eHealth application and AI-solutions for early detection of cerebral palsy in newborns - based on home video recordings for general movement assessment

Kircheiner Brown, Annemette

2025

Document Version:
Publisher's PDF, also known as Version of record

eHealth applications and AI-solutions for early detection of cerebral palsy in newborns

– based on home video recordings for general movement assessments

ANNEMETTE KIRCHHEINER BROWN
DEPARTMENT OF HEALTH SCIENCES | FACULTY OF MEDICINE | LUND UNIVERSITY

eHealth applications and AI-solutions for early detection of cerebral palsy in newborns

– based on home video recordings for general movement assessments

Annemette Kirchheiner Brown

LUND
UNIVERSITY

Coverphoto by *In-Motion Instructional Video, St Olavs Hospital, Trondheim Norway*
Copyright Annemette Kirchheiner Brown

Faculty of Medicine Lund University
Department of Health Sciences

ISBN 978-91-8021-718-7
ISSN 1652-8220

Printed in Sweden by Media-Tryck, Lund University
Lund 2025

“I am deeply grateful to all the families and their infants who have contributed to this work, enriching my perspective and broadening my horizons.”

Table of Contents

Abstract

Background
Early detection of cerebral palsy (CP) is essential to initiate timely intervention and improve long-term outcomes for infants at risk. The General Movements Assessment (GMA) is a well-established tool for early identification of CP, yet its implementation in routine clinical practice faces challenges related to access and scalability.

Aim
This thesis explores the use of GMA as a screening tool for newborns with detectable risk for CP, focusing on digital innovations, parental experiences, screening strategies, and future perspectives involving artificial intelligence (AI).

Methods and Results
Through four interconnected studies, the thesis examines: (1) the feasibility of performing GMA remotely using smartphone-recorded home videos, (2) parents' experiences of participating in home-based GMA screening, (3) the potential use of the Ages and Stages Questionnaire (ASQ) as a pre-screening tool to select infants born before 32 weeks' gestation for GMA, and (4) interpretability of the AI-based In-Motion model.

The findings support the feasibility and clinical utility of remote GMA, with parents reporting empowerment and increased accessibility. While ASQ is widely used in developmental monitoring, it was not effective in identifying all infants who should undergo GMA, limiting its value as a pre-screening tool. The In-Motion model has earlier demonstrated strong predictive accuracy but relies on movement features that differ from traditional fidgety movements, raising important questions about transparency and how to interpret it in a clinical practice.

Conclusion
This thesis supports the use of GMA, particularly via smartphone technology, as a viable and equitable screening method for CP in at-risk infants. It highlights the importance of involving parents, optimising resource allocation, and carefully considering the future role of AI in early detection. Together, these findings contribute to the development of more accessible, effective, and family-centred models for early CP screening.

Original Papers

Paper 1	Adde L, Brown A, van den Broeck C, DeCoen K, Eriksen BH, Fjørtoft T, Groos D, Ihlen EAF, Osland S, Pascal A, Paulsen H, Skog OM, Sivertsen W, Støen R. *In-Motion-App for remote General Movement Assessment: a multi-site observational study.* BMJ Open. 2021 Mar 4;11(3):e042147. doi: 10.1136/bmjopen-2020-042147. PMID: 33664072; PMCID: PMC7934716
Paper II	Brown A, Tornberg ÅB, Kristensson Hallström I. *Parents' lived experience of early risk assessment for cerebral palsy in their young child using a mobile application after discharge from hospital in the newborn period.* Ann Med. 2024 Dec;56(1):2309606. doi: 10.1080/07853890.2024.2309606. Epub 2024 Feb 1. PMID: 38300887; PMCID: PMC10836479
Paper III	Brown A, Mølholm Hansen B, Lauruschkus K, Tornberg AB. E-health Follow-up: Using Home-Based General Movement Assessment and the Ages and Stages Questionnaire. - A Cohort Study of Preterm Infants Born Before 32 Weeks. *In manuscript*
Paper IV	Brown A, Tornberg AB, Mølholm Hansen B, Lauruschkus K, Bech Knudsen M, Kryger Jensen A, Strümke I, Adde L. Exploring the In-Motion deep learning method: Predicting cerebral palsy in 3-month-old infants and the role of key movements from General Movement Assessment in Risk Scores. *In manuscript*

Abbreviations

AI	Artificial Intelligence
ASQ-3	The Ages and Stages Questionnaire is a screening tool for infants aged 4–60 months, used for evaluation of developmental delays.
CP	Cerebral Palsy
FMs	Fidgety Movements
GMs	General Movements
GMA	General Movement Assessment
MRI	Magnetic Resonance Imaging
GMFCS	Gross Motor Function Classification System
MACS	Manual Ability Classification System
GA	Gestational Age
CIMT	Constraint-Induced Movement Therapy
HINE	Hammersmith Infant Neurological Examination
NICU	Neonatal Intensive Care Unit

Introduction

eHealth solutions refer to the application of digital technologies – such as mobile health (mHealth) applications, telemedicine platforms, and cloud-based data infrastructures – to enhance the delivery, monitoring, and evaluation of healthcare services (1). Within the field of neonatal care and early detection of neurodevelopmental disorders, eHealth tools have been developed to support remote developmental surveillance, family-centred care, and interdisciplinary collaboration. Specifically, in *General Movements Assessment* (GMA), eHealth solutions enable parents or caregivers to record and upload videos of their infant's spontaneous movements from the home environment, allowing trained clinicians to assess motor quality asynchronously.

This approach has been shown to increase accessibility, reduce geographic and socioeconomic barriers to care, and improve parental engagement during critical periods of infant development (2,3). The integration of eHealth into GMA aligns with the UK Medical Research Council's framework for complex interventions, which emphasises the importance of real-world feasibility, stakeholder involvement, and adaptability in healthcare innovation (4,5). By embedding GMA within a digitally supported infrastructure, eHealth solutions provide a scalable and cost-effective means of extending early detection services to infants at risk of cerebral palsy across diverse clinical and community settings.

The GMA is a clinical method developed to assess the integrity of the young nervous system through observation of spontaneous motor activity in early infancy. This method was pioneered by Professor Heinz Prechtl, a leading figure in developmental neurology, whose work has profoundly influenced early neurodevelopmental diagnostics (6).

Beginning in the 1980s, Prechtl and his collaborators conducted systematic studies on spontaneous movements in foetuses and infants. Through meticulous video analysis, they identified a class of movements termed *General Movements* (GMs), which are complex, variable, and smooth spontaneous motor patterns involving the whole body. These movements occur from early foetal life through the first month's post-term and reflect the maturation and functional state of the developing central nervous system (6,7).

Prechtl's research demonstrated that the quality of general movements, particularly during the preterm and early postnatal period, is predictive of later neurological

outcomes. Abnormal patterns – such as *cramped-synchronized movements*, and the absence of *fidgety movements* – were found to be strong early markers of neurological impairments, most notably cerebral palsy (CP) (7,8).

In the 1990s, these findings resulted in the development of the GMA, a structured clinical tool based on visual gestalt perception. This method enables trained observers to evaluate the quality of an infant's spontaneous movements through video recordings. GMA is non-invasive, low-cost, and can be applied in both hospital and community settings, making it particularly valuable for the early detection of CP and other neurodevelopmental disorders (9,10).

GMA has been extensively validated in clinical research and is now considered one of the most reliable early biomarkers for cerebral palsy, especially when combined with neuroimaging techniques such as cranial ultrasound or magnetic resonance imaging (8).

As a clinician who has used GMA in my practice for over two decades, stepping into the world of research has been a truly eye-opening experience. In clinical work, GMA has been a valuable tool, one that I have relied on with a deep sense of trust and confidence, based on years of hands-on experience and observable outcomes. However, entering the research field has challenged me to re-examine many of the assumptions I had taken for granted.

Putting on a more critical lens has revealed nuances and complexities that often remain hidden in day-to-day clinical practice. I've come to appreciate how the evidence base is built, how methodological choices shape conclusions, and how important it is to remain open to questioning even the tools we think we know best. This shift has taught me the value of balancing clinical intuition with scientific rigor.

This transition into research has prompted a critical reflection on the use of GMA in clinical populations. Specifically, it has raised the question as to whether all infants with detectable risk factors are appropriate candidates for GMA, or whether GMA's utility may be limited or context dependent. While GMA has proven to be a valuable tool for the early detection of neurodevelopmental impairment, particularly CP, its interpretation can be influenced by a variety of factors not always considered in everyday clinical practice. These include the timing of the assessment, the nature of the risk factors (e.g., neurological, genetic, environmental), and the infant's clinical state at the time of recording.

All these reflections inspired me to explore whether an eHealth approach could improve the use of GMA in clinical practice.

Background

Cerebral palsy (CP)

CP is a neurodevelopmental disorder that primarily affects movement and posture due to early brain injury or abnormal brain development. One of the earliest indicators of CP is delayed motor development, often seen as late acquisition of head control and other motor impairments (8,11). However, these delays are not exclusive to CP and can be observed in various developmental conditions, making early identification particularly challenging (12,13). Since clear neurological signs may not be apparent in infancy, healthcare providers often struggle to distinguish between typical and atypical motor development at an early stage. CP is therefore an umbrella term encompassing multiple motor deficits resulting from an adverse neurological developmental pattern in early childhood. The primary characteristic of CP is impaired motor function, which often presents as spasticity, dystonia, or, less commonly, ataxia (11,14).

These motor impairments can significantly impact a child's daily life, affecting abilities such as walking, maintaining balance, and fine motor skills. The earliest signs of CP often appear as delayed motor development, which may be one of the first indicators prompting further assessment (15).

> Cerebral palsy is described a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems. (Rosenbaum et al., 2007, p 8-14) (16).

This definition highlights that CP is more than just a motor disorder – it can also involve sensory, cognitive, and behavioral challenges (16-18).

Distribution of CP

Infants with detectable risk of high risk for CP can be divided into two major groups, preterm and term infants (8). Below follows a definition of term and preterm birth as well as the prevalence of CP within the different groups.

Gestational age (GA) is the number of weeks since the first day of the last menstrual period and is used to classify births into term and preterm categories. A term birth occurs at 37 weeks or later, further categorised into early term (37–38 weeks), full term (39–40 weeks), late term (41 weeks), and post-term (42 weeks and beyond)**.** A preterm birth happens before 37 weeks and is classified as late preterm (34–36 weeks), moderate preterm (32–33 weeks), very preterm (28–31 weeks), and extremely preterm (<28 weeks) (19-21).

Gestational age is determined through three primary methods. The last menstrual period method estimates GA based on the first day of the woman's last menstrual period, though it may be inaccurate for women with irregular cycles. Ultrasound assessment, particularly in the first trimester, provides the most precise GA estimation. These methods together ensure accurate classification of births into term and preterm categories, which is crucial for neonatal care and management Table 1 (21-23).

Tabel 1. Livebirth in Denmark 2019-2022 (22)

Classification	Range of gestational age (weeks)	Approximate proportion of all liveborn infants
Extreme preterm	<28	0.3
Very preterm	28–31	0.6
Moderate to late preterm	32–36	5.4
Term	37–41	91.8
Late term	≥42	1.9
Unknown GA	-	0

In Denmark the distribution of CP 2007-2013; 56.6% was boys with no difference of distribution between term and preterm. The distribution of CP was 51.3% born term, 7.9% extremely preterm, 19.2% very preterm, 18.6% moderate preterm and 3.3% post term. Approximately 100 new cases of CP are diagnosed yearly (24,25).

Benefits of early intervention

Timely early intervention is paramount for children with CP as it can significantly improve their development and quality of life. There are indications that early intervention gears the brain's neuroplasticity and may benefit the development of new neural pathways and thereby improve the child's functional skills (26-28).

There are several key aspects that are important in obtaining the benefits of early intervention. One aspect is to improve motor function to optimise the child's ability to perform daily tasks. Early physiotherapy and occupational therapy focus on improving motor function and techniques as *Constraint-induced movement therapy* (CIMT) and task-specific training have shown effect to improve motor skills by encouraging repetitive, active movements that reinforce neural pathway (8,26,27,29,30).

Early intervention for children aged 0-2 years with or at high risk of CP should begin as soon as possible according to international clinical practice guidelines. Early intervention builds on a critical developmental time for the plasticity of developing systems (26,29,31,32).

Early intervention plays a critical role in enhancing cognitive development and supporting families in their journey to secure appropriate care. Targeted cognitive interventions stimulate self-generated movements by encouraging real-life tasks that involve social interactions with people and objects (31). These interactions not only benefit the child's motor and cognitive development but also provide parents with opportunities for active engagement with their child (26).

Providing parents with guidance on integrating task-oriented interventions into daily activities is essential for maximizing developmental outcomes (33). However, factors such as feeding, and sleep disorders may interfere with both motor and cognitive development**.** These challenges arise because the child is learning under suboptimal conditions**,** and often under conditions involving pain, low caloric intake, and irritability.

To ensure optimal outcomes, it is highly recommended that families with a young child diagnosed with or at risk for CP receive care from a comprehensive, multidisciplinary team**.** This approach provides holistic support**,** addressing medical, motor, and cognitive needs while empowering families to play an active role in their child's development (28,34).

Early detection of CP is critical for timely intervention**,** as early therapies can significantly improve functional outcomes by taking advantage of the brain's neuroplasticity. Therefore, the development and accessibility of accurate screening and diagnostic tools are essential**.** Equally important is providing parents with the opportunity to express concerns about their child's development, as parental observations can play a key role in early diagnosis and intervention planning (8,27,29,31,32,35-37).

The role in CP classification systems in CP management

Historically, CP severity was categorised using subjective terms such as mild, moderate, or severe**.** However, the introduction of the *Gross Motor Function Classification System* (GMFCS) has provided a standardized classification gross motor function in individuals with CP (16,18,38).

This system consists of five levels, offering a structured way to describe motor abilities:

- Level I represent children with the highest level of motor function, who can walk independently with minimal restrictions.
- Level V includes individuals with the most severe motor impairments, requiring full assistance for mobility and activities of daily living.

The *Manual Ability Classification System* (MACS) is a standardised tool used to classify the hand function of children with CP. It assesses how children handle objects in daily activities and helps determine the level of assistance they may need.

The system classifies manual ability on a five-level scale based on how children use their hands to manipulate objects in daily activities. It focuses on real-world function, rather than isolated movement assessments (39-41).

- Level I: The child handles objects easily and successfully.
- Level V: The child does not handle objects or has very limited hand use.

The GMFCS and MACS play a crucial role in clinical practice and research**,** offering a common language for healthcare providers, therapists, and families to assess motor function, predict developmental trajectories, and plan interventions. By facilitating clear communication and informed decision-making**,** the GMFCS and MACS help ensure that children receive appropriate support tailored to their functional abilities.

