with your child?

☐ Never
☐ 1-2 times
☐ 3-5 times
☐ 6-10 times
☐ more than 10 times

24. Has your child been given the vaccinations recommended by the health centre?

☐ Yes
☐ No, don't want vaccination
☐ No, your child has been often ill
☐ No, vaccinations postponed for practical reasons
☐ Don't know

25. Referring to your child's health card, enter a cross for the vaccinations which your child has received and whether the vaccinations had any side-effect. *(Enter a cross in a box for each item.)*

Vaccinations	Has your child received the vaccination?		Was there any side-effect after the vaccination?		Was there any side-effect resulting in contact with a doctor?		Was there any side-effect resulting in hospital admission?	
	No	Yes	No	Yes	No	Yes	No	Yes
1. DTP (Infanrix)	☐	☐	☐	☐	☐	☐	☐	☐
2. DT (diphtheria/tetanus)	☐	☐	☐	☐	☐	☐	☐	☐
3. Polio – Hib (Act-Hib polio)	☐	☐	☐	☐	☐	☐	☐	☐
4. Hepatitis B (Engerix-B)	☐	☐	☐	☐	☐	☐	☐	☐
5. BCG (tuberculosis)	☐	☐	☐	☐	☐	☐	☐	☐
6. Pneumococcus (Prevenar)	☐	☐	☐	☐	☐	☐	☐	☐
7. Other vaccination:_____	☐	☐	☐	☐	☐	☐	☐	☐

26. Referring to your child's health card, enter below your child's weight, length and head circumference when he/she was around 6 weeks, 3 months and 6 months.

+	Date of examination: Day	Month	Year	Length	Head circumference	Weight
Approx. 6 weeks				, cm	, cm	g
Approx. 3 months				, cm	, cm	g
5-6 months				, cm	, cm	g

The following questions concern any illnesses or health problems your child has had. We will first ask you about more longterm problems, then about illnesses and problems of a more acute nature.

27. Does your child have or has he/she had any of the following health problems? If yes, has the mother and child health centre or someone else referred your child for further specialist investigation? *(Enter a cross in a box for each item.)*

+	Has(had) your child problems? No	Yes	Has your child been referred for a specialist investigation? No	Yes, referred from health centre	Yes, referred by someone else
1. Hip disorder/dislocated hip	☐	☐	☐	☐	☐
2. Impaired hearing	☐	☐	☐	☐	☐
3. Impaired vision	☐	☐	☐	☐	☐
4. Delayed motor development (movement development)	☐	☐	☐	☐	☐
5. Too little weight gain	☐	☐	☐	☐	☐
6. Too much weight gain	☐	☐	☐	☐	☐
7. Abnormal head circumference	☐	☐	☐	☐	☐
8. Heart defect	☐	☐	☐	☐	☐
9. Testicles not descended into scrotum	☐	☐	☐	☐	☐
10. Asthma	☐	☐	☐	☐	☐ +
11. Atopic eczema (childhood eczema)	☐	☐	☐	☐	☐
12. Hives	☐	☐	☐	☐	☐
13. Food allergy/intolerance	☐	☐	☐	☐	☐
14. Delayed psychomotor development (several functions)	☐	☐	☐	☐	☐
15. (Other) malformations: _____	☐	☐	☐	☐	☐
16. Other:_____	☐	☐	☐	☐	☐

28. If your child was referred for a specialist investigation, what did this investigation show?

☐ Everything was fine +
☐ Still some doubts/further investigations needed
☐ Don't know
☐ Given the following diagnosis: _____

_____

_____

29. Is you child suspected of having a syndrome or chromosomal defect?

☐ No
☐ Yes, a syndrome
☐ Yes, a chromosomal defect
☐ If yes, specify the name or describe the problem:_____

_____

_____

30. Has your child been treated for a hip problem (hip dysplasia)?

☐ No
☐ Yes, treated with a cushion
☐ Yes, treated with a plaster cast
☐ Yes, treated with braces +

If yes, how long did the treatment go on for? ☐ months

31. Has your child had the following illness/health problem? If yes, did you go to a doctor or hospital about it? *(Enter a cross in a box for each item.)*

	Has your child had health problems?		Number of times doctor/clinic	Did you go to a doctor/clinic?		Has your child been admitted to hospital for this?	
	No	Yes		No	Yes	No	Yes
1. Common cold	☐	☐		☐	☐	☐	☐
2. Throat infection	☐	☐		☐	☐	☐	☐
3. Ear infection	☐	☐		☐	☐	☐	☐
4. Pseudocroup	☐	☐		☐	☐	☐	☐
5. Bronchitis/RS virus/pneumonia	☐	☐		☐	☐	☐	☐
6. Gastric flu/diarrhoea	☐	☐		☐	☐	☐	☐
7. Urinary tract infection	☐	☐		☐	☐	☐	☐
8. Conjunctivitis	☐	☐		☐	☐	☐	☐
9. Febrile convulsions	☐	☐		☐	☐	☐	☐
10. Other convulsions (without any fever)	☐	☐		☐	☐	☐	☐
11. Colic	☐	☐		☐	☐	☐	☐
12. Nappy rash	☐	☐		☐	☐	☐	☐
13. Other, describe _____	☐	☐		☐	☐	☐	☐

32. Have your child ever been given any medication?

☐ No
☐ Yes

33. If yes, give the name of the medicines and when they were given. *(Include all types of medication, as well as natural medicines, taken both on a regular and occasional basis.)*

Name of medicine *(e.g. Apocilin, Paracetamol)*	How old was your child when you gave the medicine? <1 Month	1-2 months	3-4 months	5-6 months	Number of days given in total
_____	☐	☐	☐	☐	
_____	☐	☐	☐	☐	
_____	☐	☐	☐	☐	
_____	☐	☐	☐	☐	

34. Has your child been examined at or admitted to hospital (since returning home from hospital after birth)?

☐ No

☐ Yes, specify: _____

35. Has your child been operated on or does he/she have a condition requiring an operation?

☐ No

☐ Yes, specify:

_____

Development, childcare and life style

36. The following questions concern your child's development. If you haven't actually observed your child, spend a little time looking at what he/she can actually do. *(Enter a cross in a box for each question.)*

	Yes often	Yes, but seldom	No, not yet	Don't know
1. When your child is lying on his/her back, does he/she play by grabbing hold of his/her feet?	☐	☐	☐	☐
2. When your child is lying on his/her tummy, does he/she raise his/her upper body off the ground with straight arms?	☐	☐	☐	☐
3. Does your child roll over from his/her back onto his/her tummy?	☐	☐	☐	☐
4. When you "chat" to your child, does he/she try to "chat" back to you?	☐	☐	☐	☐
5. Does your child babble and make sounds when he/she is lying on his/her own?	☐	☐	☐	☐
6. Can you tell how your child is just by listening to the sounds he/she is making *(e.g. contented, hungry, angry,in pain)?*	☐	☐	☐	☐
7. Do you get a smile from your child when you just smile at him/her *(without touching or tickling him/her and without holding up a toy)?*	☐	☐	☐	☐
8. When you call your child, does he/she turn towards you one of the first times you say his/her name?	☐	☐	☐	☐
9. Does your child grab hold of a toy you give him/her and then put it in his/her mouth or hold it?	☐	☐	☐	☐
10. When your child is sitting on your lap, does he/she stretch out for a toy or something else on the table in front of you?	☐	☐	☐	☐
11. Does your child hold onto a toy with both hands when he/she is examining it?	☐	☐	☐	☐

37. Where is your child cared for during the day?

☐ At home with mother/father/other family member
☐ At home with an unqualified childminder
☐ At a childminder's
☐ In a family day nursery
☐ In a day nursery

38. How many other children are there usually along with your child during the day?

☐☐ children

39. Does your child go to baby swimming?

☐ No
☐ Yes

If yes, indicate the number of times during the last 2 months ☐☐

40. How often is your child outside? *(Enter just one cross.)*

☐ Seldom
☐ Often, but less than 1 hour a day
☐ 1-3 hours a day
☐ More than 3 hours a day

41. Does your child use a dummy/pacifier?

☐ Seldom or never
☐ Only when he/she goes to sleep
☐ Often
☐ Most of the time

42. How many hours in total does your child sleep per 24 hours?

☐ Less than 8 hours
☐ 8 - 10 hours
☐ 11 - 13 hours
☐ 13 - 14 hours
☐ More than 14 hours

43. How do you put your child down when he/she is going to sleep? *(Enter a cross in a box for each item.)*

	On back	On side	On tummy
After the birth	☐	☐	☐
At 2 months	☐	☐	☐
At 4 months	☐	☐	☐
At 6 months	☐	☐	☐

44. Does your child share a bed with his/her mother/father (at least half the night)? *(Enter a cross in a box for each item.)*

	No	sometimes	Often
After the birth	☐	☐	☐
At 2 months	☐	☐	☐
At 4 months	☐	☐	☐
At 6 months	☐	☐	☐

45. Enter a cross to indicate whether you agree or disagree with the following statements about your child's mood and temperament. Think about how he/she usually is. *(Enter a cross in a box for each item.)*

	Totally disagree	Disagree	Slightly disagree	Neither agree or disagree	Slightly agree	Agree	Totally agree
1. Your child whimpers and cries a lot	☐	☐	☐	☐	☐	☐	☐
2. Your child is usually easy to pacify when he/she is crying	☐	☐	☐	☐	☐	☐	☐
3. It doesn't take much for your child to become upset and start crying	☐	☐	☐	☐	☐	☐	☐
4. When your child is crying, he/she usually screams angrily and loudly	☐	☐	☐	☐	☐	☐	☐
5. Your child is very easy to deal with	☐	☐	☐	☐	☐	☐	☐
6. Your child demands an awful lot of attention	☐	☐	☐	☐	☐	☐	☐
7. When your child is left alone, he/she usually plays contentedly on his/her own	☐	☐	☐	☐	☐	☐	☐
8. Your child is so demanding that he/she would pose a major problem for most parents	☐	☐	☐	☐	☐	☐	☐
9. Your child smiles and laughs often	☐	☐	☐	☐	☐	☐	☐
10. Your child is easy to put down and goes to sleep quickly	☐	☐	☐	☐	☐	☐	☐

46. Currently how often does your child usually wake up during the night? *(Enter just one cross.)*

- ☐ 3 or more times every night
- ☐ Once or twice every night
- ☐ A few times a week
- ☐ Seldom or never

Comments

About yourself

The last time you completed a questionnaire was around week 30 of your pregnancy. The questions we are asking you now are mainly about the period after this up until your child was 6 months old.