Towards a more inclusive and effective approach

The challenges of early CP detection and classification highlight the need for integrated approaches that combine clinical assessment, parental input, and standardised classification systems (8,26,28,36,42,43). As research advances, incorporating early screening tools, neuroimaging, and movement assessments into routine care can improve early diagnosis, allowing for personalised intervention strategies that enhance long-term outcomes (26,27,33,44-46).

Early detection of infants at high risk for CP

Early detection of CP is critical for timely intervention**,** as early therapies can significantly improve functional outcomes by taking advantage of the brain's neuroplasticity. Therefore, the development and accessibility of accurate screening

and diagnostic tools are essential**.** Equally important is providing parents with the opportunity to express concerns about their child's development, as parental observations can play a key role in early diagnosis and intervention planning. Certain newborns and infants have a higher likelihood of developing CP due to perinatal and postnatal complications. There are important groups of infants that would benefit from early detection, including a) newborns with detectable risk of CP in the early neonatal period and b) infants with detectable risk of CP later in infancy (8).

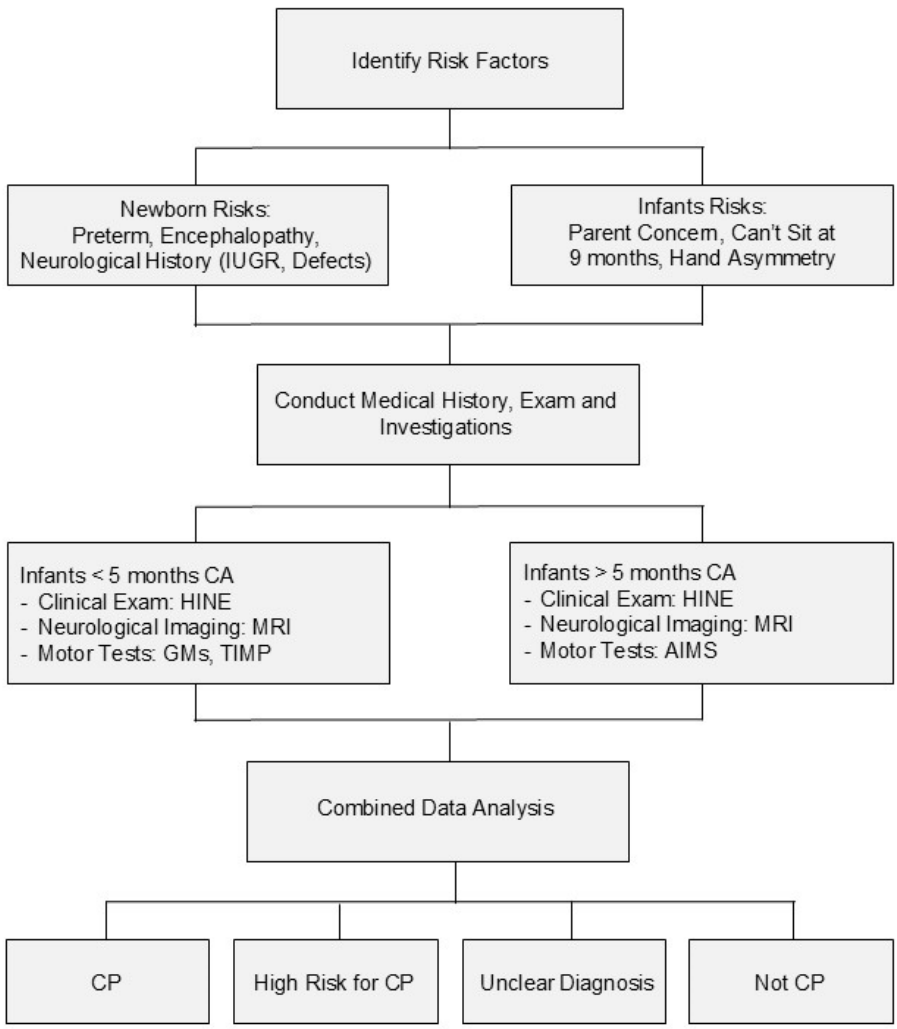


Figure 1. Flow chart for detectable risk in newborn and infants

Newborns with detectable risk of CP in the early neonatal period

Prematurity

Around 15 million preterm infants are born worldwide every year according to WHO and the number is rising. Preterm infants born before 28 weeks are considered extremely preterm and when born prior to 32 weeks they are considered very preterm. The survival rate among the extreme and very preterm continues to increase due to advances within neonatal care (15,47,48).

Being born extremely and very preterm poses an increased risk of developing CP in conjunction with other medical risk factors such as neonatal encephalopathy, interventricular haemorrhages, ischemic stroke, and intrauterine infection (48).

Hypoxic ischemic encephalopathy

Hypoxic ischemic encephalopathy is a condition caused by oxygen deprivation (perinatal asphyxia) before, during, or shortly after birth, leading to brain injury. It can result from complications such as umbilical cord prolapse, placental abruption, or prolonged labour. Often affects term and late-preterm infants, with MRI findings showing damage to the basal ganglia and thalamus (25,49).

Neonatal stroke

Neonatal stroke is a disruption of blood flow to the brain, leading to ischemic injury in critical motor regions. It most commonly affects the middle cerebral artery, leading to unilateral motor impairments. Risk factors include congenital heart disease, clotting disorders, and placental abnormalities. The risk of CP is in the range of 50%–70% of infants surviving perinatal arterial ischemic stroke, primary developing unilateral spastic CP (50-53).

Structural brain abnormalities

Some cases of CP are linked to genetic mutations or congenital brain malformations that impair normal neurological function. Brain malformations such as lissencephaly and polymicrogyria can disrupt normal motor function. As well as inherited conditions affecting brain growth and myelination can contribute to CP (54,55).

Infants with detectable risk later in infancy

Infants at risk for CP may not show signs immediately after birth, but certain motor delays and movement abnormalities can become apparent in the first year of life. Recognising these early indicators is essential for timely evaluation and intervention.

Infants with CP often display noticeable differences in movement and muscle tone. They have difficulty achieving motor skills such as not sitting independently by nine months. Furthermore, they can show hand preference before 12 months, which may

suggest weakness on one side. Additionally, they may present abnormal muscle tone such as hypertonia or hypotonia (56).

Finally, the parents could raise concern about their infant's development or unusual movement patterns. Parents may observe persistent clenched fists beyond four months, scissoring of legs in standing or uncoordinated, jerky, or restricted movements compared to other infants.

These signs warrant further assessment through neurological or motor assessment to determine if the infant is at high risk for CP.

Standardised methods for early detection

To confirm a high risk of CP, clinicians use a combination of neurological and motor assessments, and neuroimaging.

Clinical neurological examination

Hammersmith Infant Neurological Examination (HINE)

The HINE is a standardised neurological assessment used for infants between 2 and 24 months of age to evaluate neurological function and predict neurodevelopmental outcomes, particularly in identifying CP. It is widely used in both clinical and research settings (57-60).

HINE helps in detecting neuromotor disorders, including CP, motor delays, and other neurological impairments. This examination is particularly useful for infants who are preterm, at high risk due to perinatal complications, or showing signs of developmental delay**.** The exam typically includes assessments of muscle tone, reflexes, posture, movement quality, and sensory responses (61-64).

HINE is a reliable toll for predicting CP, particularly in infants with detectable risk for CP. The method has shown a 90% sensitivity for CP with a total score 40 at 6 months and a strong predictor of motor impairments with a score below 60 at 6–12 months. Furthermore, it has demonstrated that the absence of head control at three months and sitting at nine months is highly predictive for severe CP (57,58).

Motor assessment

The General Movement Assessment (GMA)

The GMA is an observational method used to evaluate the spontaneous motor repertoire of infants and has emerged as one of the most accurate clinical tools for early identification of infants at high risk of developing CP and other neurodevelopmental disorders. Furthermore, GMA is a non-invasive and cost-effective method used to identify neurological issues in infants that may lead to cerebral palsy and other developmental disabilities (6,65,66).

The purpose of GMA is to assess infants' spontaneous movements, as abnormalities or absence of these movements signal a high risk of later cerebral palsy or neurological impairment (7,65,66).

GMA can be performed from birth until 20 weeks post term when corrected from prematurity. The procedure of assessing general movement is based on a 3–5-minute video sequence where the infant is laying in supine without being disturbed from external noise or influences and in a calm and relaxed state (Table 2) (7,65,66).

Table 2. Type and quality of general movements (6,7).

Age ange	Type of Moments Observed	Quality of Movements
Preterm (before 37 weeks GA)	Writhing movements begin	Movements may be jerky, cramped, or lacking variation in high-risk infants.
Term (37-42 weeks GA)	Writhing movements continue	Smooth, variable, and complex movements are expecte: reduced complexity may indicate neurological concerns
Early Postnatal (0-6 weeks post-term)	Writhing movements peak	Should be fluent, complex, and variabled: monotonous or jerky may signal abnormalities
2-9 weeks post-term	Writhing movements transition	Movements should show more fluidity and variation.
9-20 weeks post-term	Fidgety movements emerge (small, circular, continuous movements of the limbs, neck, and trunk)	Normal: Variable, continuous, and small-amplitude movements. Abnormal: Absent or sporadic fidgety movments (predictiv of motor impairment).
3-5 months post-term	Fidgety movements gradually fade	Smooth, controlled, grasping, and postural adjustments should develop.
6+ months post-term	Goal-directed movements replace fidgety movements	Controlled reaching, grasping, and postural adjustments should develop

There are two types of General Movements (GM) according to the age of the infant. Writhing movements can be seen from preterm- and term age until nine weeks post term corrected age. Fidgety movements can be seen from nine weeks post term until 20 weeks post term corrected age (6,65-67).

Writhing movements are typically observed from term age until approximately six to nine weeks post-term. These movements involve the entire body and are characterized by a variable, flowing quality, with smooth, slow to moderate-speed motions and small to moderate amplitude. When writhing movements are complex,

elegant, and variable in sequence, direction, and intensity, they are considered indicative of typical neurodevelopment. Conversely, deviations from this pattern – such as poor repertoire (monotonous and lacking variation) or cramped-synchronized movements (rigid, simultaneous muscle contractions without the normal fluidity) – are associated with an increased risk of neurological impairment. Cramped-synchronized movements have been identified as a strong early predictor of cerebral palsy (6).

- From approximately 9–20 weeks post-term age, healthy infants typically display a different form of spontaneous activity known as fidgety movements. These are continuous, small-amplitude, moderate-speed movements of the neck, trunk, and limbs, occurring in all directions. Fidgety movements appear irregular in timing and are typically seen when the infant is awake, alert, and not engaged in purposeful actions. The presence of normal fidgety movements is a robust indicator of intact central nervous system function (6).

- The GMA places particular emphasis on the assessment of fidgety movements due to their high predictive value. Abnormalities – such as increased amplitude, jerkiness, or a complete absence of fidgety movements – are strongly associated with CP and other developmental disorders. Notably, the absence of fidgety movements has been shown to be a highly sensitive and specific early marker of CP, reinforcing the importance of early motor assessments in clinical and research settings (8).

Table 3. Predictability of general movements in the writhing and fidgety phase

Age Range	Movementt Phase	Sensitivity* (%)	Specificity** (%)
Preterm to Term (Birth to ~ 9 weeks post-term	Writhing Movements	93 (86-89)	59 (45-71)
~ 9 to 20 weeks post-term	Fidgety Movements	97 (93-99)	89 (83-93)

* **Sensitivity:** proportion of infants with the condition correctly identified (true positives).
** **Specificity:** proportion of infants without the condition correctly identified (true negatives).

The fidgety period is highly predictive of CP when the fidgety movements are either abnormal or absent. During writhing cramped synchronized movement are highly predictive of CP and other developmental disabilities. One of the main challenges is the requirement for highly trained professionals to accurately assess and interpret infant movements (68-72). The availability of such experts is often limited, making it difficult to implement GMA in all healthcare settings. Additionally, despite being a standardized assessment, subjectivity in interpretation can sometimes lead to variability in results (7,8,73,74).

Despite its recognised value the GMA has several limitations value, several limitations that must be acknowledged. Its predictive reliability is highest during the first five months of life, particularly in the fidgety movement period, but decreases thereafter, restricting its utility for infants evaluated later in infancy (7). In addition, the method requires highly trained and certified assessors. Although standardized, the qualitative nature of the assessment demands substantial expertise, and inter-observer variability remains a concern, particularly in contexts where consistent calibration and quality assurance procedures are not maintained (70,75).

Assessment quality may also be influenced by external factors such as infant alertness, environmental distractions, or postural restrictions, which highlights the importance of optimal recording conditions (7). The method also depends on high-quality video recordings with correct infant positioning, adequate lighting, and unobstructed movement capture – requirements that may be difficult to achieve in resource-limited settings (6).

While GMA is highly predictive of CP, its ability to identify other neurodevelopmental disorders, such as autism spectrum disorder or broader cognitive delays, remains limited (76,77). Moreover, the process is resource-intensive, requiring time for video recording, transfer, scoring, and interpretation by experienced personnel. In busy clinical environments, these demands on staff and time can restrict its broader implementation (78,79).

These limitations underscore the need for complementary approaches, including eHealth solutions and parent-reported screening tools, to optimise early detection strategies and improve accessibility in neonatal follow-up.

Neuroimaging

Neuroimaging is a key component in the early detection of brain injuries associated with CP, such as white matter damage, haemorrhages, or structural malformations. The two primary imaging techniques used in neonates are cranial ultrasound and *Magnetic Resonance Imaging* (MRI).

Cranial ultrasound

This is the first-line imaging tool used in neonates, especially in preterm infants in neonatal intensive care units (NICUs). It is performed via the anterior fontanelle, providing real-time imaging of the brain.

The advantage of cranial ultrasound is that it is widely available and cost-effective. It is portable, non-invasive, and safe. Finally cranial ultrasound can be performed at the bedside which makes it ideal for critically ill infants. Its sensitivity for CP is moderate ranging between 50% and 70%.

The cranial ultrasound findings associated with CP are periventricular leukomalacia (PVL) and grade III-IV intraventricular haemorrhage (IVH). PVL is the most

significant predictor of CP in preterm and is strongly associated with spastic bilateral CP (80-82).

MRI

A gold standard for detecting brain injuries in infants at risk for CP. It provides high-resolution images of both white matter and deep gray matter structures**.**

The MRI plays a crucial role in the diagnosis and evaluation of CP by identifying structural brain abnormalities associated with the condition. Since CP is caused by early brain injuries or developmental disturbances, MRI provides detailed neuroimaging that helps in determining the timing, location, and severity of brain damage (43,83-85).

MRI is a tool for confirming CP diagnosis**,** understanding brain pathology, and guiding interventions. It plays a key role in early detection, prognosis, and therapy planning, particularly when used alongside clinical assessments such as GMA and *Hammersmith infant neurological examination* (HINE).

Combining GMA, HINE, and MRI for CP prediction

The GMA, HINE, and MRI together provide a structured and evidence-based approach for the early diagnosis of CP**.**

Each of these tools independently has high predictive accuracy for CP. When two of these tools are combined, the predictive accuracy for CP increases significantly. However, when all three tools are used together, the predictability for CP approaches nearly 100% (8,76). This multi-modal approach ensures early and precise identification of infants at risk, allowing for early interventions that can improve long-term functional outcomes (8).

Developmental delay

Early detection of developmental delay is crucial for initiating timely interventions. Several standardised developmental tests are used to assess infants and young children, but their predictive accuracy varies based on the child's age, condition, and test sensitivity. These assessment tools are used to identify motor delay, global developmental delay, and other developmental disorders in infants and young children (86).

For assessing global cognitive and motor delays, the *Bayley Scales of Infant and Toddler Development* (BSID-4) is widely used and considered golden standard in children aged 1–42 months (86-90). Another screening tool is the *Ages and Stages Questionnaire* (ASQ-3) in children aged 4–60 months, provide a broader evaluation of developmental delays.

The ASQ-3 is a parent-completed developmental monitoring system for screening children. It consists of 19 different questionnaires covering the age range of 4–60 months. The reading level required to fill in the questionnaires is elementary school, thus ensuring easy parental comprehension, and they take 10–15 minutes to complete. ASQ covers 5 different domains: communication, gross motor, fine motor, problem solving and personal social skills. Each domain is assessed by six questions on developmental milestones. The parent can answer "yes", "sometimes" or "not yet" and the child is scored with 10, 5 or 0 points. Referral to further assessment is advised when the score on any domain is below the cut-off point, which is set at 2 standard deviations below the mean of the reference group. The original ASQ has proved to be both reliable and cost-effective with a concurrent validity ranging from 76% to 88% and an overall sensitivity and specificity of 75% and 88% respectively and has been used in many scientific studies (91-99). ASQ has been validated on Korean, Chinese, French, Norwegian and Dutch children and the Norwegian validation was performed on a total of 1172 children with the cut-off score by and large resembling the American normative data (100).

New aspects of early detection

The GMA has changed the early detection of CP by identifying abnormal spontaneous movements in infants. With advancements in technology, artificial intelligence (AI), and motion analysis, the future of CP diagnosis is evolving toward greater accuracy, automation, and accessibility.

Several smartphone applications have been developed to assist parents in recording their infants' movements at home for GMA. These apps play a crucial role in the early detection of neurodevelopmental disorders, such as cerebral palsy, by enabling remote assessment of an infant’s spontaneous movements. To ensure the accuracy and reliability of the assessment, it's essential to follow specific guidelines during the recording process. Furthermore, engaging parents in doing home-based video recordings for GMA could be a way forward in empowering the parents for active participation (2,101-103).

Parents' perspectives on using smartphone applications for home-based GMA are generally positive, highlighting several key benefits and considerations: In a study where parents used the Baby Moves app for GMA assessment, they responded on a survey that they did not become more worried about their baby’s risk of developing CP from using the app (2,102,103). However, it is still unknown why they did not get more worried by using the app. Further research is needed if we are fully going to understand the lived experience of the parent when using an app for home GMA video recordings.

Additional approaches for early detection

In recent years, several new computer-based methods for assessing infant movements have emerged. While wearable sensors have been explored as a potential solution, their use has been limited. These devices may interfere with infants' natural, spontaneous movements, potentially affecting the accuracy of movement classification. Additionally, applying wearable sensors to infants can be labour-intensive for healthcare personnel.

An alternative approach involves wireless systems that analyse infants' movements by tracking pixel changes between frames in video recordings. These systems have shown promising results in assessing *fidgety movements* (FMs). However, their accuracy can be compromised by factors such as lighting conditions, infant clothing, skin tone, and video contrast (3,104-107).

One of the more recent innovations, known as *In-Motion*, employs a deep learning model to predict the risk of developing cerebral palsy (CP). This model tracks infants' movements by identifying 19 key skeletal points in video recordings and generates a risk score ranging from 0 to 1.0. The model has demonstrated accuracy comparable to that of expert-conducted *General Movement Assessment* (GMA) in predicting CP. However, it has been trained exclusively on stationary video recordings taken in hospital environments and has not yet been validated for videos recorded at home by parents (108-110).

For the development of a reliable computer-based method for early detection of CP the need for data is huge and would likely necessitate greater cooperation within the research world for early detection of the risk for CP.

Conceptual framework

Family-Centered Care: A Collaborative Approach to Healthcare

Family-Centred Care (FCC) is a healthcare approach that prioritises collaboration between healthcare providers, patients, and families. It recognises the essential role families play in patient well-being and recovery, fostering an inclusive, respectful, and supportive environment.

Core Principles of Family-Centered Care

Healthcare professionals must honour the values, beliefs, and preferences of patients and their families, providing culturally sensitive care that respects diversity. Clear, timely, and accurate communication ensures families receive comprehensive information to make informed decisions. Families should be given opportunities to participate in decision-making at their preferred level, fostering shared

responsibility and adherence to treatment plans. Providers and families should work together in care planning, delivery, and evaluation, extending to policymaking, program development, and professional education (111-113).

Benefits of Family-Centred Care of infants' detectable risk of CP and eHealth solutions

There are several benefits associated with this approach. Improved patient outcomes can be achieved by involving families directly in the home video recordings of their infant for GMA analysis. This engagement not only enhances parental satisfaction but also contributes to a more positive healthcare experience, empowering families in the care of their child. Moreover, active family involvement in follow-up management has the potential to minimise healthcare costs and reduce the frequency of hospital visits.

Challenges and Considerations

When changing from a traditional health systematic follow-up to a more collaborative approach there can be hesitancy from both the medical professions as well as families. For a shift in clinical practice is possible is requires family support, training, and resources.

Family-Centred Care is a transformative approach that strengthens healthcare by fostering meaningful partnerships between providers, patients, and families. Prioritizing respect, communication, and collaboration ensures a more inclusive, effective, and compassionate healthcare experience.

Rationale

Early detection of CP is essential to ensure timely intervention and improve long-term outcomes. The GMA is a validated tool for early identification of infants at high risk of CP, particularly when used in the first month of life. However, implementing GMA in routine practice poses challenges related to access, scalability, and integration into screening pathways.

This thesis explores the use of GMA for screening newborns with detectable risk for CP through four interconnected studies. These include the feasibility of GMA via home video, parents' experiences with the process, the potential use of the ASQ to prioritise which infants should receive GMA, and the future role of artificial intelligence in early movement analysis. Together, these studies aim to advance practical, family-centred, and innovative approaches for the early detection of CP.

Aims and objectives

The overarching aim of this thesis was to provide a comprehensive examination of the development, feasibility, and evaluation of eHealth applications and AI-based solutions for general movement assessment (GMA) in infants identified with detectable risk of CP in eastern Denmark. The thesis is grounded in three, distinct studies and is comprised of four papers. The specific objectives of each paper were as follows:

I: To determine whether it is feasible for parents to use a handheld camara to video record their child to provide recordings that could be used for GM scoring by a trained GMA observer and additionally to explore how the parents perceived filming their child at home.

II: To explore parents lived experience of early risk assessment for CP using a mobile application for home video GMA recording after discharge from the neonatal ward.

III: To evaluate the utility of the ASQ questionnaire in identifying infants who may benefit from additional neurodevelopmental assessment via GMA, thereby facilitating targeted early screening for CP.

IV: To explore whether the deep learning In-Motion models' CP scores are linked to fidgety movements

Methods

Design

This thesis contains three studies and four papers that all fit in the UK's Medical Research Council (MRC) methodological framework for development, feasibility, evaluation, and implementation of complex interventions (114-116).

The first study corresponds to the feasibility phase and resulted in Paper I and Paper II. In Paper I, the feasibility of a mobile application for parent-recorded home videos was tested in a multicenter setting across three countries, assessing its usability, technical performance, and reliability for GMA. Building on these findings, Paper II adopted a hermeneutic phenomenological approach to explore parents' lived experiences with the application. This qualitative study, informed by survey data from Paper I, provided deeper insight into how parents engaged with the intervention and how it affected their sense of control and involvement during a vulnerable period

The second study, reported in Paper III, the mobile application for home-video recordings is evaluated in large clinical cohort of very and extreme preterm infants from two health regions in Eastern Denmark.

Finally, Paper IV returns to the developmental phase by examining the underlying movement features identified by the In-Motion deep learning model when predicting cerebral palsy. This study sought to enhance understanding and interpretability of the algorithm prior to clinical implementation. (Table 4).

Table 4. Study overview

Study	Design and analysis	Population	Data collection	Paper
1	Prospective observational descriptive	Multi-center study (Norway, Denmark, and Belgium) 89 newborns with detectable risk for cerebral palsy	In-motion app and survey	I
	Inductive qualitative hermeneutic phenomenological	14 parents of the Danish participants	Interviews	II
2	Cross sectional comparative	Preterm infants <32 weeks from the health regions of Copenhagen and Sjælland 232 newborns with detectable risk for cerebral palsy	Baby Moves app and ASQ	III
3	Cross sectional experimental	Norwegian newborns with detectable risk for CP, from the mid-Norway health region. 14 newborns with detectable risk for cerebral palsy	Homevideo recordings from a follow-up study in Mid-Norway	IV

Methodological Framework

The thesis adheres to the UK Medical Research Council (MRC) Framework, a structured methodology for the development, evaluation, and implementation of complex healthcare interventions. The framework offers a comprehensive guide for researchers to ensure that interventions are not only effective but also feasible and sustainable within real-world clinical settings. In this context, the MRC framework was applied to develop, test, and evaluate an eHealth mobile application aimed at early, targeted screening for CP in newborns identified with detectable risk factors. The application was assessed in a clinical cohort of newborns with detectable risk for CP, with the broader goal of potential implementation across Denmark.

Following its 2021 revision, the MRC framework emphasizes the integration of key elements throughout all research phases. These include consideration of context, theory development, stakeholder engagement, identification of key uncertainties, refinement of the intervention, and economic evaluation. These elements were systematically incorporated into the design and evaluation process of this thesis to support the robustness, scalability, and clinical relevance of the proposed intervention (4,5).

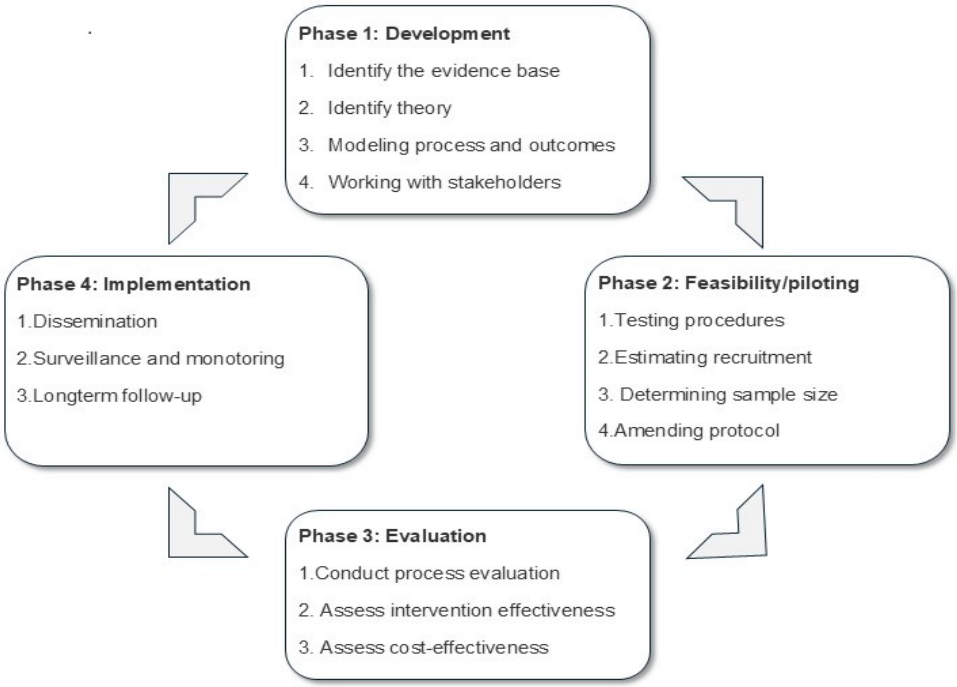


Figure 2. The Medical Research Council FrameworkIn the developmental phase the Norwegian In-Motion app was developed and tested inspired from on the development of the Australian app Baby Moves. However, it was important for the development of the Norwegian app that the quality of the home recording could be used in an AI-solution. For that reason, an instructional film was developed to eliminates eventual shortcomings of the recording in view of the use in an AI-solution. A mock-up was performed using important stakeholder parents, neonatal nurses, neonatal physiotherapists, and neonatologists. No data from the development is part of this thesis.

The feasibility of the home video recordings for GMA was tested using this Norwegian mobile application *In-Motion* together with an instructional video (Study I). The mobile app was tested to investigate if it was possible for parents to make a home recording of their infant fulfilling the criteria of the GMA methodology as well as the quality necessary for an AI-solution. Furthermore, the parents answered a questionnaire on how they perceived using the app. In a feasibility study several key components are important such as technical issues, stakeholders' view on the product, and financial aspects before implementing the intervention in full scale clinical trial. Exploring an in-debt Study I (Paper II) understanding of how the parents' experiences recording their infant for GMA was performed using a hermeneutic phenomenological approach. For this purpose, Max van Manen was used to capture the lived experiences using a mobile app for GMA recordings at home. van Manen describes the phenomenon through four existential: lived body, lived space, lived time and lived human relations. The hermeneutics

appear through collecting data, analysis, writing and rewriting the lived experience, while the phenomenology deals with how the phenomenon discloses itself. Hermeneutic phenomenology explores by formulating the essence of parents lived experience (117-119).

The financial aspects of the mobile app proved to be costly to implement in clinical practice as two small agencies had developed the app and did not have the capability to continue to maintain the app. Consequently, the app was suspended.

Due to suspension of the Norwegian *In-Motion app*, the Australian *Baby Moves app* was used with permission for my thesis, for transferring the video recordings from home to Redcap a data management storage system for research data in the region of Copenhagen.