Health and use of medication

47. Did you go to your doctor/midwife/health visitor for your own health problems during the first month after the birth?

☐ No
☐ Yes ☐☐ times

48. If yes, what was the reason for this?

☐ Perninealwound/stitches
☐ Caesarean section wound
☐ Mastitis
☐ Sore nipples
☐ Breastfeeding problems
☐ Other, specify: _____

49. When you think back to the time just after the birth, did you feel depressed during that period?

☐ No
☐ Yes, specify how long: ☐☐ weeks

50. Apart from being in hospital for the birth, have you been admitted to hospital since you completed the previous questionnaire?

☐ No
☐ Yes, specify hospital: _____

51. Do you have a chronic/long-term illness which has started since you completed the previous questionnaire?

☐ No
☐ Yes, specify: _____

52. Overall, how would you describe your physical health at the moment?

☐ Very good
☐ Good
☐ Poor
☐ Very poor

53. Have you had any of the following problems/illnesses since you completed the previous questionnaire? If yes, are you taking or have you taken medication for these problems? *(This includes every type of medication, including natural medicines, taken on both a regular and occasional basis.) (Enter a cross in a box for each item.)*

Have you suffered from?				If you have taken medication				
Illness / problem	No	Yes, last part of during pregnancy	Yes, after the birth	Name of medication taken	Last part of this pregnancy	After the birth 0-3 mth	After the birth 4-6 mth	Number of days taken in total
1. Sugar in urine	☐	☐	☐	_____	☐	☐	☐	☐☐☐
2. Protein in urine	☐	☐	☐	_____	☐	☐	☐	☐☐☐
3. High blood pressure . .	☐	☐	☐	_____	☐	☐	☐	☐☐☐
4. Swelling (oedema)	☐	☐	☐	_____	☐	☐	☐	☐☐☐
5. Cystitis	☐	☐	☐	_____	☐	☐	☐	☐☐☐
6. Sluggish bowels/constipation	☐	☐	☐	_____	☐	☐	☐	☐☐☐
7. Diarrhoea/vomiting	☐	☐	☐	_____	☐	☐	☐	☐☐☐
8. Heartburn/acidity	☐	☐	☐	_____	☐	☐	☐	☐☐☐
9. Common cold/influenza	☐	☐	☐	_____	☐	☐	☐	☐☐☐
10. Sore throat/sinusitis/earinfection	☐	☐	☐	_____	☐	☐	☐	☐☐☐

cont. next page

Have you suffered from?				If you have taken medication				
Illness / problem	No	Yes, last part of during pregnancy	Yes, after the birth	Name of medication taken	Last part of this pregnancy	After the birth 0-3 mth	After the birth 4-6 mth	Number of days taken in total
11. Pneumonia/bronchitis . .	☐	☐	☐	_____	☐	☐	☐	
12. Asthma	☐	☐	☐	_____	☐	☐	☐	
13. Hay fever/other allergy.	☐	☐	☐	_____	☐	☐	☐	
14. Headache/other pains .	☐	☐	☐	_____	☐	☐	☐	
15. Vaginitis	☐	☐	☐	_____	☐	☐	☐	
16. Mental health problems	☐	☐	☐	_____	☐	☐	☐	
17. Mastitis.	☐	☐	☐	_____	☐	☐	☐	
18. Fever	☐	☐	☐	_____	☐	☐	☐	
19. Other, specify: _____	☐	☐	☐	_____	☐	☐	☐	

54. Have you taken medicines other than those mentioned in Question 53? *(For instance, sleeping tablets, sedatives or analgesics.)*

☐ No ☐ Yes

55. If yes, give the name of the medicines and when you took them. *(Include all types of medication, as well as natural medicines, taken both on a regular and occasional basis.)*

Name of medicine (e.g. Valium, Rohypnol, Paracetamol)	Last part of pregnancy: Taken medication	Last part of pregnancy: Number of days	0-3 months after the birth: Taken medication	0-3 months after the birth: Number of days	4-6 months after the birth: Taken medication	4-6 months after the birth: Number of days
_____	☐		☐		☐	
_____	☐		☐		☐	
_____	☐		☐		☐	

56. Do you take or have you taken cod liver oil, vitamins or other dietary supplements since the previous questionnaire?

☐ No ☐ Yes

57. If yes, which product, when did you take it and how often? *(One line for each product.)*

Name of product	When did you take the product? Last part of pregnancy	0-3 months after the birth	4-6 months after the birth	How often? Taken daily	Taken sometimes
_____	☐	☐	☐	☐	☐
_____	☐	☐	☐	☐	☐
_____	☐	☐	☐	☐	☐

58. Have you experienced any pain in your back or pelvis since you completed the previous questionnaire?

☐ No
☐ Yes

59. If yes, enter a cross to indicate where you have experienced pain, when and how much.

Where was the pain?	Last part of pregnancy: Some pain	Last part of pregnancy: Major pain	0-3 months after the birth: Some pain	0-3 months after the birth: Major pain	4-6 months after the birth: Some pain	4-6 months after the birth: Major pain
Small of the back	☐	☐	☐	☐	☐	☐
One of the pelvic/sacroiliac joints at the back	☐	☐	☐	☐	☐	☐
Both pelvic/sacroiliac joints at the back	☐	☐	☐	☐	☐	☐
Over the coccygeal bone	☐	☐	☐	☐	☐	☐
In the buttocks	☐	☐	☐	☐	☐	☐
Over the pubic bone	☐	☐	☐	☐	☐	☐
Groin	☐	☐	☐	☐	☐	☐
Other back pains	☐	☐	☐	☐	☐	☐

60. Currently, do you wake up at night because of pelvic pain?

☐ No, never
☐ Yes, but only sometimes
☐ Yes, often

61. Do you have such problems walking at the moment due to pelvic pain that you have to use a stick or crutches?

☐ No, never
☐ Yes, but not every day
☐ Yes, every day

62. Have you *ever* received treatment for pelvic pain?

☐ No
☐ Yes

63. If yes, enter a cross to indicate the type of treatment and when it was.

	Before this pregnancy	During this pregnancy	After this birth
Physiotherapy	☐	☐	☐
Chiropractic	☐	☐	☐
Medication	☐	☐	☐
Other, specify: _____	☐	☐	☐

64, How long was it before you resumed sexual intercourse after the birth?

☐☐ weeks

☐ Have not had sexual intercourse

65. Do you have any of the following problems at the moment; if so, how often and to what extent? *(Enter a cross in a box for each item.)*

Problem	How often do you have these problems? Never	1-4 times a month	1-6 times a week	Once a day	More than Once a day	How much at a time? Drops	Large amounts
Incontinence when coughing, sneezing or laughing	☐	☐	☐	☐	☐	☐	☐
Incontinence during physical activity (running/jumping)	☐	☐	☐	☐	☐	☐	☐
Incontinence with a strong need to urinate	☐	☐	☐	☐	☐	☐	☐
Problems retaining faeces	☐	☐	☐	☐	☐	☐	☐
Problems with flatulence	☐	☐	☐	☐	☐	☐	☐

66. How many times did you go for an ultrasound scan during your pregnancy?

☐☐ times

67. Was everything OK with the ultrasound scan(s)?

☐ Yes
☐ No

68. If no, what was the problem?

☐ The baby was not growing enough.
☐ Suspected malformation,describe:

_____

☐ Other, specify: _____

69. How much did you weigh at the end of your pregnancy and how much do you weigh now?

At end of pregnancy ☐☐☐,☐ kg

Now ☐☐☐,☐ kg

+

70. Were you completely or partly on sick leave after week 30 of your pregnancy? *(Don't include maternity leave)*

- ☐ No
- ☐ Yes,partly on sick leave
- ☐ Yes,completely on sick leave

+

71. If you were on sick leave after week 30 of your pregnancy, complete the table below with a line for each time you were on sick leave. Give the reason and enter a cross indicating which weeks of your pregnancy you were on sick leave. Specify how many days and what percentage of the period you were on sick leave each time.