The evaluation phase in Study II, was a cross-sectional study of preterm infants born before 32 weeks GA in eastern Denmark. By data from this study, we aimed to determine if ASQ at three–four months of age can be used to detect the infants that need further neurodevelopmental assessment by GMA for early detection of high risk for CP. In this phase home video for GMA from the study was also evaluated in in large clinical cohort to highlight obstacles prior to implementation. A cross-sectional design is descriptive, and its aim is retrieving data on and entire population in a certain timeframe.

Returning to the developmental phase in Study III, informed by the insights gained from Study II, it became clear that the GMA in clinical practice is a resource intensive and requires several trained and experienced observers. It is difficult to expect that the method of GMA can be improved. It has been used for 20-30 years, and the assessment has not been further developed. Contrary it requires many years of training to be experienced, and the reliability is dependent on the observers' experience. A further limitation is that the assessment is focused on CP and seems less accurate predicting other developmental impairments. Finally, in a hospital setting, where financial resources are limited, it is crucial to explore the future deployment of AI-solutions for early detection of high risk for CP.

AI-solutions analysing the videos has shown promising results, and in the future, it is likely that these solutions can be helpful in early targeted screening for CP. The Norwegian deep learning model has proven highly predictive for CP however it is still unknown what kind of movement data that lies behind the prediction. This is important to understand for implementation in clinical use in the future. A cross-sectional design was used to explore the correlation between the deep learning In-Motion model and fidgety movements found by GMA.

Study setting

The study was divided into three different hospitals settings. Study I (Paper I) was a multi-centre study including three different setting in Norway, Denmark, and Belgium, including different categories of infants with detectable risk of CP. In Study I (Paper II) the setting focused on the parents of the Danish infants included in Study I. In Study II (Paper III) the setting was eastern Denmark, eight different NICU sites from the health region of Copenhagen and Sjælland. In Study III (Paper IV) the setting was mid-Norway, and the study was focused on infants with detectable risk for CP.

Study participants

In Study I (Paper I) participants were recruited from neonatal ICU in Norway (27 families), Denmark (43 families) and Belgium (15 families) from 2018 to 2019 prior to discharge from hospital. Families were included based on willingness to participate and the infant being part of the follow-up program. In Study I (Paper II) 14 Danish parents from Study I, were strategically included in the study. All families were included based on willingness.

In Study II (Paper III) participants were recruited from neonatal ICU in Eastern Denmark. The cohort included infants from the region of Copenhagen and the region of Sjælland and 232 infants were included based on willingness and the infant being born preterm before 32 weeks GA. Eight study sites were part of the study, four in each region.

In Study III (Paper IV) participants were recruited from a study in mid-Norway of remote follow-up of newborn with detectable risk for CP. A total of 14 infants were included in this study.

Data collection

Included participants in Study I and Study III were assisted by a research physiotherapist to download and install the *In-Motion/Baby Moves app*. Families could ask questions about the app. They were informed about the timeframe when to record their child. The *In-Motion app* was linked to a secure server at St Olav's Hospital in Trondheim, Norway, and the *Baby Moves* was linked to Redcap database at the region of Copenhagen.

In Study II the participants were asked to participate in an interview based on socio-economic background and the infants with detectable risk factors for CP.

In Study IV the participants are selected among participants in an existing Norwegian study. The selected video recordings are selected based on global GMA classification performed by several GMA experts at St Olav's University Hospital, Trondheim, Norway.

Data analysis

Questionnaire

The survey questionnaire for the In-Motion app was developed using the evaluation framework proposed by Jin and Kim (120), designed for assessing healthcare smartphone applications. In addition, the survey was informed by and adapted from a previous study employing the Baby Moves app.

Survey on parents' perception of using the In-Motion app Study I

The Danish parent's perception of using the In-Motion app was collected using Smart Trails data management (MEDI Aps, www.medi.dk) A week after uploading the last video a link in an e-mail containing the survey was sent to the parents. The surveys questions were tailored for the In-Motion app using the tool developed by Jin and Kim and the survey resembled the survey used in the Baby Moves app. The survey questions were based on fixed topics covering 1) the *In-Motion app*, 2) In-Motion standards for remote GMA, 3) Parental worries. A 5-point scale was used to validate the parents' perception of the In-Motion app indicating agreement to disagreement.

Qualitative analysis

Hermeneutical phenomenological analysis

The hermeneutical phenomenological analysis began with active listening and reflection following each interview. A thematic process, guided by Van Manen's hermeneutical phenomenological approach, was initiated in parallel with data collection by the first author. All three authors then independently read all interviews in a naïve and open-minded manner. Phrases and paragraphs that emerged from the mothers' and fathers' lived experiences – through the existentials of lived body, lived space, lived time, and lived others – were independently noted by the co-authors(118). Each existential was marked with a distinct colour code to highlight its presence in the transcribed interviews. No themes were predetermined; instead, themes were constructed during the analysis process, in alignment with the hermeneutical phenomenological methodology. Once the subthemes were

identified, an overarching theme was developed to capture the essence of the parents' lived experiences(118).

Preunderstanding

van Manen argues that the challenge of phenomenological inquiry is not necessarily that we know too little, but rather that we know too much. This pre-existing, unexamined knowledge can lead to preconceived interpretations of a phenomenon before we fully grasp the significance of the phenomenological question. While it is impossible to completely set aside what we already know, we can make our assumptions, biases, and understandings explicit, consciously revealing the ways in which they might obscure or shape our perception of the phenomenon (117,118).

The author of this thesis has been a paediatric physiotherapist for 25 years and a GMA observer for 20 years working with infants with detectable CP risk. She has experience with early interventions for infants at high risk of developing CP and with follow-up programs designed for children with CP or at high risk of CP. The supervisors and co-authors have extended broad experience within research, GMA, and clinical knowledge in the field of neonatology and high-risk infants.

Quantitative analysis

Descriptive statistics

Nominal data was described number and proportion in percent was used (Paper I, III and IV). Ordinal and not normally distributed continuous data were presented as median and interquartile range (IQR) (Paper III). While normally distributed continuous data was presented as mean and standard deviation (SD) (Paper I, III and IV).

Analytic statistics

When comparisons were made between different outcomes in the thesis, different statistical tests were chosen depending on the natura of the data collected.

In the analysis of whether parents can take videos with handheld camera (Paper I), comparisons of the infants' characteristics between infants with returned video to infantas with no returned video were made. Continuous variables were analysed with Mann-Whitney U test, since they weren't normally distributed, and dichotomous data were analysed with $\chi 2$ test and proportions with Fisher's exact test (121). In the analysis of the coherence between risk assessment of CP with ASQ4 and GMA evaluation (Paper III), a cross-table analysis was used, since the data findings were dichotomous and less than five positive GMA evaluations (121).

To evaluate the reliability of home-based video recordings for GMA (Paper III), the interobserver agreement in classifying fidgety movements as typical or atypical was assessed using *Gwet's Agreement Coefficient 1 (AC1)*, which provides more robust

estimates than *Cohen's kappa* in the presence of prevalence imbalance (122). For comparison and interpretability, *Cohen's kappa coefficient* was also calculated as it remains the most widely reported measure of agreement in previous GMA studies. (123).

In Paper III, which investigated the coherence between cerebral palsy (CP) risk assessment using the ASQ-4 and GMA, different analyses were applied depending on data type. A *cross-tabulation analysis* was performed to evaluate coherence between dichotomous outcomes, and since fewer than five positive GMA evaluations were present, *Fisher's exact test* was chosen to ensure robust statistical inference (118). The association between ASQ-4 total scores and GMA classification was examined using the *Mann–Whitney U test*, comparing median ASQ-4 scores between infants with typical and atypical GMA results. In addition, *Fisher's exact test* was used to analyse the association between categorical ASQ-4 outcomes (classified as low versus normal) and GMA classification. Considering GMA as the reference standard for early identification of CP risk, the *sensitivity* and *specificity* of the ASQ-4 in predicting GMA outcomes were also calculated.

Inter-rater reliability between GMA assessors (Paper IV) was analysed with *Cohens' kappa* since the FMs scores were ordinal with three scoring options: continuous FMs, intermittent FMs and absent FMs. The kappa was weighted according to the definition of Landis and Koch (123) slight agreement (0.00-0.20), fair agreement (0.21-0.40), substantial agreement (0.61-0.80) and almost perfect (0.81-1.00).

In the analysis of different associations in the thesis different tests were chosen depending on the nature and complexity of the data. For the association between ASQ and GMA evaluations (Paper III), Spearman's correlation coefficients was chosen since the data were both ordinal and continuous, and not normally distributed. When analysing the association between GMA observers' classification of the FMs and the In-Motion algorithm CP risk scores (Paper IV), several levels of complexity hade to be considered. Firstly, that FMs were dichotomous, present / absent FM annotations, and In-Motion algorithm CP risk scores were continuous time-series. To make them comparable a Latent Gaussian Process (LGP) regression time-series model was used. Afterwards the LGP processed In-Motion CP risk scores was related to the GMA observers' classification using Spearman's correlation in the 4000 5 second epochs collected. Since the 5 second epochs were collected from 16 different video recordings, a per-video analysis was performed. The video-recordings contained different number of epochs classified as present / absent FM. Since the main aim was to identify the children with at risk of CP, the classification of absent FM was chosen in the per-video analysis. The mean value of the In-Motion CP risk scores was calculated using the epochs in the video that were classified as absent FM. Since the FMs only could be classified 0–1, the proportion of absent FM was used in the relation analysis. In the regression analyses, generalized linear models were used with Gaussian residuals combined with both a

linear link function (corresponding to linear regression) and a logit link function to account for that the FMs only could be classified 0-1. Furthermore, the observations (averages) were weighted by the inverse of their empirical variance estimate to account for the fact that the averages were taken over different numbers of epochs.

The significance level in all analyses was set at $p<0.05$. Analysis was conducted using IBM SPSS Statistics 26.0 (Paper I), 29 (Paper III and IV) Windows (IBM Corporation, Armonk, NY, USA). The LGP models were fitted using the lgpr package in R (124) (Paper IV).

Due to the complexity of the statistical analysis in Paper IV, which investigated the relationship between GMA observers' classifications and In-Motion algorithm risk scores, we collaborated with the Biostatistics Department at the University of Copenhagen. Several meetings were held to outline the study aims and data structure. The biostatisticians conducted the analysis and provided a written report of the statistical methods and results. We interpreted the findings in a clinical context and returned our interpretation for feedback. The final interpretation was approved in consensus with the biostatistical team.

Ethical considerations

This thesis was conducted in accordance with the ethical principles set forth in the Declaration of Helsinki, which governs medical research involving human participants. Ethical, legal, and regulatory standards were carefully considered throughout the research process. In all aspects of the study, the rights, dignity, and well-being of the participants were prioritised above any potential benefits of the research outcomes. The Declaration of Helsinki was developed to guide physicians in conducting research involving patients and to encourage all individuals involved in human research to apply its principles, as every researcher holds responsibility for both ethical conduct and scientific integrity (125).

Research ethics approval and research registration

The Study I and Study II was approved by the Danish Committee System on health Research Ethics, reg.no 1701117778 and by the Danish Data Protection Agency NOH-2017-025, I-Suite no. 05988. Study III from The Committees on Health Research Ethics for the Capital Region of Denmark (H-20006986) and approval from the Knowledge Centre on Data Protection Compliance (P-2021-125) has been granted. All parents will sign a consent form including with the possibility to withdraw from the study at any time.

Beneficence and non-maleficence

Beneficence and non-maleficence are two fundamental ethical principles in medicine, healthcare, and bioethics. Beneficence refers to the moral obligation to act for the benefit of others, promoting their well-being and taking actions that enhance their health or life quality. In healthcare, this means that medical professionals must actively seek to help patients by providing treatments that improve their conditions. The principle of non-maleficence means "do no harm" and obligates healthcare professionals to avoid causing unnecessary harm or suffering to patients. It ensures that actions or treatments do not result in more harm than good (126-129).

Using a qualitative test in GMA for early identification of the risk for CP always poses the risk of false positive or false negative response. All parents were given written and oral information about the study prior to signing a consent form. To minimising the risk of false response at least two experienced GMA observers classified each video and if the two observers did not agree a third observer classified the video and consensus was reached between all three observers. Furthermore, all participants were followed until the age of two years where upon CP status was established.

Justice

The principle of justice deal with issues and fairness and non-discrimination of participants in recruitment and treatment (130). Mothers and father both signed the consent form, and they were both present during the interviews in Study II. However, parents who did not speak either Danish or English were excluded from participating. These parents were offered standard care follow-up care at the department of neonatology follow-up clinics for high-risk infants.

Scientific requirements and research protocols

This thesis is underpinned by established scientific knowledge, with all studies conducted in accordance with predefined study protocols developed at the commencement of the research. These protocols incorporated ethical considerations, funding sources, and institutional affiliations.

Findings

This thesis explores innovative approaches to support earlier identification of infants at high risk of CP by integrating mobile technology, parent-recorded home videos, and AI.

The studies contributed new knowledge on the potential and limitations of digital tools in early CP detection, with implications for both clinical practice and future technological development.

The aim of Study I (Paper I/In-Motion for remote for General Movement Assessment: A multi-site observational study) was threefold firstly to examine if video-recording done by the parents if feasible for GMA, secondly to test a seven-point movement tracker for AI GMA using a smartphone recording and thirdly the parents' perception of filming their baby at home. Our findings contribute to the use of home video recordings for remote GMA giving parents to infants with detectable risk for CP equal access to GMA, reducing the cost to outpatient cost for early detection of CP and demonstrating the feasibility of computer-based movement analysis for accurate detection of CP based on home video recordings. In our study 86 parents returned 130 videos and 121 (96%) of them were in accordance with the requirements for GMA. Among the parents that did not upload any video 3 did not download the app and 16 did not record due to forgetfulness, social issues or unknown reasons which constitutes of a total of 19.8% of all included. The 7-point body tracker software detected more than 80% of the body key point positions correctly. Most families found the instructions for filming their infant useful to follow, below is a screenshot of the In-Motion instructional film (Figure 4), they reported that it was easy to return to the In-Motion film, before recording and uploading a film of their own child. The parents' further perception of using the In-Motion app reported that 17.8% of them found it difficult to video record their child without moving the smartphone or disturbing the child and 19.1% did not find the numbers of reminders suitable or they experienced technical problems with uploading or sending the videos. However, in conclusion of their perception of the In-Motion app, more than 90% reported that they did not become more worried about their infants' development through using the application.

The aim of Study I (Paper II/Parents' lived experience of early risk assessment for cerebral palsy in their young child using a mobile application after discharge from hospital in the newborn period) was to gain a deeper understanding of why parents did not become more worried when using the mobile application for GMA. Our findings show that the parents struggle with loss of control and anxiety after giving birth to a child with detectable risk for CP. The mobile application provided the parents a sense of empowerment and getting in uncontrolled life situation. Danish parents of preterm infants were interviewed about their experiences with the app. The overarching theme that emerged from the analysis was *"Finding control in an uncontrolled life situation"* (Table 6, Brown et al.; Annals of Medicine No 56, Vol 1, 2024).

This central experience was supported by three main themes:

A challenging start to parenthood

Parents described experiencing a difficult pregnancy and birth, and many struggled to cope with the demands of highly specialised neonatal care. This period was characterised by emotional distress, uncertainty, and a sense of being overwhelmed (Table 6, Brown et al.; Annals of Medicine No 56, Vol 1, 2024).

> This was the wildest rollercoaster I have ever been on. At first it made me physically sick, I had to go to the restroom to collect myself. The staff got very anxious, thought I was doing drugs, but I just had to collect myself and get the strength to be there for my child and wife (Brown et al.; Annals of Medicine No 56, Vol 1, 2024).

Living in a bubble

During the hospital stay, parents found it difficult to process information and emotions. They described feeling isolated and detached from everyday life and trusting the healthcare system made it possible for the as parents to grow. This "bubble" made it challenging to engage fully with their child's care and process their emotions and the information provided by the health care system (Table 6).

> I felt that I was going mad, I needed normality. One of the nurses recommended me to go for a walk, I went downtown for a coffee, making believe that I had not been admitted with my newborns, it felt good but at the same time I felt guilty leaving my children. (Brown et al.; Annals of Medicine No 56, Vol 1, 2024)

Getting control in a safe environment

Returning home marked a turning point for many parents. In the home environment, they felt safer and more in control. The mobile application contributed to this sense of security by enabling them to follow their child's development independently of the hospital. Parents reported feeling more empowered, confident, and actively involved in their child's progress (Table 6, Brown et al.; Annals of Medicine No 56, Vol 1, 2024).

> We felt so much in control, being able to select a video that was a true picture of our child's abilities for clinical assessment. To be honest we took five videos before uploading the video showing the true movements of our child. (Brown et al.; Annals of Medicine No 56, Vol 1, 2024)

Table 6. Overall theme, themes, and subthemes.

Finding control in an uncontrolled life situation		
A challenging start to parenthood	Living in a bubble	Getting control in a safe environment
Difficult pregnancy and delivery	Difficulty in processing emotions	Feeling safe at home
Difficulty in coping with highly specialized care	Difficulty in processing information	Can see that the child is developing
Separation and difficulty in bonding with the newborn child	Handing over responsibility to the experts	The app gives control and security

The ASQ was evaluated in Study II (Paper III/E-health Follow-up: Using Home-Based General Movement Assessment and the Ages and Stages Questionnaire A Cohort Study of Preterm Infants Born Before 32 Weeks"). This study aimed to determine whether the ASQ could serve as a pre-screening tool for identifying infants in need of GMA. The ASQ was completed and scorable in 199 infants (86%). Of these, 160 (80%) scored within the normal range, while 39 (20%) were classified as low. Infants with atypical GMA had significantly lower ASQ scores (median 172.5) than those with typical GMA (median 220; p=0.05). ASQ classification (normal vs. low) was significantly associated with GMA outcome (p=0.048), yielding a sensitivity of 0.50 (95% CI: 0.22–0.78) and specificity of 0.82 (95% CI: 0.75–0.87). These findings indicate that although a significant relationship was found, the ASQ missed half of the infants with absent fidgety movements. Consequently, the ASQ may not be suitable as a stand-alone pre-screening tool for identifying infants who would benefit from GMA.

In Study III (Paper IV/Exploring the In-Motion deep learning method: Predicting cerebral palsy in 3-months old infants and the role of key movements from General Movement Assessment in Risk Scores) the aim was to improve knowledge and clinical interpretability of the In-Motion deep learning model and our findings indicates that the In-Motion deep learning model is using other movements than fidgety general movements to predict CP this could indicate that the In-Motion model and GMA could supplement each other in predicting CP. The study was an experimental study analysing what movement pattern the deep learning In-Motion

model for prediction of CP was using. It was presumed that the model was using general movements for the model's risk assessment. First a consensus between two experienced GMA observers was reach where the distribution of global GMA classification.

The GMA observers agreed on 547 of 598 epochs which gave an interrater reliability of a mean kappa value of 0.82 (95% CI: 0.77–0.87). Among these consensus epochs, a moderate correlation emerged between fidgety movement classifications and CP risk scores. The association between CP risk scores and epochs with absent fidgety movements was however stronger when a higher proportion of epochs were classified as absent. A result suggesting convergent validity. The In-Motion model might to some extend use general movements, however it seems that it should not be regarded as "a machine generating an automatic GMA".

Across the four studies, the feasibility and acceptability of using home video recordings and mobile applications for early detection of CP were supported. Most parents successfully recorded videos that met the requirements for GMA, and the majority found the app and instructions easy to use. Despite some technical challenges, more than 90% of parents reported that the process did not increase their anxiety about their child's development. Qualitative findings revealed that parents experienced a sense of control and empowerment in a vulnerable period, especially once they returned home from the hospital.

Attempts to use the ASQ as a pre-screening tool for identifying infants at risk of CP were unsuccessful, as the ASQ failed to detect half of the infants with absent fidgety movements. Finally, the experimental analysis of the In-Motion deep learning model showed moderate convergent validity with human-rated fidgety movement classifications. However, the model should not be considered a fully automated replacement for clinical GMA, as it likely integrates broader movement patterns beyond those used in traditional assessments.

Discussion

The integration of eHealth technologies into neonatal follow-up care offers new opportunities to improve the early detection of CP in infants with identifiable risk factors. Mobile applications for GMA, such as the Baby Moves app, the NeuroMotion app, and the GMApp, enable parents to record their infant's spontaneous movements at home for later clinical evaluation (131). Studies have shown these tools to be feasible and acceptable across diverse populations and healthcare systems, maintaining sufficient video quality for accurate classification by trained assessors (2,103,131). By increasing accessibility – particularly in geographically remote or resource-limited settings – and allowing asynchronous video submission when the infant is in an optimal behavioural state, mobile GMA platforms align with broader digital health strategies that prioritise decentralised care, parental engagement, and early intervention.

The findings of this thesis contribute to this growing body of evidence, demonstrating the feasibility of home-based video recordings for GMA and exploring their impact on clinical processes, parental experiences, and the potential role of AI in early CP risk detection. While these approaches offer notable benefits, their integration into routine clinical practice raises important considerations – not only about clinical performance but also about methodological rigour. Evaluating the internal and external validity of the studies, the reliability of the assessments, and the trustworthiness of the qualitative findings is essential for interpreting the results and understanding the strength of the evidence base.

Methodological considerations

This thesis includes several methodological strengths and limitations that must be considered when interpreting the results. These relate primarily to internal validity, external validity, and the reliability of the assessments used across the included studies.

Internal Validity

Internal validity refers to the degree to which a study's findings are accurate and trustworthy, free from systematic bias, measurement error, or confounding.

It reflects the methodological rigor of the research and the extent to which the results can be considered a valid representation of the phenomena under investigation within the study context.

In this thesis, internal validity is considered moderate, primarily due to the use of cross-sectional designs. These designs do not allow for the establishment of temporal relationships between variables. While causality was not the aim of the included studies, the simultaneous collection of exposure and outcome data increases the risk of reverse associations and limits the interpretability of observed findings.

Although the absence of fidgety movements is a recognised early marker of elevated risk for CP, a definitive diagnosis is typically made at approximately two years of age. In this context, internal validity relates primarily to the accuracy and consistency of the assessments and procedures used to collect data on early motor behaviour and later outcomes.

Data completeness also had an influence on internal validity. In Study I, 17% of families did not upload a video recording for General Movements Assessment (GMA), and in Study II (Paper III), the non-submission rate was 21%. These missing data may introduce selection bias, particularly if families who did not submit recordings differed systematically from those who did. Barriers such as limited access to technology, storage capacity on mobile devices, and varying levels of parental engagement may have contributed to this attrition. However, all families who chose not to continue active participation provided consent for the use of their child's CP outcome status at two years of age. This helped to mitigate potential data loss and preserve the integrity of the outcome dataset.

External Validity

External validity refers to the extent to which the results of a study can be generalised to populations, settings, and conditions beyond those specifically studied. It is essential for translating research findings into clinical practice and public health decision-making. This thesis demonstrates high external validity due to the diversity of the study population and the deliberate efforts made to promote inclusivity and reduce barriers to participation.

The study cohort included preterm infants and term infants with a range of CP risk profiles, including those at moderate risk. Families represented a broad spectrum of socioeconomic and cultural backgrounds, and several participants did not speak Danish as their first language. To facilitate participation across language groups, the instructional video used to guide parents in recording their child's movements for GMA was designed to be highly visual, with minimal written text.

Participation rates were consistently high: 83% of families submitted videos in Study I, and 79% submitted videos in Study III. Furthermore, in Study III, 89% of

parents completed the ASQ at 3 to 4 months of age. Non-responders were contacted through multiple reminders by text message and telephone. All parents who declined further participation consented to the use of their child's outcome data at two years of age, minimising the impact of loss to follow-up.

Technical limitations of the Baby Moves app were encountered by some parents, primarily due to insufficient storage space on their mobile devices, which prevented successful video upload to Redcap. In relation to the questionnaire, non-Danish-speaking parents commonly used digital translation tools such as Google Translate. A very small number of parents (fewer than five) had difficulties due to illiteracy. The remaining non-responders mostly forgot to complete the questionnaire despite reminders.

These strategies to reduce barriers to participation and retain outcome data support the conclusion that the findings of this thesis are likely generalisable to a broader population of preterm infants and their families, thereby contributing to high external validity.

Reliability

Reliability refers to the consistency and reproducibility of assessments or measurements over time, across different observers, and in varying settings. High reliability is essential for ensuring that findings are dependable and not substantially influenced by random error or subjective judgment.

As GMA is an observational tool used to assess spontaneous movements in infants, its validity depends heavily on the consistency of scoring between trained raters. Across the studies included in this thesis, all assessments were conducted by certified and experienced GMA observers.

In Study I, only one experienced observer rated the videos, as the primary focus was on evaluating the feasibility of the In-Motion app rather than outcome prediction. Similarly, Study II (Paper III) focused on the assessment process at 3 to 4 months of age and did not include formal outcome evaluation.

In contrast, Study III included a formal assessment of inter-rater reliability. Two certified GMA observers independently evaluated the same video recordings, both globally and using five-second epoch scoring. Inter-rater agreement was assessed using Cohen's Kappa, resulting in a mean kappa value of 0.82 (95% CI: 0.77–0.87), indicating substantial to almost perfect agreement. This estimate was based on 598 five-second epochs, with agreement on 547 epochs. These findings confirm a high level of consistency between raters and support the reliability of the GMA procedures employed in the study.

Trustworthiness

In qualitative research, trustworthiness is essential to ensure that findings authentically represent participants' lived experiences. Unlike quantitative research, which emphasises statistical reliability and validity, qualitative inquiry is evaluated through criteria such as credibility, confirmability, and transferability (132). In this study (Paper II), various strategies were employed to enhance trustworthiness, although some limitations remain.

Credibility

Credibility refers to the confidence in the truth and accuracy of the data and the interpretations derived from it. It concerns whether the findings genuinely reflect the participants' perspectives and experiences. In Paper II, credibility was strengthened by creating a trusting and open environment in which participants could share their stories in depth. Participants were given sufficient time to speak freely, whether they discussed challenges in conceiving, complex birth experiences, or caring for a critically ill newborn. This approach fostered a relationship of trust between the researcher and participants.

Further, triangulation was used to enhance credibility by including both mothers and fathers in the interviews, providing a more nuanced and comprehensive understanding of the parental experience. Field notes capturing emotional expressions and contextual observations were taken during each interview and later discussed within the research team to support interpretation and limit individual bias. The extended duration of the interviews (60–90 minutes) allowed participants to return to topics they wished to elaborate on, contributing to the richness and depth of the data.

Confirmability

Confirmability refers to the degree to which findings are shaped by the participants and not by researchers' biases, assumptions, or personal motivations. In Paper II, several steps were taken to support confirmability. All interviews were audio-recorded and transcribed verbatim to ensure the integrity of participants' narratives. The data were analysed using thematic analysis, guided by van Manen's phenomenological approach, and organised into sub-themes and themes to systematically trace meaning.

Despite these efforts, a limitation is that participants did not review the manuscript or provide feedback on the identified themes. Member checking – where participants validate interpretations – could have further strengthened confirmability by ensuring that the thematic analysis truly reflected their perspectives. This omission should be considered when interpreting the findings.

Transferability

Transferability relates to the applicability of the findings to other contexts or populations. It does not seek statistical generalisation but instead depends on the provision of thick, contextual description so that readers can judge the relevance in their own settings.

In Paper II, a potential limitation to transferability lies in the homogeneity of the sample. All participants were recruited from the same health region in Denmark, and shared similar socio-demographic characteristics. As a result, the findings may not be directly transferable to parents in other regions, healthcare systems, or cultural contexts. However, by providing detailed contextual information regarding participants and the study setting, efforts were made to enable readers to assess the applicability of the findings to other environments.

General discussion

The overarching aim of this thesis was to evaluate the feasibility, accuracy, and experiential impact of implementing remote GMA and related tools for early detection of CP in infants at detectable risk. Across four interlinked studies, this research provides new insights into the implementation of digital health solutions in neonatal follow-up, parental experiences, screening tool performance, and the potential of AI to support early risk detection.

Feasibility of remote General Movement Assessment

Study I, Paper I demonstrated that remote GMA using parent-recorded videos is feasible in a neonatal follow-up context. A high proportion of videos (96%) met the requirements for GMA, and most parents successfully used the In-Motion app to upload recordings. These findings align with previous studies supporting the implementation of remote GMA (133,134), highlighting the potential to reduce clinical workload and improve accessibility, especially for families living far from tertiary care centres. Notably, despite some technical and behavioural challenges, most families found the recording instructions user-friendly, and the process did not appear to increase parental anxiety.

Parental Empowerment and Lived Experience

Study I (Paper II) provided a deeper understanding of the emotional and psychological dimensions of using a mobile app for early neurodevelopmental assessment. Through hermeneutical phenomenological analysis, three main themes emerged challenges in early parenthood, living in a medicalised bubble, and gaining control at home. The overarching theme, “Finding control in an uncontrolled life

situation," underscores how digital tools can support, not only clinical objectives but also emotional resilience and parental agency. These findings support, prior research indicating that family-centred eHealth solutions can empower parents in neonatal care (135). The study also adds to the literature by addressing a common concern among clinicians - that early screening for CP may induce anxiety - by demonstrating that structured, accessible tools may instead promote reassurance and confidence.