Reason for sick leave:	Was on sick leave during pregnancy weeks 30-33	34-37	38+	Number of days	% sick leave
Example: pelvic girdle pains	☐	☒	☐	10	50
	☐	☐	☐		
	☐	☐	☐		
	☐	☐	☐		

Finances – lifestyle

72. Would your current financial situation allow you to cope with an unexpected bill of NOK 10,000 for a dental visit or a repair, for a instance?

- ☐ No
- ☐ Yes
- ☐ Don't know

73. Have you found it difficult sometimes during the last six month to cope with running expemces for food, transport, rent etc.?

- ☐ No, never
- ☐ Yes, but infrequently
- ☐ Yes, sometimes
- ☐ Yes, often

74. Are there pets in the child's home?

- ☐ No
- ☐ Yes

+

75. If yes, which type(s)? *(You can enter a cross in more than one box.)*

- ☐ Dog
- ☐ Cat
- ☐ Guinea pig, rabbit, mouse, rat, etc.
- ☐ Budgie, other type of bird
- ☐ Other type of animal:

_____

76. Do you have heating based on electrical heating cables under the floor in rooms where you child is? (Do <u>not</u> include waterborne heating)

- ☐ No
- ☐ Yes

77. If yes, in which rooms? *(You can enter a cross in more than one box.)*

- ☐ Living room
- ☐ Kitchen
- ☐ Child's room
- ☐ Bedroom
- ☐ Hall
- ☐ Bathroom
- ☐ Other rooms

78. How often do you exercise these muscle groups at home or at the gym at present? *(Enter a cross in a box for each item.)*

	Never	1-3 times times a month	Once a week	Twice a week	Three times or more a week
Stomach muscles	☐	☐	☐	☐	☐
Back muscles	☐	☐	☐	☐	☐
Pelvic floor muscles (muscles around the vagina, urethra, rectum)	☐	☐	☐	☐	☐

79. How often are you physically active at present? *(Enter a cross in a box for each item.)*

	Never	1-3 times a month	Once a week	Twice a week	Three times or more a week
1 Walking	☐	☐	☐	☐	☐
2 Brisk walking	☐	☐	☐	☐	☐
3 Running/jogging/orienteering	☐	☐	☐	☐	☐
4 Cycling	☐	☐	☐	☐	☐
5 Training studio/weight training	☐	☐	☐	☐	☐
6 Special gymnastics/aerobics for pregnant women	☐	☐	☐	☐	☐
7 Aerobics/gymnastics/dancing without running and jumping	☐	☐	☐	☐	☐
8 Aerobics/gymnastics/dancing with running and jumping	☐	☐	☐	☐	☐
9 Dancing (swing, rock, folk)	☐	☐	☐	☐	☐
10 Skiing	☐	☐	☐	☐	☐
11 Ball sport	☐	☐	☐	☐	☐
12 Swimming	☐	☐	☐	☐	☐
13 Riding	☐	☐	☐	☐	☐
14 Other	☐	☐	☐	☐	☐

80. Currently how often are you physically active (during your spare time or at work) that you get out of breath or sweat?

	Spare time	At work
Never	☐	☐
Less than once a week	☐	☐
Once a week	☐	☐
Twice a week	☐	☐
3-4 times a week	☐	☐
5 times or more a week	☐	☐

81. What were your and your partner/husband's smoking habits during the last 3 months of your pregnancy and in the period after the birth? *(Enter a cross in a box for each period.)*

	Yourself			Your partner/husband		
	Last 3 mths during pregnancy	0-3 mths after birth	4-6 mths after birth	Last 3 mths during pregnancy	0-3 mths after birth	4-6 mths after birth
Didn't smoke	☐	☐	☐	☐	☐	☐
Smoked sometimes	☐	☐	☐	☐	☐	☐
Smoked every day	☐	☐	☐	☐	☐	☐
If every day, number of cigarettes per day	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐
If sometimes, number of cigarettes per week	☐☐	☐☐	☐☐	☐☐	☐☐	☐☐

82. Is your child ever present in a room where someone smokes?

- ☐ No
- ☐ Yes, sometimes
- ☐ Yes, several times a week
- ☐ Yes, every day

If every day, number of hours ☐☐

83. Did you take any of the following substances during the last 3 months of your pregnancy and after the birth? *(Enter a cross in a box for each item.)*

	No	Yes, last 3 month of pregnancy	Yes after birth
Hanish	☐	☐	☐
Amphetamines	☐	☐	☐
Ecstasy	☐	☐	☐
Cocaine	☐	☐	☐
Heroin	☐	☐	☐
Other, specify: _____	☐	☐	☐

84. Have you taken any of the following substances during the last 3 months of your pregnancy and after the birth? *(Enter a cross in a box for each item.)*

	No	Yes, last 3 months of pregnancy	Yes, after birth
Anabolic steroids	☐	☐	☐
Testosterone preparations	☐	☐	☐
Growth hormone (e.g. genotropin/somatropin)	☐	☐	☐

85. How often did you drink alcohol during the last 3 months of your pregnancy and how often do you drink now? *(Enter a cross in a box for each period.)*

	Last 3 months of pregnancy	After the birth	
		0-3 months	4-6 months
Roughly 6-7 times a week	☐	☐	☐
Roughly 4-5 times a week	☐	☐	☐
Roughly 2-3 times a week	☐	☐	☐
Roughly once a week	☐	☐	☐
Roughly 1-3 times a month	☐	☐	☐
Less often than once a month	☐	☐	☐
Never	☐	☐	☐

Alcohol units
In order compare different types of alcohol, we ask for the number of alcohol units (= 1.5 cl of pure alcohol). In practice, this means the following:

1 glass (1/3 litre) of beer	= 1 alcohol unit
1 wine glass of red or white wine	= 1 alcohol unit
1 sherryglass of sherry	= 1 alcohol unit
1 brandy glass of spirits or liquer	= 1 alcohol unit
1 bottle of alcopop/cider	= 1 alcohol unit

86. How many units of alcohol do you usually drink when you consume alcohol (complete both for the last 3 months of your pregnancy and afterwords)? *(See explanation about alcohol units.) (Enter a cross in a box for each period.)*

Number of alcohol units	Last 3 months of pregnancy	After the birth	
		0-3 months	4-6 months
10 or more	☐	☐	☐
7-9	☐	☐	☐
5-6	☐	☐	☐
3-4	☐	☐	☐
1-2	☐	☐	☐
Less than 1	☐	☐	☐

A little more about yourself and how you are keeping now

87. Do you have a boyfriend/ husband/partner?

☐ Yes
☐ No

88. If yes, to what extent do you agree with the following descriptions? *(Enter just one cross in a box for each item.)*

	Totally agree	Agree	Slightly agree	Slightly disagree	Disagree	Totally disagree
My husband/partner and I have a close relationship	☐	☐	☐	☐	☐	☐
My partner and I have problems in our relationship	☐	☐	☐	☐	☐	☐
I am very happy in my relationship	☐	☐	☐	☐	☐	☐
My partner is usually understanding	☐	☐	☐	☐	☐	☐
I often think about ending our relationship	☐	☐	☐	☐	☐	☐
I am satisfied with my relationship with my partner	☐	☐	☐	☐	☐	☐
We often disagree about important decisions	☐	☐	☐	☐	☐	☐
I have been lucky in my choice of partner	☐	☐	☐	☐	☐	☐
We agree on how children should be raised	☐	☐	☐	☐	☐	☐
I think my partner is satisfied with our relationship	☐	☐	☐	☐	☐	☐

89. In your daily life, how often do you *(Enter just one cross in a box for each item.)*

	Seldom never	Fairly seldom	A few times	Often	Very often
Feel pleased about something	☐	☐	☐	☐	☐
Feel happy	☐	☐	☐	☐	☐
Feel joyful, as though everything is going your way	☐	☐	☐	☐	☐
Feel that you will scream at someone or hit something	☐	☐	☐	☐	☐
Feel angry, irritated or annoyed	☐	☐	☐	☐	☐
Feel mad at somebody	☐	☐	☐	☐	☐

90. Indicate with a cross whether you agree or disagree with the following statements.
(Enter just one cross in a box for each item.)