Limitations of the ASQ as a Pre-Screening Tool

Study II (Paper III) evaluated the combined use of remote GMA and the ASQ to determine whether the ASQ at 3–4 months corrected age could serve as a pre-screening tool for GMA. Remote video-based GMA proved feasible, with 79% of families submitting suitable recordings and a very high inter-rater reliability (Gwet's AC1 = 0.97). Among infants with assessable videos, 5% were classified as showing atypical fidgety movements, in line with expected prevalence in this high-risk population.

The ASQ was returned and scorable in 86% of infants. A significant association was found between ASQ classification (normal vs. low) and GMA outcomes (typical vs. atypical), and infants with atypical GMA had significantly lower ASQ scores. However, the sensitivity of ASQ for detecting infants with absent fidgety movements was only 0.50, meaning that half of these infants would have been missed if ASQ alone had been used to guide referral for GMA. Specificity, in contrast, was higher (0.82), suggesting that ASQ was more effective in identifying infants unlikely to need further assessment.

Taken together, these findings demonstrate that while GMA can be reliably implemented remotely using parent-recorded videos, the ASQ lacks sufficient accuracy to serve as a stand-alone pre-screening tool. This aligns with previous research showing that parent-reported developmental questionnaires may not capture the subtle motor abnormalities detected by GMA (136). Reliance solely on ASQ could therefore lead to missed opportunities for early identification and intervention, underscoring the continued need for universal GMA in very preterm infants.

Loss to follow-up

Loss to follow-up was only systematically reported in Study II, Paper III, which evaluated the combined use of GMA and ASQ. In this cohort, although 21% of families did not return video recordings and 14% did not complete the ASQ, almost all of these infants were subsequently assessed in outpatient clinics between 3- and 5-months' corrected age. Only four infants in total (<2% of the cohort) were lost entirely to follow-up. This very low attrition rate is an important strength, as

follow-up loss is a common challenge in studies of high-risk infants. The findings suggest that integrating eHealth tools such as remote video recording and electronic questionnaires does not substantially compromise retention, thereby strengthening the robustness and generalisability of the results.

Exploring AI as a supplementary tool for GMA

Study III (Paper IV) examined the performance and interpretability of the In-Motion deep learning model, an AI tool designed to predict CP risk from infant movement data. The study showed moderate agreement between the model's risk scores and human-rated classifications of fidgety movements, with stronger correlations emerging when a higher proportion of movement epochs were rated as absent. While the model demonstrated promising convergent validity, it also appeared to integrate movement features beyond the traditional fidgety movement framework. These findings echo a growing body of literature suggesting that AI tools may detect broader patterns in spontaneous movement that are not captured by conventional observational methods (109,110). However, this also reinforces the need for transparency and interpretability in AI-based clinical tools. The model should be seen as a complement to, not a replacement for, expert clinical judgment.

Integration of eHealth and AI: Opportunities and Challenges

Taken together, the findings from the four studies provide important insights into the opportunities and challenges of integrating eHealth solutions and AI into neonatal follow-up programmes for early CP detection. Remote GMA using parent-recorded videos was shown to be feasible and highly reliable, offering a scalable method to reach families regardless of geographical distance (133,134,137). In contrast, while the ASQ was well-accepted and easy for families to complete, its low sensitivity meant that it failed to detect half of the infants with absent fidgety movements. This highlights that although parent-reported tools can contribute to family engagement and reduce clinical workload, they cannot replace standardised neurological assessments such as GMA in very preterm populations.

The exploration of AI-assisted movement analysis further demonstrated that deep learning models, such as the In-Motion algorithm, may provide an additional layer of support by capturing movement features beyond those identified through traditional observational methods. These results suggest that combining remote GMA with automated analysis has the potential to increase scalability, improve access, and support clinical decision-making, while parent-reported tools like the ASQ may serve better as complementary instruments to monitor broader aspects of development rather than as gatekeepers to GMA (3,105,109,110).

Overall, the integration of mobile applications, remote video assessment, and AI-based tools offer substantial promise for creating more equitable and efficient

follow-up systems. At the same time, the studies underline the need for careful implementation, including adequate technical support, standardised training for assessors, and clear communication with families, as well as caution against overreliance on tools with limited sensitivity or insufficient interpretability.

Strengths and limitations

A major strength of this thesis is its mixed-methods approach, combining quantitative outcomes with qualitative insights to provide a comprehensive understanding of the feasibility, accuracy, and experiential impact of eHealth-supported early detection tools. The studies were conducted in real-world clinical settings, enhancing ecological validity, and included a large cohort of very preterm infants, strengthening the generalisability within this high-risk group. Notably, loss to follow-up was extremely low, with fewer than 2% of infants not assessed at 3–5 months' corrected age in Study II (Paper III), strengthening the robustness of the dataset. Importantly, the thesis not only demonstrated the feasibility and high reliability of remote GMA but also critically evaluated the performance of the ASQ as a potential pre-screening tool. By showing that ASQ lacks sufficient sensitivity despite being user-friendly and widely adopted, this work highlights the value of directly comparing different tools within the same population rather than evaluating them in isolation. The integration of parent perspectives further enhances the relevance of the findings for family-centred models of neonatal follow-up.

However, several limitations must be acknowledged. First, long-term neuro-developmental outcomes were not available, which restricts conclusions about the predictive value of early assessments for later CP or broader developmental disorders. Second, there is a potential selection bias, as families who were more engaged or technologically confident may have been more likely to participate in video submissions or questionnaire completion. Third, while inter-rater reliability for GMA was high, implementation in routine practice requires ongoing training and calibration to maintain consistency. Finally, the AI algorithm tested in Study III (Paper IV) remains experimental, with limited interpretability, and further validation is needed before clinical adoption.

Conclusion

This thesis demonstrates that remote GMA based on parent-recorded videos is both feasible and highly reliable in neonatal follow-up, providing a scalable approach to the early detection of CP in very preterm infants. Smartphone-based video recordings extend access to early screening irrespective of geographical constraints, thereby promoting equity in care and enabling timely intervention for infants most in need of evaluation. Beyond feasibility, this digital approach emerged as a family-centred solution, empowering parents to participate actively in their child's care. The ability to record videos at home, at a time when the infant was in an optimal behavioural state, offered flexibility, comfort, and a sense of control. Together, these findings highlight the importance of developing screening strategies that are clinically robust while also respecting parental experience and autonomy. The thesis also showed that, although the ASQ was easy to administer and associated with GMA outcomes, its low sensitivity renders it unsuitable as a pre-screening tool, underscoring the continued need for universal GMA in very preterm infants.

Clinical implications

The exploratory work with AI-based movement analysis suggests that automated tools such as the In-Motion model may complement GMA by capturing broader or more subtle motor features. While the model demonstrated promising predictive accuracy, it's lack of transparency regarding which features drive predictions limits clinical applicability. Importantly, the model does not appear to rely exclusively on fidgety movements as defined by GMA, which may represent an opportunity to identify novel biomarkers beyond the scope of traditional assessments. Rather than replacing GMA, AI-based models may eventually serve as complementary tools, enhancing predictive accuracy and expanding early detection capabilities. To support the translation of these approaches into practice, a digital platform was developed in collaboration with Rigshospitalet and the Capital Region of Copenhagen. This platform enables home-based video recording for remote GMA, provides calibration support for assessors, and facilitates second opinions, while also allowing future integration of AI-based solutions.

Future research

Future studies should aim to further validate AI-based models, improve their interpretability, and establish ethical frameworks for their integration into neonatal care. Beyond detection, research must focus on strengthening systems that ensure rapid access to early, evidence-based interventions. This includes developing and evaluating multidisciplinary care pathways, enhancing collaboration across specialties, and creating digital infrastructures that support families throughout their care journey. The digital platform developed within this thesis represents an important step toward such integrated systems. By combining robust neurological assessments, innovative eHealth technologies, and AI solutions within family-centred models of care, early detection of CP can be made more timely, equitable, and effective for children at risk and their families.

Summary in Danish

Børn, der er født meget for tidligt eller andre risikofaktorer som iltmangel ved fødslen samt hjerneblødning, har en øget risiko for at udvikle cerebral parese (CP). CP er en tilstand, som påvirker barnets motorik og kan have stor betydning for både barnets og familiens hverdag. Forskning viser, at jo tidligere CP opdages, desto hurtigere kan man tilbyde målrettet behandling, der kan forbedre barnets udvikling og livskvalitet.

En af de mest pålidelige metoder til tidlig opsporing af CP er General Movements Assessment (GMA). Ved GMA vurderer fagfolk barnets spontane bevægelser i de første levemåneder. Hvis de såkaldte *fidgety movements* mangler ved 3–5 måneders alder, er der forhøjet risiko for CP. Men i praksis kan det være udfordrende at tilbyde GMA til alle børn, fordi undersøgelsen kræver specialuddannede fagpersoner og ofte et fysisk fremmøde på hospitalet.

Med den teknologiske udvikling er nye muligheder blevet tilgængelige. Forældre kan i dag optage små videoer af deres barns bevægelser derhjemme med en smartphone og sende videoen til vurdering. Det gør undersøgelsen mere fleksibel og kan reducere behovet for hospitalsbesøg. Derudover kan spørgeskemaer som Ages and Stages Questionnaire (ASQ) og ny teknologi som kunstig intelligens (AI) måske bruges til at støtte eller supplere den traditionelle metode.

Formålet med denne afhandling var at undersøge, hvordan tidlig opsporing af CP kan gøres mere tilgængelig, effektiv og familievenlig ved hjælp af digitale løsninger. Afhandlingen bygger på fire studier, der tilsammen belyser:

1. Om GMA kan udføres hjemme via smartphone-videoer.
2. Hvordan forældre oplever at deltage i hjemmebaseret GMA.
3. Om ASQ kan bruges som filter til at udvælge, hvilke børn der skal have GMA.
4. Hvordan AI kan bruges til at analysere børns bevægelser, og hvilke udfordringer det medfører.

- Studie I var et multicenterstudie med børn fra Norge, Danmark og Belgien. Forældrene optog hjemmevideoer af deres spædbørn via In-Motion-appen, som blev vurderet af certificerede GMA-observatører. Studie II omfattede de danske familier fra Studie I. Her blev forældrene interviewet om deres oplevelser med at optage og indsende videooptagelserne. Studie III undersøgte, om ASQ kunne

bruges til at afgøre, hvilke børn født før 32. gestationsuge der skulle tilbydes GMA. Studie IV blev gennemført i Midt-Norge og handlede om brugen af AI i GMA. Her blev det undersøgt, hvordan AI analyserer bevægelsesmønstre sammenlignet med den traditionelle metode.

- Studie I viste, at det er muligt at gennemføre GMA derhjemme. Hele 96 % af videoerne havde tilstrækkelig kvalitet, og forældrene fandt appen nem at bruge. - Studie II viste, at forældrene oplevede større inddragelse og følte sig styrket i rollen som forældre. Flere beskrev, at de fik en følelse af kontrol i en ellers usikker situation.
- Studie III viste, at ASQ ikke kan erstatte GMA som screeningsværktøj. Selvom ASQ er let at anvende, overså det mange børn, der havde behov for yderligere undersøgelse.
- Studie IV viste, at AI kan finde andre bevægelsesmønstre end dem, fagpersoner normalt vurderer. Det gør teknologien lovende, men samtidig svær at tolke og endnu ikke klar til klinisk brug.

Denne afhandling viser, at hjemmebaseret GMA via smartphone er en realistisk og brugbar løsning. Det gør det lettere for familier at deltage i tidlig opsporing, og mange oplever, at de får en aktiv rolle i barnets opfølgning.

ASQ kan bruges som supplement i opfølgning af udviklingen, men ikke som filter til at afgøre, hvem der skal have GMA, da risikoen for at overse børn er for stor.

Kunstig intelligens rummer et stort potentiale, men teknologien skal videreudvikles og gøres mere gennemsigtig, før den kan anvendes i praksis.

Fremtidens tidlige opsporing af CP bør være:

- Digital – med apps og hjemmevideoer,
- Familiecentreret – hvor forældre er aktive medspillere,
- Effektiv og ligelig – så alle børn i risiko kan få tilbudt undersøgelse, uanset hvor de bor,
- Innovativ – hvor nye teknologier som AI kan understøtte, men ikke erstatte, den kliniske vurdering.

Samlet peger afhandlingen på, at kombinationen af digitale løsninger, familie-inddragelse og innovation kan skabe mere tilgængelige og retfærdige modeller for tidlig opsporing af CP i neonatal opfølgning.

Acknowledgements

This thesis was carried out at the Department of Health Sciences, Faculty of Medicine, Lund University. I wish to express my deepest gratitude to everyone who has contributed in any way to this project.

First and foremost, I extend my heartfelt thanks to all the parents and their infants who participated in the studies. By sharing your time, experiences, and insights, you made this research possible. Your willingness to contribute may help other families in similar situations, and for that I am truly grateful.

I owe my warmest thanks to my supervisors:

- Associated Professor Åsa Tornberg, for your enthusiastic encouragement, generous sharing of knowledge, and for guiding me into the world of research. Thank you for trusting me, for your inspiring companionship, and for your constant support throughout this journey.

- Associated Professor Bo Mølholm Hansen, for your structured supervision, patience, and dedication. You went far beyond what could be expected of a supervisor, providing invaluable expertise in neonatology and inspiring guidance through the ups and downs of research. I am also grateful for the good company during our research travels to NTNU in Trondheim.

- PhD Katarina Lauruschkus, for stimulating and critical discussions, always emphasizing the clinical relevance of my work for families. Thank you for believing in me, for your positivity and good humour, and for enjoyable research travels together.

I am especially grateful to Professor Emeritus Gorm Greisen for valuable input to study design and insightful discussions, and to Senior Researcher Lars Adde, my shadow supervisor, for your enormous contribution to all my work involving GMA. Your in-depth discussions and critical reviews pushed me to achieve higher quality. I also thank your colleagues at NTNU – PhD Daniel Groos, PhD Espen Ihle, Professor Ragnhild Strøen, and PhD Toril Fjørtoft– for their valuable input, as well as the team at St. Olavs University Hospital for fruitful discussions and planning of future studies.

The neonatal wards in the Region of Copenhagen and Region Sjælland played a crucial role in recruiting families. My sincere thanks go to Associated Professor Mia Bjerager, MD Per Albertsen, MD Anna Lewis, MD Ane Lando, MD Porntiva Poorisrisak, MD Gitte Hahn, MD Anne Mette Plomgaard, RN Helene Nathansen, MD Sven Andreas Binato, MD Hristo Stanchev, RN Linea Larsen, RN Mille Svendsen, MD Kristian Vestergård Jensen, MD Sarah Grunnet, and MD Gholamreza Dayani. Your extraordinary efforts enabled us to achieve inclusion within the limited timeframe of this PhD.

I would also like to thank my colleagues in the research group Families and Children's Health for stimulating discussions, knowledge-sharing, and valuable comments on my manuscripts. The coffee breaks and Teams meetings during the pandemic were an important source of support. A special thanks to Charlotte Castor, Kajsa Lamm, Petra Pålson, Mariette Derwig, Malin Skoog, Angela Afua Quaye and Trille Jakobsson, for sharing the ups and downs of our PhD lives—you are the best.

To Freja Marie Nejsum, thank you for your tireless dedication in managing the data from eight different sites in REDCap. Your commitment and positivity made a challenging task possible.

To physiotherapist-in-charge Lisbet Lind, Nordsjælland Hospital, thank you for granting me leave of absence and for your genuine interest and support. I also extend warm thanks to my fellow paediatric physiotherapists at Nordsjælland Hospital for your continuous encouragement over the years.

To Professor Alicia Spittle and the Murdoch Children's Research Institute, thank you for allowing us to use the Baby Moves application in the OptimaGMA study.

To my physiotherapy colleagues Marianne Schacht Nielsen, Ingelise Rosenstand, Gitte Kristensen and Lene Weber, thank you for always finding time for discussions and for the many good laughs along the way.

To my dear friends Elena Dahlquist, Tina Jensen, Helle Stig, Birgitte Hillerup and Lis Dam, thank you for supporting me during the hardest times of my PhD studies and for helping so many times with my beloved horses, Tarka and Petey. I am deeply grateful.

To Anna Blomgren, thank you for the beautiful layout – where would I be without you?

To the late Professor Inger Kristensson Hallström, who introduced me to the scientific world and especially to qualitative research: thank you. You are greatly missed in the scientific community and in life. Rest in peace.

To the late translator Benny Pedersen, thank you for your help with proofreading during the first part of my PhD. You are dearly missed.

To my mother, Sonja Jørgensen, thank you for always believing in me and encouraging me to do my best. To my stepsister, Berit Kirchheiner, thank you for listening over the years and for your genuine interest in the progress of my PhD. I cherish our kitchen discussions.

Finally, I gratefully acknowledge the financial support that made this thesis possible:

- Nordsjællands Hospital
- The Swedish Research Council for Health, Working Life and Welfare (FORTE)
- The Elsass Foundation

References

1. WHO. Definition of mHealth. , 2025.
2. Spittle AJ, Olsen J, Kwong A, Doyle LW, Marschik PB, Einspieler C, et al. The Baby Moves prospective cohort study protocol: using a smartphone application with the General Movements Assessment to predict neurodevelopmental outcomes at age 2 years for extremely preterm or extremely low birthweight infants. BMJ Open 2016 October 03;6(10):e013446–013446.
3. Silva N, Zhang D, Kulvicius T, Gail A, Barreiros C, Lindstaedt S, et al. The future of General Movement Assessment: The role of computer vision and machine learning – A scoping review. Research in Developmental Disabilities 2021 -02-08;110.
4. Skivington K, Craig N, Craig P, Rycroft-Malone J, Matthews L, Simpson SA, et al. Introducing the revised framework for developing and evaluating complex interventions: A challenge and a resource for nursing research. Int J Nurs Stud 2024 June 01;154:104748.
5. Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby JM, et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. Int J Nurs Stud 2024 June 01;154:104705.
6. Einspieler C. Prechtl's Method on the Qualitative Assessment of General Movements in Preterm, Term and Young Infants. London :; Somerset : Mac Keith Press; John Wiley & Sons, Incorporated Distributor; 2008.
7. Einspieler C, Peharz R, Marschik PB. Fidgety movements - tiny in appearance, but huge in impact. J Pediatr (Rio J) 2016 June 01;92(3 Suppl 1):64.
8. Novak I, Morgan C, Adde L, Blackman J, Boyd RN, Brunstrom-Hernandez J, et al. Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment. JAMA Pediatr 2017 Sep 1;171(9):897–907.
9. Adde L, Aberg KB, Fjortoft T, Grunewaldt KH, Lade R, Osland S, et al. Implementation of remote general movement assessment using the in-motion instructions in a high-risk norwegian cohort. BMC Pediatr 2024 July 10;24(1):442–4.
10. Adde L, Helbostad JL, Jensenius AR, Taraldsen G, Grunewaldt KH, Stoen R. Early prediction of cerebral palsy by computer-based video analysis of general movements: a feasibility study. Dev Med Child Neurol 2010 Aug;52(8):773–778.
11. Graham HK, Rosenbaum P, Paneth N, Dan B, Lin J, Damiano DL, et al. Cerebral palsy. Nat Rev Dis Primers 2016 January 07;2:15082.
12. Evensen KAI, Ustad T, Tikanmäki M, Haaramo P, Kajantie E. Long-term motor outcomes of very preterm and/or very low birth weight individuals without cerebral palsy: A review of the current evidence. Semin Fetal Neonatal Med 2020 Jun;25(3):101116.

13. Pascal A, Govaert P, Oostra A, Naulaers G, Ortibus E, Van den Broeck C. Neuro-developmental outcome in very preterm and very-low-birthweight infants born over the past decade: a meta-analytic review. Dev Med Child Neurol 2018 Apr;60(4):342–355.
14. Volpe J editor. Neurology of the Newborn. Fifth Edition ed.: Saunders elsevier; 2008.
15. McIntyre S, Morgan C, Walker K, Novak I. Cerebral palsy--don't delay. Dev Disabil Res Rev 2011;17(2):114–129.
16. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, et al. A report: the definition and classification of cerebral palsy April 2006. Dev Med Child Neurol Suppl 2007 Feb;109:8–14.
17. Rosenbaum PL, Palisano RJ, Bartlett DJ, Galuppi BE, Russell DJ. Development of the Gross Motor Function Classification System for cerebral palsy. Dev Med Child Neurol 2008 Apr;50(4):249–253.
18. Bax M, Goldstein M, Rosenbaum P, Leviton A, Paneth N, Dan B, et al. Proposed definition and classification of cerebral palsy, April 2005. Dev Med Child Neurol 2005 August 01;47(8):571–576.
19. Machado LCJ, Passini RJ, Rosa IR, Carvalho HB. Neonatal outcomes of late preterm and early term birth. Eur J Obstet Gynecol Reprod Biol 2014 August 01;179:204–208.
20. Kvalvik LG, Wilcox AJ, Skjaerven R, Ostbye T, Harmon QE. Term complications and subsequent risk of preterm birth: registry based study. BMJ 2020 April 29;369:m1007.
21. Delnord M, Zeitlin J. Epidemiology of late preterm and early term births - An international perspective. Semin Fetal Neonatal Med 2019 February 01;24(1):3–10.
22. Dansk kvalitets database for nyfødte2025; . Accessed 26 february, 2025.
23. Dansk selskab for obstetrik og gynækologi/Kliniske retningslinjer.
24. Fogh MV, Greisen G, Clausen TD, Krebs L, Larsen ML, Hoei-Hansen CE. Increasing prevalence of cerebral palsy in children born very preterm in Denmark. Dev Med Child Neurol 2025 January 01;67(1):68–76.
25. Larsen ML, Rackauskaite G, Greisen G, Laursen B, Uldall P, Krebs L, et al. Declining prevalence of cerebral palsy in children born at term in Denmark. Dev Med Child Neurol 2022 June 01;64(6):715–722.
26. Morgan C, Fetters L, Adde L, Badawi N, Bancale A, Boyd RN, et al. Early Intervention for Children Aged 0 to 2 Years With or at High Risk of Cerebral Palsy: International Clinical Practice Guideline Based on Systematic Reviews. JAMA Pediatr 2021 August 01;175(8):846–858.
27. Morgan C, Badawi N, Boyd RN, Spittle AJ, Dale RC, Kirby A, et al. Harnessing neuroplasticity to improve motor performance in infants with cerebral palsy: a study protocol for the GAME randomised controlled trial. BMJ Open 2023 March 10;13(3):e070649–070649.
28. Spittle AJ, Morgan C, Olsen JE, Novak I, Cheong JLY. Early Diagnosis and Treatment of Cerebral Palsy in Children with a History of Preterm Birth. Clin Perinatol 2018 September 01;45(3):409–420.
29. Morgan C, Novak I, Dale RC, Badawi N. Optimising motor learning in infants at high risk of cerebral palsy: a pilot study. BMC Pediatr 2015 April 01;15:30–2.
30. Jackman M, Novak I, Lannin N. Effectiveness of hand splints in children with cerebral palsy: a systematic review with meta-analysis. Dev Med Child Neurol 2014 February 01;56(2):138–147.

31. Morgan C, Novak I, Badawi N. Enriched environments and motor outcomes in cerebral palsy: systematic review and meta-analysis. Pediatrics 2013 September 01;132(3):735.
32. Benfer KA, Whittingham K, Ware RS, Ghosh AK, Chowdhury S, Moula G, et al. Efficacy of Early Intervention for Infants With Cerebral Palsy in an LMIC: An RCT. Pediatrics 2024 April 01;153(4):e2023063854. doi: 10.1542/peds.2023–063854.
33. Wise NJ, Gellasch PA. Identification to Intervention: A Perspective From Parents of Children With Cerebral Palsy. Nurs Res 2022;71(6):441–449.
34. Novak I, Morgan C, Fahey M, Finch-Edmondson M, Galea C, Hines A, et al. State of the Evidence Traffic Lights 2019: Systematic Review of Interventions for Preventing and Treating Children with Cerebral Palsy. Curr Neurol Neurosci Rep 2020 February 21;20(2):3–z.
35. Novak I, Berry J. Home program intervention effectiveness evidence. Phys Occup Ther Pediatr 2014 November 01;34(4):384–389.
36. McNAMARA LM, Scott KM, Boyd RN, Webb AE, Taifalos CJ, Novak IE. Effectiveness of early diagnosis of cerebral palsy guideline implementation: a systematic review. Minerva Pediatr (Torino) 2024 June 01;76(3):414–424.
37. McIntyre S, Morgan C, Walker K, Novak I. Cerebral palsy--don't delay. Dev Disabil Res Rev 2011;17(2):114–129.
38. Piscitelli D, Ferrarello F, Ugolini A, Verola S, Pellicciari L. Measurement properties of the Gross Motor Function Classification System, Gross Motor Function Classification System-Expanded & Revised, Manual Ability Classification System, and Communication Function Classification System in cerebral palsy: a systematic review with meta-analysis. Dev Med Child Neurol 2021 November 01;63(11):1251–1261.
39. Klevberg GL, Elvrum AG, Zucknick M, Elkjaer S, Ostensjo S, Krumlinde-Sundholm L, et al. Development of bimanual performance in young children with cerebral palsy. Dev Med Child Neurol 2018 May 01;60(5):490–497.
40. Klevberg GL, Ostensjo S, Krumlinde-Sundholm L, Elkjaer S, Jahnsen RB. Hand Function in a Population-Based Sample of Young Children with Unilateral or Bilateral Cerebral Palsy. Phys Occup Ther Pediatr 2017 October 20;37(5):528–540.
41. Eliasson A, Krumlinde-Sundholm L, Rosblad B, Beckung E, Arner M, Ohrvall A, et al. The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. Dev Med Child Neurol 2006 July 01;48(7):549–554.
42. Glass HC, Li Y, Gardner M, Barkovich AJ, Novak I, McCulloch CE, et al. Early Identification of Cerebral Palsy Using Neonatal MRI and General Movements Assessment in a Cohort of High-Risk Term Neonates. Pediatr Neurol 2021 May 01;118:20–25.
43. Badawi N, Novak I, Morgan C, Crowle C. Early detection of cerebral palsy using general movements assessment and MRIs - a sensible way forward. Pediatr Res 2024 April 01;95(5):1191–1192.
44. Spittle AJ, Doyle LW, Boyd RN. A systematic review of the clinimetric properties of neuromotor assessments for preterm infants during the first year of life. Dev Med Child Neurol 2008 April 01;50(4):254–266.
45. Orton J, Doyle LW, Tripathi T, Boyd R, Anderson PJ, Spittle A. Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. Cochrane Database of Systematic Reviews 2024 -02-13;2024(2).

46. Byrne R, Duncan A, Pickar T, Burkhardt S, Boyd RN, Neel ML, et al. Comparing parent and provider priorities in discussions of early detection and intervention for infants with and at risk of cerebral palsy. Child Care Health Dev 2019 November 01;45(6):799–807.
47. McIntyre S, Goldsmith S, Webb A, Ehlinger V, Hollung SJ, McConnell K, et al. Global prevalence of cerebral palsy: A systematic analysis. Dev Med Child Neurol 2022 Dec;64(12):1494–1506.
48. Pascal A, Govaert P, Oostra A, Naulaers G, Ortibus E, Van den Broeck C. Neuro-developmental outcome in very preterm and very-low-birthweight infants born over the past decade: a meta-analytic review. Dev Med Child Neurol 2018 April 01;60(4): 342–355.
49. Pappas A, Korzeniewski SJ. Long-Term Cognitive Outcomes of Birth Asphyxia and the Contribution of Identified Perinatal Asphyxia to Cerebral Palsy. Clin Perinatol 2016 September 01;43(3):559–572.
50. Felling RJ, Sun LR, Maxwell EC, Goldenberg N, Bernard T. Pediatric arterial ischemic stroke: Epidemiology, risk factors, and management. Blood Cells Mol Dis 2017 September 01;67:23–33.
51. Steggerda SJ, de Vries LS. Neonatal stroke in premature neonates. Semin Perinatol 2021 November 01;45(7):151471.
52. Srivastava R, Kirton A. Perinatal Stroke: A Practical Approach to Diagnosis and Management. Neoreviews 2021 March 01;22(3):e163–e176.
53. Bastrup J, Truelsen T, Bindslev JB, Hoei-Hansen CE. Recurrence Rate in Children With Arterial Ischemic Stroke: A Systematic Review. Acta Paediatr 2025 March 26.
54. McIntyre S, Blair E, Goldsmith S, Badawi N, Gibson C, Scott H, et al. Congenital anomalies in cerebral palsy: where to from here? Dev Med Child Neurol 2016 February 01;58 Suppl 2:71–75.
55. Reid SM, Hinwood GL, Guzys AT, Hunt RW, Reddihough DS. Major structural congenital anomalies and causal pathways in people with cerebral palsy. Dev Med Child Neurol 2025 March 01;67(3):374–381.
56. Morgan C, Fahey M, Roy B, Novak I. Diagnosing cerebral palsy in full-term infants. J Paediatr Child Health 2018 October 01;54(10):1159–1164.
57. Kapil N, Majmudar-Sheth B, Johnson T. Hammersmith Infant Neurological Examination Subscores Are Predictive of Cerebral Palsy. Pediatr Neurol 2024 February 01;151:84–89.
58. Maitre NL, Chorna O, Romeo DM, Guzzetta A. Implementation of the Hammersmith Infant Neurological Examination in a High-Risk Infant Follow-Up Program. Pediatr Neurol 2016 December 01;65:31–38.
59. Romeo DM, Apicella M, Velli C, Brogna C, Ricci D, Pede E, et al. Hammersmith Infant Neurological Examination in low-risk infants born very preterm: a longitudinal prospective study. Dev Med Child Neurol 2022 July 01;64(7):863–870.
60. Romeo DM, Ricci D, Brogna C, Mercuri E. Use of the Hammersmith Infant Neurological Examination in infants with cerebral palsy: a critical review of the literature. Dev Med Child Neurol 2016 March 01;58(3):240–245.
61. Romeo DM, Cowan FM, Haataja L, Ricci D, Pede E, Gallini F, et al. Hammersmith Infant Neurological Examination for infants born preterm: predicting outcomes other than cerebral palsy. Dev Med Child Neurol 2021 August 01;63(8):939–946.