	Totally disagree	Disagree	Slightly disagree	Neither agree or disagree	Slightly agree	Agree	Totally agree
My life is largely what I wanted it to be	☐	☐	☐	☐	☐	☐	☐
My life is very good	☐	☐	☐	☐	☐	☐	☐
I am satisfied with my life	☐	☐	☐	☐	☐	☐	☐
I have achieved so far what is important for me in my life	☐	☐	☐	☐	☐	☐	☐
If I could start all over, there is very little I would do differently	☐	☐	☐	☐	☐	☐	☐

91. Have you experienced any of the following situations since the previous questionnaire? If yes, how painful or difficult was this for you? *(Enter a cross in a box for each item.)*

			If yes		
	No	Yes	Not so bad	Painful/ difficult	Very painful/ difficult
Have you had problems at work or where you study?	☐	☐	☐	☐	☐
Have you had financial problems?	☐	☐	☐	☐	☐
Have you been divorced, separated or ended your relationship with your partner?	☐	☐	☐	☐	☐
Have you had problems or conflicts with family, friends or neighbours?	☐	☐	☐	☐	☐
Have you been seriously worried that there is something wrong with your child?	☐	☐	☐	☐	☐
Have you been seriously ill or injured?	☐	☐	☐	☐	☐
Has anyone close to you been seriously ill or injured?	☐	☐	☐	☐	☐
Have you been involved in a serious accident, fire or robbery?	☐	☐	☐	☐	☐
Have you lost someone close to you?	☐	☐	☐	☐	☐
Have you been pressurized into having sexual intercourse?	☐	☐	☐	☐	☐
Other	☐	☐	☐	☐	☐

92. Have you experienced any of the following feelings during the last week? *(Enter just one cross in a box for each item.)*

	Yes, almost all the time	Yes, now and then	Not very often	No, never
Really reproached yourself when something went wrong	☐	☐	☐	☐
Have been anxious or worried for no reason	☐	☐	☐	☐
Have been afraid or panicked for no reason	☐	☐	☐	☐
Have been so unhappy that you've had problems sleeping	☐	☐	☐	☐
Felt down or unhappy	☐	☐	☐	☐
Have been so unhappy that you've cried	☐	☐	☐	☐

93. How do you feel about yourself? *(Enter just one cross in a box for each item.)*

	Totally agree	Agree	Disagree	Totally disagree
I have a positive attitude towards myself	☐	☐	☐	☐
I feel completely useless at times	☐	☐	☐	☐
I feel that I do not have much to be proud about	☐	☐	☐	☐
I feel that I am a valuable person, as good as anyone else	☐	☐	☐	☐

94. Have you been bothered by any of the following feelings during the past 2 weeks? *(Enter just one cross in a box for each item.)*

	Not bothered	A little bothered	Quite bothered	Very bothered
Feeling fearful	☐	☐	☐	☐
Nervousness or shakiness inside	☐	☐	☐	☐
Feeling hopeless about the future	☐	☐	☐	☐
Feeling blue	☐	☐	☐	☐
Worrying too much about things	☐	☐	☐	☐
Feeling everything is an effort	☐	☐	☐	☐
Feeling tense or keyed up	☐	☐	☐	☐
Suddenly scared for no reason	☐	☐	☐	☐

Thank you very much for your help!

Insert the completed questionnaire in the stamped addressed envelope.

APPENDIX III

Questionnaire 6
36 months postpartum

den norske **Mor & barn undersøkelsen**

Questionnaire 6 – Your child at 36 months

In this questionnaire we will ask you some questions which you may recognise from previous questionnaires. We do this because we want to continue following your and your child's development. You are welcome to consult your child's Health card so that you can use the information contained in it.

If you feel that a question is too upsetting or difficult to answer you can skip this question and go on to the next one.

The questionnaire will be processed by a computer. It is therefore important that you follow these instructions when completing it:

- Use a blue or black ballpoint pen.
- Put a *cross* in the box that is most relevant like this: ☒
- If you put a cross in the wrong box, correct it by filling in the box completely like this: ■
- Write *numbers* in the large boxes. ***It is important that you only write in the white area of each box like this:***

  Number: 1 2 3 4 5 6 7 8 9 0

- Numbered boxes have two or more squares. When you enter a single-digit number, use the square on the right.

  Example: 5 is entered as follows | | 5 |
- Specific information concerning, *for example, medication* should be written on the lines provided. *Write clearly in CAPITAL LETTERS.*
- Remember to fill in the date on which you completed the questionnaire

As soon as you have completed this questionnaire, return it to us in the stamped addressed envelope provided.

Specify the day, month and year when the questionnaire was completed

Day ☐☐ Month ☐☐ Year ☐☐☐☐ *(write the year in full, e.g. 2005)*

Your child's development, health and history of illness

1. What is your child's height and weight (without clothes) at 3 years? If you know your child's height and weight at 2 years and 15-18 months, enter these measurements too. (If you don't know them, go on to the next question.) Give the date when the measurements were taken and enter a cross to indicate whether they were taken by you.

	Date of measurement (Day ☐☐ Month ☐☐ Year ☐☐)	Height	Weight	Own measurement
Approx. 3 years	☐☐ ☐☐ ☐☐	☐☐☐.☐ cm	☐☐.☐ kg	☐
Approx. 2 years	☐☐ ☐☐ ☐☐	☐☐☐.☐ cm	☐☐.☐ kg	☐
Approx. 15-18 months	☐☐ ☐☐ ☐☐	☐☐☐.☐ cm	☐☐.☐ kg	☐

2. How many months old was your child when he/she took his/her first steps unaided? ☐☐ mth ☐ Still not walking unaided.

The following questions concern any illnesses or health problems your child has had. We will first ask you about longer-term problems and then about illnesses and problems of a more acute nature.

3. Has your child suffered any long-term illness or health problems since the age of 18 months?

Health problem	No	Yes, has now	Yes, had previously	If so, has child been referred to a specialist: No	Yes
1. Impaired hearing	☐	☐	☐	☐	☐
2. Impaired vision	☐	☐	☐	☐	☐
3. Delayed motor development (e.g. sits/walks late)	☐	☐	☐	☐	☐
4. Cerebral palsy	☐	☐	☐	☐	☐
5. Joint problems	☐	☐	☐	☐	☐
6. Diabetes	☐	☐	☐	☐	☐
7. Gained too little weight	☐	☐	☐	☐	☐
8. Gained too much weight	☐	☐	☐	☐	☐
9. Heart defect	☐	☐	☐	☐	☐
10. Testicles not descended into scrotum	☐	☐	☐	☐	☐
11. Asthma	☐	☐	☐	☐	☐
12. Allergy affecting eyes or nose, e.g. hay fever	☐	☐	☐	☐	☐
13. Atopic eczema (childhood eczema)	☐	☐	☐	☐	☐
14. Other type of eczema	☐	☐	☐	☐	☐
15. Frequent diarrhoea	☐	☐	☐	☐	☐
16. Frequent stomach pains	☐	☐	☐	☐	☐
17. Food allergy/intolerance	☐	☐	☐	☐	☐
18. Other gastrointestinal problems	☐	☐	☐	☐	☐
19. Late or abnormal speech development	☐	☐	☐	☐	☐
20. Sleep problems	☐	☐	☐	☐	☐
21. Trouble relating to others	☐	☐	☐	☐	☐
22. Hyperactivity	☐	☐	☐	☐	☐
23. Autistic traits	☐	☐	☐	☐	☐
24. Other behavioural problems	☐	☐	☐	☐	☐
25. Other long-term illness/condition	☐	☐	☐	☐	☐

Specify _____

4. If your child has been to see a specialist or to the hospital, what did the investigation show?

☐ Everything was fine
☐ Still some doubts/further investigations needed
☐ Has not been for any investigation yet

☐ Received diagnosis I:_____

_____

☐ Received diagnosis II: _____

_____

☐ Received diagnosis III:_____

_____

5. If your child has a serious or long-term illness, describe it, if possible, in more detail:

_____

_____

6. Has your child ever been exposed to or involved in a serious incident?

☐ No ☐ Yes

7. If yes, give a description:

_____

_____

_____

_____

_____

_____

8. Do you think that this has affected your child's behaviour or development?

☐ No ☐ Yes

9. Has your child suffered any acute illness/health problem since the age of 18 months?
(Specify how many times and whether your child has been admitted to or examined at a hospital for this health problem.)

	No	Yes	Number of times	If yes, has child been admitted to or examined in hospital? No	Yes
1. Common cold	☐	☐		☐	☐
2. Throat infection with a confirmed streptococci	☐	☐		☐	☐
3. Other type of throat infection	☐	☐		☐	☐
4. Ear infection	☐	☐		☐	☐
5. Pseudocroup	☐	☐		☐	☐
6. Bronchitis	☐	☐		☐	☐
7. Pneumonia	☐	☐		☐	☐
8. Gastric flu/diarrhoea	☐	☐		☐	☐
9. Urinary tract infection	☐	☐		☐	☐
10. Encephalitis/meningitis	☐	☐		☐	☐
11. Febrile convulsions	☐	☐		☐	☐
12. Other convulsions (without any fever)	☐	☐		☐	☐
13. Injury or accident	☐	☐		☐	☐
14. Other _____	☐	☐		☐	☐

10. If your child has been examined in or admitted to hospital, give the name of the hospital:

Hospital name: _____

Hospital name: _____

Hospital name: _____

11. Has your child been referred to the following services since the age of 18 months?

	No	Yes
Habilitation service	☐	☐
Educational psychology service	☐	☐
Child psychiatric clinic/department	☐	☐

12. Has your child taken any medication during the last 12 months? *(This means any type of medication, including fever-reducing medicines, alternative medicines and herbal remedies)*

☐ No ☐ Yes

13. If yes, give the name of the medicines and indicate how long your child took these medicines for altogether and whether he/she is still taking them now.

Name of medicine: (CAPITALS)	Duration of use					Still being taken now?	
	0-2 weeks	3-4 weeks	1-2 mth	3-6 mth	7-12 mth	No	Yes
_____	☐	☐	☐	☐	☐	☐	☐
_____	☐	☐	☐	☐	☐	☐	☐
_____	☐	☐	☐	☐	☐	☐	☐
_____	☐	☐	☐	☐	☐	☐	☐

14. Has your child been given any vaccinations since you completed the previous questionnaire (at around 18 months or 6 months)? ☐ No ☐ Yes

15. If yes, specify which vaccinations and when your child received them.

Type of vaccination: Date given:

_____ ☐☐ ☐☐ ☐☐

_____ ☐☐ ☐☐ ☐☐

Day Month Year

16. Is your child taking at the moment any cod liver oil, vitamins or other dietary supplements?

	Yes, daily	Sometimes	No
1. Cod liver oil	☐	☐	☐
2. Fluoride tablets	☐	☐	☐
3. Vitamin preparations, specify _____	☐	☐	☐
4. Iron supplement, specify _____	☐	☐	☐
5. Other dietary supplements, specify_____	☐	☐	☐

Your child's development and ability to cope

In this section you will find some questions repeated in a different form. We do this so that we can compare your child's development with other similar studies and try out the best way to ask the question. The questions will relate to children who have reached different stages of development. Answer all the questions as well as you can, even if everything does not necessarily apply to your child.

17. About your child's motor development. *(Enter a cross in a box for each item.)*

	Yes	A few times	Not yet
1. Can your child kick a ball by swinging his/her leg forward without holding onto anything for support?	☐	☐	☐
2. Can your child catch a large ball with both hands?	☐	☐	☐
3. When drawing, does your child hold a pencil, crayon or pen between his/her fingers and thumb like an adult does?	☐	☐	☐
4. Can your child undo one or more buttons?	☐	☐	☐

18. About your child's language skills. *(Enter a cross for the option which best describes the way your child talks.)*

☐ Not yet talking
☐ He/she is talking, but you can't understand him/her
☐ Talking in one-word utterances, such as "milk" or "down"
☐ Talking in 2- to 3-word phrases, such as "me got ball" or "give doll"
☐ Talking in fairly complete sentences, such as "I got a doll" or "can I go outside?"
☐ Talking in long and complicated sentences, such as "when I went to the park, I went on the swings" or "I saw a man standing on the corner"

19. Your child's body language. *(Enter a cross in the box of the answer that fits your child best for each statement.)*

	Yes, usually	Very seldom	Not yet
1. When you enthusiastically say: "Where is the ball (or other toy)?", will your child point towards the toy, even if it is more than 1 metre away?	☐	☐	☐
2. When you look at a distant object and, surprised and excited, say: "Waoo...what's that?", - does he/she turn his/her head in the same direction as you?	☐	☐	☐
3. Does your child use sounds or words together with gestures? (for example, uses sounds when pointing or reaching towards toys or objects)	☐	☐	☐
4. Does your child show you toys by looking at you and holding the toy up towards you? (from a distance just so you can look at it)	☐	☐	☐

20. About your child's social skills.
(Enter a cross in a box for each statement to indicate whether you agree or disagree.)

	Disagree	Partially agree	Totally agree
1. Your child shares readily with other children (treats, toys, pencils, etc.)	☐	☐	☐
2. Your child is helpful if someone is hurt, upset or feeling ill	☐	☐	☐
3. Your child is considerate of other people's feelings	☐	☐	☐
4. Your child is kind to younger children	☐	☐	☐
5. Your child often volunteers to help others (parents, teachers, other children)	☐	☐	☐
6. Your child pays careful attention when you try to teach him/her something new	☐	☐	☐

21. Understanding what others say and being able to communicate
(Enter a cross in the box of the answer that fits your child best for each statement.)

	Yes	A few times	Not yet
1. Without showing him/her first, does your child point to the correct picture when you say, "Where is the cat" or "Where is the dog"? Your child must only point at the correct picture.	☐	☐	☐
2. When you ask your child to point at his/her eyes, nose, hair, feet, ears, etc., does he/she point correctly at least seven parts of the body? (The child can point at himself/herself, you or a doll.)	☐	☐	☐
3. Does your child use sentences made up of three or four words?	☐	☐	☐
4. Without giving him/her help by pointing or using gestures, ask your child to "Put the shoe on the table" and "Put the book under the chair". Does your child carry out both of these directions correctly?	☐	☐	☐
5. When looking at a picture book, does your child tell you what is happening or what action is taking place in the picture? (For example, "Barking", "Running", "Eating" and "Crying"?) You may ask, "What is the dog (or boy) doing?"	☐	☐	☐
6. Can your child tell you at least two things about an object he/she is familiar with? If you say, for example, "Tell me about your ball", will your child answer by saying something like "It is round, I can throw it, it is big"?	☐	☐	☐

22. About body language and other ways of communicating with others. *(We are asking you about how your child usually is. If the behaviour is rare , e.g. you have only seen it once or twice, enter a cross in the 'No' box. Enter a cross in a box for each question.)*

	Yes	No
1. Does your child respond to his/her name one of the first two times you call?	☐	☐
2. Does your child ever bring objects over to you to show you something?	☐	☐
3. Does your child imitate you (e.g. you make a face - will your child imitate it?)?	☐	☐
4. Does your child ever use his/her index finger to point, to indicate interest in something?	☐	☐
5. Does your child take an interest in other children?	☐	☐
6. If you point at a toy across the room, does your child look at it?	☐	☐
7. Is it easy to make eye contact with your child?	☐	☐
8. Does your child react when spoken to, for instance, by looking, listening, smiling, speaking or babbling?	☐	☐
9. Does you child ever seem oversensitive to noise (e.g. plugging ears)?	☐	☐
10. Does you child only choose a very small number of particular toys or objects, even if you try to make him/her interested in more things?	☐	☐
11. Does your child wave to people to greet or say goodbye to them?	☐	☐
12. Can your child hurt himself/herself a lot without seeming to be bothered (has a high pain threshold)?	☐	☐

23. About talking with others. *(Enter a cross in a box for each question to indicate whether you think it applies to your child or not.)*

	Yes	No
1. Does your child talk using short phrases or sentences?	☐	☐
2. Do you have a to-and-fro "conversation" with your child that involves taking turns or building on what you have said?	☐	☐
3. Does your child ever use odd phrases or say the same thing over and over again in almost exactly the same way? (either phrases that the child hears other people use or ones that he/she makes up)	☐	☐
4. Does your child ever use socially inappropriate questions or statements? For example, does your child ever regularly ask personal questions or make personal comments at awkward times?	☐	☐
5. Does your child ever get his/her pronouns mixed up (i.e. saying "you" or "he/she" instead of "I")?	☐	☐
6. Does your child ever use words that he/she seems to have invented or made up himself/herself, put things in odd, indirect ways or use metaphorical ways of saying things? (e.g. saying "hot rain" for "steam")	☐	☐
7. Does your child ever say the same thing over and over in exactly the same way or insist that you say the same thing over and over again?	☐	☐
8. Does your child ever have things that he/she seems to have to do in a very particular way or order, or rituals that the child insists that you go through?	☐	☐

24. About behaviour and specific things that children can think of doing. *(Enter a cross in a box for each question to indicate whether you think it applies to your child or not.)*

	Yes	No
9. Does your child's facial expression usually seem appropriate to the particular situation, as far as you can tell?	☐	☐
10. Does your child ever use your hand like a tool or as if it were part of his/her own body (e.g. pointing with your finger or putting your hand on a doorknob to get you to open the door)?	☐	☐
11. Does your child ever have any interests that preoccupy him/her and might seem odd to other people (e.g. traffic lights, drainpipes or timetables)?	☐	☐
12. Does your child ever seem to be more interested in parts of a toy or an object, rather than in using the object as it was intended (e.g. spinning the wheels of a car)?	☐	☐
13. Does your child ever have any special interests that are unusual in their intensity, but otherwise appropriate for his/her age and peer group (e.g. trains or dinosaurs)?	☐	☐
14. Does your child ever seem to be unusually interested in the sight, feel, sound, taste or smell of things or people?	☐	☐
15. Does your child ever have any mannerisms or odd ways of moving his/her hands or fingers, such as flapping or moving his/her fingers in front of his/her eyes?	☐	☐
16. Does your child ever have any complicated movements of his/her whole body, such as spinning or repeatedly bouncing up and down?	☐	☐
17. Does your child ever injure himself/herself deliberately, such as by biting his/her arm or banging his/her head?	☐	☐
18. Does your child ever have any objects that he/she has to carry around (other than a soft toy or comfort blanket)?	☐	☐

25. About your child's social development and interest in others. *(Enter a cross in a box for each question to indicate whether you think it applies to your child or not.)*

	Yes	No
19. Does your child have any particular friends or a best friend?	☐	☐
20. Does your child ever talk with you just to be friendly (rather than to get something)?	☐	☐
21. Does your child ever spontaneously copy you (or other people) or what your are doing (such as vacuuming, gardening or mending things)?	☐	☐
22. Does your child ever spontaneously point at things around him/her just to show you things (not because he/she wants them)?	☐	☐
23. Does your child ever use gestures, other than pointing or pulling your hand, to let you know what he/she wants?	☐	☐
24. Does your child nod his/her head to indicate yes?	☐	☐
25. Does your child shake his/her head to indicate no?	☐	☐
26. Does your child usually look at you directly in the face when doing things with you or talking with you?	☐	☐
27. Does your child smile back if someone smiles at him/her?	☐	☐
28. Does your child ever show you things that interest him/her to engage your attention?	☐	☐

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	Yes	No
29. Does your child ever offer to share things other than food with you?	☐	☐
30. Does your child ever seem to want you to join in his/her enjoyment of something?	☐	☐
31. Does your child ever try to comfort you when you are sad or hurt?	☐	☐
32. If your child wants something or wants help, does he/she look at you and use gestures with sounds or words to get your attention?	☐	☐
33. Does your child show a normal range of facial expressions?	☐	☐
34. Does your child ever spontaneously join in and try to copy the actions in social games, such as "The Mulberry Bush" or "London Bridge is Falling Down"?	☐	☐
35. Does your child play any pretend or make-believe games?	☐	☐
36. Does your child seem interested in other children of approximately the same age whom he/she does not know?	☐	☐
37. Does your child respond positively when another child approaches him/her?	☐	☐
38. If you come into a room and start talking to your child without calling his/her name, does he/she usually look up and pay attention to you?	☐	☐
39. Does your child ever play imaginative games with another child in such a way that you can tell that each child understands what the other is pretending?	☐	☐
40. Does your child play cooperatively in games that need some form of joining in with a group of other children, such as hide-and-seek or ball games?	☐	☐

26. Loss of skills. *(Is there something your child used to be able to do, but has lost the ability to do?)*

	No	Yes	Not sure
1. Has your child lost any language skills? (For example, used single words or sentences for a time and then stopped using the words)	☐	☐	☐
2. Has your child lost any social skills? (For example, could wave or say "Hi" to greet someone, then lost this skill)	☐	☐	☐
3. Has your child turned out to be less sociable? (For example, he/she is more difficult to have eye contact with, is less interested in other people now)	☐	☐	☐
4. Has your child lost any motor skills? (For example, could run and jump while remaining steady, but falls over much more now)	☐	☐	☐

Your child's temperament and behaviour

27. To what extent do the following statements apply to your child's behaviour during the last two months? *(Enter a cross in a box for each item.)*

	Very typical	Quite typical	Neither/ nor	Not so typical	Not at all typical
1. Your child cries easily	☐	☐	☐	☐	☐
2. Your child is always on the go	☐	☐	☐	☐	☐
3. Your child prefers playing with others rather than alone	☐	☐	☐	☐	☐
4. Your child is off and running as soon as he/she wakes up in the morning	☐	☐	☐	☐	☐
5. Your child is very sociable	☐	☐	☐	☐	☐
6. Your child takes a long time to warm up to strangers	☐	☐	☐	☐	☐
7. Your child gets upset or sad easily	☐	☐	☐	☐	☐
8. Your child prefers quiet, inactive games to more active ones	☐	☐	☐	☐	☐
9. Your child likes to be with people	☐	☐	☐	☐	☐
10. Your child reacts intensely when upset	☐	☐	☐	☐	☐
11. Your child is very friendly with strangers	☐	☐	☐	☐	☐
12. Your child finds other people more fun than anything else	☐	☐	☐	☐	☐
13. Your child complains that certain garments are too tight	☐	☐	☐	☐	☐
14. Your child is distressed by having his/her face or hair washed	☐	☐	☐	☐	☐

28. The following list contains statements describing children's behaviour and manner from the age of 2-3. Some of these features are temporary while others continue for a longer period of time. To what extent are the following statements true of your child's behaviour during the last two months? *(Enter a cross in a box for each item.)*

	Not true	Somewhat or sometimes true	Very true or often true
1. Afraid to try new things	☐	☐	☐
2. Can't concentrate, can't pay attention for long	☐	☐	☐
3. Can't sit still, restless or hyperactive	☐	☐	☐
4. Can't stand waiting, wants everything now	☐	☐	☐
5. Clings to adults or too dependent	☐	☐	☐
6. Constipated, doesn't move bowels	☐	☐	☐
7. Defiant	☐	☐	☐
8. Demands must be met immediately	☐	☐	☐
9. Disturbed by any change in routine	☐	☐	☐
10. Doesn't want to sleep alone	☐	☐	☐
11. Doesn't eat well	☐	☐	☐
12. Doesn't seem to feel guilty after misbehaving	☐	☐	☐
13. Eats or drinks things that are not food (don't include sweets)	☐	☐	☐
14. Gets in many fights	☐	☐	☐
15. Gets into everything	☐	☐	☐
16. Gets too upset when separated from parents	☐	☐	☐
17. Hits others	☐	☐	☐
18. Poorly coordinated or clumsy	☐	☐	☐
19. Punishment doesn't change his/her behaviour	☐	☐	☐
20. Quickly shifts from one activity to another	☐	☐	☐
21. Resists going to bed at night	☐	☐	☐
22. Stomach aches or cramps (without medical cause)	☐	☐	☐
23. Sudden changes in moods or feelings	☐	☐	☐
24. Too fearful or anxious	☐	☐	☐
25. Vomiting, throwing up (without medical cause)	☐	☐	☐
26. Doesn't seem to be happy eating food (don't include sweets)	☐	☐	☐

29. Some more statements follow about your child's behaviour and manner. We are again asking to what extent you feel the statements are true of your child during the last two months? *(Enter a cross in a box for each item.)*

	Not true	Somewhat or sometimes true	Very true or often true
1. Becomes distracted or diverted by outside stimuli (sounds or events)	☐	☐	☐
2. Finds it difficult waiting his/her turn	☐	☐	☐
3. Has problems keeping focused on tasks or activities	☐	☐	☐
4. Is excessively talkative	☐	☐	☐
5. Doesn't differentiate between adults; behaves the same way to all of them	☐	☐	☐
6. Will wander after other adults, even if they are strangers	☐	☐	☐
7. Doesn't seem to listen when he/she is being spoken to	☐	☐	☐
8. Has a habit of rolling his/her head around or making humming sounds	☐	☐	☐
9. Mood can vary greatly from day to day	☐	☐	☐
10. Is extremely passive, needs help to get going	☐	☐	☐
11. "Tests" other children to see whether they get angry	☐	☐	☐
12. Becomes aggressive when he/she is frustrated	☐	☐	☐
13. His/her body is affected by twitches or contortions that seem difficult to control (e.g. eyes, mouth, nose or legs)	☐	☐	☐
14. Hits, shoves, kicks and bites other children (not including siblings)	☐	☐	☐
15. Is very anxious about getting dirty	☐	☐	☐
16. Wants things to be clean and tidy	☐	☐	☐
17. Places toys or other objects in a certain order/sequence over and over again	☐	☐	☐
18. Wakes up in the night and needs help to get back to sleep	☐	☐	☐
19. Gets distressed when you go out and he/she is going to be looked after by family or a babysitter he/she knows	☐	☐	☐

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	Not true	Somewhat or sometimes true	Very trueor often true
20. Does things he/she is not allowed to do to attract attention from adults	☐	☐	☐
21. Seems to have less fun than other children	☐	☐	☐
22. Is extremely noisy. Shouts and screams a lot	☐	☐	☐
23. Is disobedient or defiant (e.g. refuses to do anything you ask)	☐	☐	☐
24. Comes over to you when something happens that makes him/her afraid or anxious	☐	☐	☐
25. Runs off when you are outside	☐	☐	☐
26. Seems to have less energy	☐	☐	☐
27. Is very fussy when it comes to food	☐	☐	☐
28. Seems to be unhappy, sad or depressed	☐	☐	☐
29. Wakes up several times during the night	☐	☐	☐

30. About your child's eating habits and appetite and your attitude to it.

	Totally disagree	Slightly disagree	Neither/ nor	Slightly agree	Totally agree
1. I have to be sure that my child does not eat too many sweet things (sweets, ice cream, cakes or pastries)	☐	☐	☐	☐	☐
2. I have to be sure that my child does not eat too many high-fat foods	☐	☐	☐	☐	☐
3. I have to be sure that my child does not eat too much of his/her favourite food	☐	☐	☐	☐	☐
4. I intentionally keep some foods out of my child's reach	☐	☐	☐	☐	☐
5. I offer sweet things (sweets, ice cream, cakes, pastries) to my child as a reward for good behaviour	☐	☐	☐	☐	☐
6. I offer my child his/her favourite foods in exchange for good behaviour	☐	☐	☐	☐	☐
7. If I did not guide or regulate my child's eating he/she would eat too many junk foods	☐	☐	☐	☐	☐
8. If I did not guide or regulate my child's eating he/she would eat too much of his/her favourite foods	☐	☐	☐	☐	☐
9. My child should always eat all of the food on his/her plate	☐	☐	☐	☐	☐
10. I have to be especially careful to make sure that my child eats enough	☐	☐	☐	☐	☐
11. If my child says: "I'm not hungry", I try to get him/her to eat anyway	☐	☐	☐	☐	☐
12. If I did not guide or regulate my child's eating, he/she would eat much less than he/she should.	☐	☐	☐	☐	☐

31. About your concerns.

	No	Yes
1. Are you concerned because your child is demanding and difficult to cope with?	☐	☐
2. Have you every wondered if your child's hearing is impaired?	☐	☐
3. Have others (family, nursery, health visitor) expressed concerns about your child's development?	☐	☐
4. Are your concerned because your child is hardly interested at all in playing with other children?	☐	☐
5. Do you have any other concern about your child's health?	☐	☐

If so, specify _____

Your child's everyday life and environment

32. Do you live with your child's father?

☐ No ☐ Yes

33. If no, how much time does your child spend with his/her mother and father respectively?

	Mother	Father
More than half the time	☐	☐
Roughly half the time	☐	☐
At least once a week	☐	☐
At least once a month	☐	☐
Less often than once a month	☐	☐
Never	☐	☐

34. How often does your child have his/her teeth brushed?

☐ Twice a day or more
☐ Once a day
☐ Sometimes
☐ Never

35. Does your child use fluoride toothpaste?

☐ No
☐ Sometimes
☐ Yes, usually

36. Is your child ever present in a room where someone smokes?

- ☐ Yes, every day — Number of hours a day: ☐☐
- ☐ Yes, several times a week
- ☐ Yes, sometimes
- ☐ Don't know
- ☐ No

37. How often is your child outside at present?

- ☐ Seldom
- ☐ Frequently, but less than 1 hour a day on average
- ☐ 1-3 hours a day on average
- ☐ More than 3 hours a day

38. How many hours on average does your child sit in front of a TV/video every day?

- ☐ 4 hours or more
- ☐ 3 hours
- ☐ 1-2 hours
- ☐ Less than 1 hour
- ☐ Seldom/never

39. How is your child cared for during the day at the moment? *(You can enter a cross in more than one box.)*

- ☐ At home with his/her mother
- ☐ At home with his/her father
- ☐ At home with an unqualified childminder
- ☐ At a childminder's/family creche
- ☐ In an outdoor nursery
- ☐ In a nursery

40. How many hours a week is your child looked after during the day by someone other than his/her mother or father?

☐☐

Diet

41. How often does your child drink or eat the following at present? *(Select the frequency which is most applicable on average.)*
(Enter a cross in a box for each item.)

	Seldom/ less than once a week	1-3 times a week	4-6 times a week	Once in 24 hrs	Twice in 24 hrs	3 times in 24 hrs	4 or more times in 24 hrs
1. Whole milk, sweet/sour	☐	☐	☐	☐	☐	☐	☐
2. Low-fat, extra low-fat, skimmed milk, sweet/sour	☐	☐	☐	☐	☐	☐	☐
3. Yogurt, natural	☐	☐	☐	☐	☐	☐	☐
4. Yogurt / yogurt drink with fruit	☐	☐	☐	☐	☐	☐	☐
5. Yogurt with active Lactobacillus, all types							
6. Juice	☐	☐	☐	☐	☐	☐	☐
7. Cordial / nectar / squash / fizzy drinks, sweetened	☐	☐	☐	☐	☐	☐	☐
8. Cordial / squash / fizzy drinks, with artificial sweeteners	☐	☐	☐	☐	☐	☐	☐
9. Meat filling (liver paste, ham, etc.)	☐	☐	☐	☐	☐	☐	☐
10. Fish filling (mackerel, caviar, etc.)	☐	☐	☐	☐	☐	☐	☐
11. Brown cheese, brown cheese spread	☐	☐	☐	☐	☐	☐	☐
12. Other types of cheese	☐	☐	☐	☐	☐	☐	☐
13. Jam, honey, chocolate spread, other sweet spread	☐	☐	☐	☐	☐	☐	☐
14. Eggs, boiled, fried, scrambled	☐	☐	☐	☐	☐	☐	☐
15. Other filling_____	☐	☐	☐	☐	☐	☐	☐
16. Fruit	☐	☐	☐	☐	☐	☐	☐
17. Raisins	☐	☐	☐	☐	☐	☐	☐
18. Ice cream	☐	☐	☐	☐	☐	☐	☐
19. Ice lolly	☐	☐	☐	☐	☐	☐	☐
20. Biscuits	☐	☐	☐	☐	☐	☐	☐
21. Buns, cakes, waffles	☐	☐	☐	☐	☐	☐	☐
22. Chocolate	☐	☐	☐	☐	☐	☐	☐
23. Sweets, jelly babies, etc.	☐	☐	☐	☐	☐	☐	☐
24. Crisps, potato snacks	☐	☐	☐	☐	☐	☐	☐

42. How many slices of bread/crispbread does your child eat every day? ☐☐

How many of these include fibre-rich bread/ crispbread (e.g. rye bread, Fedons bread) ☐☐

43. How often does your child eat the following at present? *(Select the frequency which is most applicable on average.) (Enter a cross in a box for each item.)*

	Once a mth or less often	2-3 times a month	Once a week	Twice a week	3 times a week	4 times a week	5 or more times a week
1. Meat, rissoles, sausages, etc.	☐	☐	☐	☐	☐	☐	☐
2. Oily fish (salmon, herring, etc.)	☐	☐	☐	☐	☐	☐	☐
3. White fish (cod, coley, etc.)	☐	☐	☐	☐	☐	☐	☐
4. Fish pudding, fish cakes, fish balls, etc.	☐	☐	☐	☐	☐	☐	☐
5. Soup	☐	☐	☐	☐	☐	☐	☐
6. Pancakes	☐	☐	☐	☐	☐	☐	☐
7. Potatoes	☐	☐	☐	☐	☐	☐	☐
8. Pasta, spaghetti, noodles	☐	☐	☐	☐	☐	☐	☐
9. Pizza	☐	☐	☐	☐	☐	☐	☐
10. Rice	☐	☐	☐	☐	☐	☐	☐
11. Cooked vegetables	☐	☐	☐	☐	☐	☐	☐
12. Raw vegetables, salad	☐	☐	☐	☐	☐	☐	☐

Questions about yourself

44. What is your civil status at present?

☐ Married
☐ Cohabiting
☐ Single
☐ Separated/divorced
☐ Widowed
☐ Other

45. Are you in paid employment at the moment?

☐ No *(go to question 49)*
☐ Yes Usual number of hours per week: ☐☐,☐

46. What type of working pattern do you have? *(You can enter a cross in more than one box.)*

☐ Permanent day work
☐ Shift work/rota system
☐ Permanent afternoon/evening work
☐ Non-permanent (relief cover, relief on-call, supply, etc.)
☐ Permanent night work

47. How many days altogether were you absent from work last year (excluding holidays and time off in lieu)?

☐☐☐ days

48. What was the reason for this? *(You can enter a cross in more than one box.)*

☐ Leave
☐ Own illness, specify_____
☐ Sick child
☐ Other

49. Do you often feel lonely?

☐ Almost never
☐ Seldom
☐ Sometimes
☐ Generally
☐ Almost always

50. Do you have anyone other than your spouse /boyfriend/partner whom you can seek advice from in a difficult situation?

☐ No
☐ Yes, 1 or 2 people
☐ Yes, more than 2 people

51. How often do you see or talk on the telephone to your family (apart from your household) or close friends?

☐ Once a month or less
☐ 2-8 times a month
☐ More than twice a week

52. Have you ever experienced the following, since you became pregnant with this child, for a consecutive period of two weeks or more..... *(Enter a cross in a box for each item.)*

	No	Yes, during pregnancy	Yes, during first year after birth	Yes, during the last 2 years
1. Felt depressed, sad, down?	☐	☐	☐	☐
2. Had problems with your appetite or eaten too much?	☐	☐	☐	☐
3. Been affected by lethargy or a lack of energy?	☐	☐	☐	☐
4. Really got down on yourself and felt worthless?	☐	☐	☐	☐
5. Had problems concentrating or found it difficult to make decisions?	☐	☐	☐	☐
6. Had at least 3 of the problems mentioned above at the same time?	☐	☐	☐	☐

53. Are you pregnant now?

☐ No ☐ Yes

54. Have you had any long-term illness or health problems which have occurred during the last 3 years?

Physical problem:

☐ No

☐ Yes, before, describe: _____

☐ Yes, now, describe: _____

Mental problem:

☐ No

☐ Yes, before, describe: _____

☐ Yes, now, describe: _____

55. Have you yourself been examined at the hospital during the last 3 years?

☐ No

☐ Yes, which hospital? _____

56. Do you have any of the following problems at present; if so, how often and how much at a time? *(Enter a cross in a box for each item.)*

	How often do you have problems?					How much at a time?		
Problems:	Never	1–4 times a month	1–6 times a week	Once a day	More than once a day	Drops	Small gushes	Large amounts
1. Incontinence when coughing, sneezing or laughing	☐	☐	☐	☐	☐	☐	☐	☐
2. Incontinence during physical activity (running/jumping)	☐	☐	☐	☐	☐	☐	☐	☐
3. Incontinence with a strong need to urinate . .	☐	☐	☐	☐	☐	☐	☐	☐
4. Problems retaining faeces	☐	☐	☐	☐	☐			
5. Problems with flatulence								

57. How physically active are you? We are asking you here about the duration of activities where you get out of breath or sweat. How often does this happen? Include activities both at home and at work. *(Enter a cross in a box for each item.)*

	How often					
Duration of activity where you get out of breath or sweat	Never	Less than once a week	Once a week	Twice a week	3-4 times a week	5 times or more a week
Less than 30 minutes	☐	☐	☐	☐	☐	☐
Between 30 and 60 minutes	☐	☐	☐	☐	☐	☐
More than 60 minutes	☐	☐	☐	☐	☐	☐

58. Overall, how would you describe your physical health?

☐ Very good
☐ Good
☐ Poor
☐ Very poor

59. Do you smoke at present?

☐ Don't smoke

☐ Smoke sometimes - no. cigarettes per week: ☐☐☐

☐ Smoke every day - no. cigarettes per day: ☐☐☐

60. Do you take:

☐ Chewing tobacco/snuff
☐ Nicotine chewing gum
☐ Nicotine patches
☐ Nicotine inhaler

61. How often do you consume alcohol at present?

☐ Roughly 6–7 times a week
☐ Roughly 4–5 times a week
☐ Roughly 2-3 times a week
☐ Roughly once a week
☐ Roughly 1-3 times a month
☐ Less than once a month
☐ Never

62. How many alcohol units do you usually drink when you consume alcohol? *(Enter a cross for both weekends and weekdays)* (See explanation below about alcohol units.)

	Weekend	Weekdays
10 or more	☐	☐
7–9	☐	☐
5–6	☐	☐
3–4	☐	☐
1–2	☐	☐
Less than 1	☐	☐

Alcohol units

In order to compare different types of alcohol, we ask for the number of alcohol units (= 1.5 cl of pure alcohol). This means the following in practice:

1 glass (1/3 litre) of beer	= 1 unit
1 wine glass of red or white wine	= 1 unit
1 wine glass of sherry or other fortified wine	= 1 unit
1 brandy glass of spirits or liqueur	= 1 unit
1 bottle of alcopop/cider	= 1 unit

63. Have you experienced any of the following during the last 3 years:

	No	Yes
Being hit, kicked or attacked physically in any other way?	☐	☐
Being pressured into having sexual intercourse?	☐	☐

64. Have you during the last 18 months:
(Enter a cross in a box for each item.)

	No	Yes
1. Thought yourself that you were too fat?	☐	☐
2. Been really afraid of putting on weight or becoming too fat?	☐	☐
3. Heard others say that you were too thin, while you yourself thought that you were too fat?	☐	☐
4. Thought that it was extremely important for your self-image to maintain a particular weight?	☐	☐

65. Have you at some time during the last 18 months or previously in your life - for a period lasting at least 3 months - experienced any of the following situations, and if so, how frequently was this? *(Enter a cross in a box for each item.)*

	At least twice a week	1-4 times a month	Seldom/ never
1. Felt that you were losing control when eating and couldn't stop before you had eaten far too much?	☐	☐	☐
2. Used vomiting to control your weight?	☐	☐	☐
3. Used laxatives to control your weight?	☐	☐	☐
4. Used fasting to control your weight?	☐	☐	☐
5. Used hard physical exercise to control you weight?	☐	☐	☐

66. Have you at some time during the last 18 months gone at least three months without a period in connection with a time when you have been having eating problems? *(without being pregnant)*

☐ No ☐ Yes

67. What is your current weight? ☐☐☐,☐ kg

How tall are you? ☐☐☐ cm

68. Feeling of anxiety and restlessness. *(Enter a cross in a box for the items that apply to you best during the last 6 months.)*

	Never	Seldom	Sometimes	Often	Very often
1. How often do you have problems completing the final aspects of a task when the challenging part is already done?	☐	☐	☐	☐	☐
2. How often do you have problems putting things in the right order when you are involved in tasks that require organisation?	☐	☐	☐	☐	☐
3. When you have a task which requires a great deal of careful preparation, how often do you avoid or put off starting it?	☐	☐	☐	☐	☐
4. How often do you have problems remembering appointments or engagements?	☐	☐	☐	☐	☐
5. When you have to sit still for a long time, how often do you move your hands and feet in an anxious, restless way?	☐	☐	☐	☐	☐
6. How often do you feel hyperactive and obliged to do things, as if you are being driven by an engine?	☐	☐	☐	☐	☐

69. If you have a husband/boyfriend/partner, to what extent do you agree with the following descriptions? *(Enter a cross in a box for each item.)*

	Totally agree	Agree	Slightly agree	Slightly disagree	Disagree	Totally disagree
1. My partner and I have problems in our relationship	☐	☐	☐	☐	☐	☐
2. I am very happy in my relationship	☐	☐	☐	☐	☐	☐
3. My partner is generally understanding	☐	☐	☐	☐	☐	☐
4. I am satisfied with the relationship with my partner	☐	☐	☐	☐	☐	☐
5. We agree on how children should be brought up	☐	☐	☐	☐	☐	☐

70. Have you been bothered during the last 2 weeks by any of the following? *(Enter a cross in a box for each item.)*

	Not bothered	A little bothered	Quite bothered	Very bothered
1. Feeling fearful	☐	☐	☐	☐
2. Nervousness or shakiness inside	☐	☐	☐	☐
3. Feeling hopeless about the future	☐	☐	☐	☐
4. Feeling blue	☐	☐	☐	☐
5. Worrying too much about things	☐	☐	☐	☐
6. Feeling everything is an effort	☐	☐	☐	☐
7. Feeling tense or keyed up	☐	☐	☐	☐
8. Suddenly scared for no reason	☐	☐	☐	☐

71. Have you experienced during the last 18 months any of the following situations? If yes, how painful and difficult was this for you?
(Enter a cross in a box for each item.)

	No	Yes	Not so bad	Painful/ difficult	Very painful/ difficult
1. Have you had problems at work or where you study?	☐	☐	☐	☐	☐
2. Have you had financial problems?	☐	☐	☐	☐	☐
3. Have you been divorced, separated or ended your relationship with your partner?	☐	☐	☐	☐	☐
4. Have you had problems or conflict with family, friends or neighbours?	☐	☐	☐	☐	☐
5. Have you been seriously worried that there is something wrong with your child?	☐	☐	☐	☐	☐
6. Have you been seriously ill or injured?	☐	☐	☐	☐	☐
7. Has anyone close to you been seriously ill or injured?	☐	☐	☐	☐	☐
8. Have you been involved in a serious accident, fire or robbery?	☐	☐	☐	☐	☐
9. Have you lost someone close to you?	☐	☐	☐	☐	☐
10. Other	☐	☐	☐	☐	☐

72. In your daily life, how often do you *(Enter a cross in a box for each item.)*

	Seldom/ never	seldom	A few times	Fairly Often	Very often
1. Feel glad about something	☐	☐	☐	☐	☐
2. Feel happy	☐	☐	☐	☐	☐
3. Feel joyful, like everything is going your way, everything is rosy	☐	☐	☐	☐	☐
4. Feel like screaming at somebody or hitting things	☐	☐	☐	☐	☐
5. Feel angry, irritated or annoyed	☐	☐	☐	☐	☐
6. Feel mad at somebody	☐	☐	☐	☐	☐

73. Indicate with a cross whether you agree or disagree with the following statements *(Enter a cross for each statement.)*

	Totally disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Totally agree
1. My life is largely what I wanted it to be	☐	☐	☐	☐	☐	☐	☐
2. My life is very good	☐	☐	☐	☐	☐	☐	☐
3. I'm satisfied with my life	☐	☐	☐	☐	☐	☐	☐
4. I've achieved so far what's important to me in my life	☐	☐	☐	☐	☐	☐	☐
5. If I could start all over, there is very little I would do differently	☐	☐	☐	☐	☐	☐	☐
6. I really enjoy my work	☐	☐	☐	☐	☐	☐	☐

74. What kind of perception do you have of yourself? *(Enter a cross in a box for each item.)*

	Totally agree	Agree	Disagree	Totally disagree
1. I have a positive attitude towards myself	☐	☐	☐	☐
2. I feel completely useless at times	☐	☐	☐	☐
3. I feel that I don't have much to be proud of	☐	☐	☐	☐
4. I feel that I am a valuable person, as good as anyone else	☐	☐	☐	☐

75. Bringing up your child *(Enter a cross to indicate whether you agree or disagree with the following statements. Enter a cross in a box for each item.)*

	Totally disagree	Partially disagree	Neither/ nor	Partially agree	Totally agree
1. What I do has little influence on my child's behaviour	☐	☐	☐	☐	☐
2. My child is used to getting what he/she wants in any case, so there's no point in even trying to refuse him/her	☐	☐	☐	☐	☐
3. Cuddles and hugs are an important way of showing my child that I love him/her	☐	☐	☐	☐	☐
4. If my child and I have a disagreement it is usually easy to divert him/her	☐	☐	☐	☐	☐
5. My life is mainly becoming controlled by my child	☐	☐	☐	☐	☐
6. I think it is very important for my child to learn to deal with the fact he/she cannot get their own way on everything	☐	☐	☐	☐	☐
7. It is often easier to let my child get his/her own way rather than having to put up with a tantrum	☐	☐	☐	☐	☐
8. Sometimes when I'm tired I let my child get to do things that I usually would not have allowed otherwise	☐	☐	☐	☐	☐
9. It isn't so important what strategies you use to bring up your children; if you love your children they will develop well	☐	☐	☐	☐	☐

Comments

Have you remembered to fill in on page 1 the date on which you completed the questionnaire?

Thank you very much for your help!

Please return the completed questionnaire in the stamped addressed envelope provided to:

Den norske Mor og Barn undersøkelsen
Nasjonalt folkehelseinstitutt
Avd. for medisinsk fødselsregister
Kalfarveien 31
5018 Bergen