62. Romeo DM, Cowan FM, Haataja L, Ricci D, Pede E, Gallini F, et al. Hammersmith Infant Neurological Examination in infants born at term: Predicting outcomes other than cerebral palsy. Dev Med Child Neurol 2022 July 01;64(7):871–880.
63. Romeo DM, Apicella M, Velli C, Brogna C, Ricci D, Pede E, et al. Hammersmith Infant Neurological Examination in low-risk infants born very preterm: a longitudinal prospective study. Dev Med Child Neurol 2022 July 01;64(7):863–870.
64. Uusitalo K, Haataja L, Nyman A, Lehtonen T, Setanen S, PIPARI Study Group. Hammersmith Infant Neurological Examination and long-term cognitive outcome in children born very preterm. Dev Med Child Neurol 2021 August 01;63(8):947–953.
65. Einspieler C, Prechtl HF. Prechtl's assessment of general movements: a diagnostic tool for the functional assessment of the young nervous system. Ment Retard Dev Disabil Res Rev 2005;11(1):61–67.
66. Einspieler C, Prechtl HF, Ferrari F, Cioni G, Bos AF. The qualitative assessment of general movements in preterm, term and young infants--review of the methodology. Early Hum Dev 1997 Nov 24;50(1):47–60.
67. Sæther R, Støen R, Vik T, Fjørtoft T, Vågen RT, Silberg IE, et al. A change in temporal organization of fidgety movements during the fidgety movement period is common among high risk infants. European Journal of Paediatric Neurology 2016 -07;20(4):512.
68. Peyton C, Pascal A, Boswell L, Deregnier R, Fjørtoft T, Støen R, et al. Inter-observer reliability using the General Movement Assessment is influenced by rater experience. Early Human Development 2021 -08-02;161.
69. Mutlu A, Einspieler C, Marschik PB, Livanelioglu A. Intra-individual consistency in the quality of neonatal general movements. Neonatology 2008;93(3):213–216.
70. Valentin T, Uhl K, Einspieler C. The effectiveness of training in Prechtl's method on the qualitative assessment of general movements. Early Hum Dev 2005 Jul;81(7):623–627.
71. Fjortoft T, Einspieler C, Adde L, Strand LI. Inter-observer reliability of the "Assessment of Motor Repertoire--3 to 5 Months" based on video recordings of infants. Early Hum Dev 2009 May;85(5):297–302.
72. Brown AK, Greisen G, Haugsted U, Jonsbo F. Formal training in general movement assessment is required to effectively evaluate infants with perinatal asphyxia in outpatient settings. Acta Paediatr 2016 Sep;105(9):1056–1060.
73. Prechtl HF, Einspieler C, Cioni G, Bos AF, Ferrari F, Sontheimer D. An early marker for neurological deficits after perinatal brain lesions. Lancet 1997 May 10;349(9062): 1361–1363.
74. Cioni G, Bos AF, Einspieler C, Ferrari F, Martijn A, Paolicelli PB, et al. Early neurological signs in preterm infants with unilateral intraparenchymal echodensity. Neuropediatrics 2000 Oct;31(5):240–251.
75. Bernhardt I, Marbacher M, Hilfiker R, Radlinger L. Inter- and intra-observer agreement of Prechtl's method on the qualitative assessment of general movements in preterm, term and young infants. Early Hum Dev 2011 Sep;87(9):633–639.
76. Einspieler C, Bos AF, Libertus ME, Marschik PB. The General Movement Assessment Helps Us to Identify Preterm Infants at Risk for Cognitive Dysfunction. Front Psychol 2016 March 22;7:406.
77. Olsen J, Marschik P, Spittle A. Do fidgety general movements predict cerebral palsy and cognitive outcome in clinical follow-up of very preterm infants? Acta Paediatr 2018 February 01;107(2):361–362.

78. Spittle A. How do we use the assessment of general movements in clinical practice? Dev Med Child Neurol 2011 August 01;53(8):681–682.
79. Adde L, Rygg M, Lossius K, Oberg GK, Stoen R. General movement assessment: predicting cerebral palsy in clinical practise. Early Hum Dev 2007 Jan;83(1):13–18.
80. Veyrac C, Couture A, Saguintaah M, Baud C. Brain ultrasonography in the premature infant. Pediatr Radiol 2006 July 01;36(7):626–635.
81. Baranger J, Demene C, Frerot A, Faure F, Delanoe C, Serroune H, et al. Bedside functional monitoring of the dynamic brain connectivity in human neonates. Nat Commun 2021 February 17;12(1):1080–x.
82. Demene C, Mairesse J, Baranger J, Tanter M, Baud O. Ultrafast Doppler for neonatal brain imaging. Neuroimage 2019 January 15;185:851–856.
83. Hadders-Algra M. Early Diagnostics and Early Intervention in Neurodevelopmental Disorders-Age-Dependent Challenges and Opportunities. J Clin Med 2021 February 19;10(4):861. doi: 10.3390/jcm10040861.
84. Eisman S, Husein N, Fehlings D, Andersen J, Oskoui M, Shevell M, et al. Early Biomarkers in the Prediction of Later Functional Impairment in Term Children with Cerebral Palsy. Pediatr Neurol 2023 March 01;140:59–64.
85. Lambert G, Husein N, Fehlings D, Andersen J, Oskoui M, Shevell M, et al. Early Biomarkers in the Prediction of Later Functional Impairment in Preterm Children With Cerebral Palsy. Pediatr Neurol 2024 December 01;161:55–60.
86. Litt JS, Campbell DE. High-Risk Infant Follow-Up After NICU Discharge: Current Care Models and Future Considerations. Clin Perinatol 2023 March 01;50(1):225–238.
87. Park J, Jung N. Developmental Characteristics of High-Risk Infants According to the Bayley Scales of Infant and Toddler Development-Third Edition. Child Care Health Dev 2025 January 01;51(1):e70018.
88. Anderson PJ, Burnett A. Assessing developmental delay in early childhood - concerns with the Bayley-III scales. Clin Neuropsychol 2017 February 01;31(2):371–381.
89. Pascal A, Govaert P, Oostra A, Naulaers G, Ortibus E, Van den Broeck C. Neurodevelopmental outcome in very preterm and very-low-birthweight infants born over the past decade: a meta-analytic review. Dev Med Child Neurol 2018 April 01;60(4): 342–355.
90. Del Rosario C, Slevin M, Molloy EJ, Quigley J, Nixon E. How to use the Bayley Scales of Infant and Toddler Development. Arch Dis Child Educ Pract Ed 2021 April 01;106(2):108–112.
91. Kerstjens JM, Nijhuis A, Hulzebos CV, van Imhoff DE, van Wassenaer-Leemhuis AG, van Haastert IC, et al. The Ages and Stages Questionnaire and Neurodevelopmental Impairment in Two-Year-Old Preterm-Born Children. PLoS One 2015 July 20;10(7):e0133087.
92. Kerstjens JM, Bos AF, ten Vergert EMJ, de Meer G, Butcher PR, Reijneveld SA. Support for the global feasibility of the Ages and Stages Questionnaire as developmental screener. Early Hum Dev 2009 July 01;85(7):443–447.
93. Hornman J, Kerstjens JM, de Winter AF, Bos AF, Reijneveld SA. Validity and internal consistency of the Ages and Stages Questionnaire 60-month version and the effect of three scoring methods. Early Hum Dev 2013 December 01;89(12):1011–1015.

94. Manti F, Giovannone F, Ciancaleoni M, De Vita G, Fioriello F, Gigliotti F, et al. Psychometric Properties and Validation of the Italian Version of Ages & Stages Questionnaires Third Edition. Int J Environ Res Public Health 2023 March 12;20(6):5014. doi: 10.3390/ijerph20065014.
95. Agarwal PK, Xie H, Sathyapalan Rema AS, Meaney MJ, Godfrey KM, Rajadurai VS, et al. Concurrent validity of the ages and stages questionnaires with Bayley Scales of Infant Development-III at 2 years - Singapore cohort study. Pediatr Neonatol 2024 January 01;65(1):48–54.
96. Gollenberg AL, Lynch CD, Jackson LW, McGuinness BM, Msall ME. Concurrent validity of the parent-completed Ages and Stages Questionnaires, 2nd Ed. with the Bayley Scales of Infant Development II in a low-risk sample. Child Care Health Dev 2010 July 01;36(4):485–490.
97. Veldhuizen S, Clinton J, Rodriguez C, Wade TJ, Cairney J. Concurrent validity of the Ages And Stages Questionnaires and Bayley Developmental Scales in a general population sample. Acad Pediatr 2015 April 01;15(2):231–237.
98. Schonhaut L, Armijo I, Schonstedt M, Alvarez J, Cordero M. Validity of the ages and stages questionnaires in term and preterm infants. Pediatrics 2013 May 01;131(5):1468.
99. Ostergaard KK, Lando AV, Hansen BM, Greisen G. A Danish reference chart for assessment of psychomotor development based on the Ages & Stages Questionnaire. Dan Med J 2012 Jun;59(6):A4429.
100. Janson Harald SL editor. Norsk manualsupplement til Ages and Stages Questionnaires. : Psykologisk institutt, Universitetet i Oslo; 2003.
101. Svensson KA, Ortqvist M, Bos AF, Eliasson A, Sundelin HE. Usability and inter-rater reliability of the NeuroMotion app: A tool in General Movements Assessments. Eur J Paediatr Neurol 2021 July 01;33:29–35.
102. Kwong AK, Eeles AL, Olsen JE, Cheong JL, Doyle LW, Spittle AJ. The Baby Moves smartphone app for General Movements Assessment: Engagement amongst extremely preterm and term-born infants in a state-wide geographical study. J Paediatr Child Health 2019 May 01;55(5):548–554.
103. Kwong AK, Eeles AL, Olsen JE, Cheong JL, Doyle LW, Spittle AJ. The Baby Moves smartphone app for General Movements Assessment: Engagement amongst extremely preterm and term-born infants in a state-wide geographical study. J Paediatr Child Health 2019 May 01;55(5):548–554.
104. Reich S, Zhang D, Kulvicius T, Bolte S, Nielsen-Saines K, Pokorny FB, et al. Novel AI driven approach to classify infant motor functions. Sci Rep 2021 May 10;11(1):9888–5.
105. Gao Q, Yao S, Tian Y, Zhang C, Zhao T, Wu D, et al. Automating General Movements Assessment with quantitative deep learning to facilitate early screening of cerebral palsy. Nat Commun 2023 -12-14;14(1).
106. Irshad MT, Nisar MA, Gouverneur P, Rapp M, Grzegorzek M. AI Approaches towards Prechtl's Assessment of General Movements: A Systematic Literature Review. Sensors 2020 -09-17;20(18).
107. Lanotte F, O'brien MK, Jayaraman A. AI in Rehabilitation Medicine: Opportunities and Challenges. Ann Rehabil Med 2023 -12-31;47(6):444.

108. Ihlen EAF, Stoen R, Boswell L, Regnier Rd, Fjortoft T, Gaebler-Spira D, et al. Machine Learning of Infant Spontaneous Movements for the Early Prediction of Cerebral Palsy: A Multi-Site Cohort Study. J Clin Med 2019 December 18;9(1):5. doi: 10.3390/jcm9010005.
109. Groos D, Adde L, Aubert S, Boswell L, de Regnier R, Fjortoft T, et al. Development and Validation of a Deep Learning Method to Predict Cerebral Palsy From Spontaneous Movements in Infants at High Risk. JAMA Netw Open 2022 July 01;5(7):e2221325.
110. Groos D, Adde L, Stoen R, Ramampiaro H, Ihlen EAF. Towards human-level performance on automatic pose estimation of infant spontaneous movements. Comput Med Imaging Graph 2022 January 01;95:102012.
111. Sigurdson K, Profit J, Dhurjati R, Morton C, Scala M, Vernon L, et al. Former NICU Families Describe Gaps in Family-Centered Care. Qual Health Res 2020 October 01;30(12):1861–1875.
112. Franck LS, Waddington C, O'Brien K. Family Integrated Care for Preterm Infants. Crit Care Nurs Clin North Am 2020 June 01;32(2):149–165.
113. Gomez-Cantarino S, Garcia-Valdivieso I, Moncunill-Martinez E, Yanez-Araque B, Ugarte Gurrutxaga MI. Developing a Family-Centered Care Model in the Neonatal Intensive Care Unit (NICU): A New Vision to Manage Healthcare. Int J Environ Res Public Health 2020 October 01;17(19):7197. doi: 10.3390/ijerph17197197.
114. Craig P, Petticrew M. Developing and evaluating complex interventions: reflections on the 2008 MRC guidance. Int J Nurs Stud 2013 May;50(5):585–587.
115. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M, et al. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ 2008 Sep 29;337:a1655.
116. Craig JW, Glick C, Phillips R, Hall SL, Smith J, Browne J. Recommendations for involving the family in developmental care of the NICU baby. J Perinatol 2015 Dec;35 Suppl 1(Suppl 1):5.
117. van Manen M, van Manen M. Doing Phenomenological Research and Writing. Qual Health Res 2021 May;31(6):1069–1082.
118. Manen MV. Researching lived experience : human science for an action sensitive pedagogy. 2 udgave ed. London, Ont.: Althouse Press; 1997.
119. Hall EO. Being in an alien world: Danish parents' lived experiences when a newborn or small child is critically ill. Scand J Caring Sci 2005 Sep;19(3):179–185.
120. Jin M, Kim J. Development and Evaluation of an Evaluation Tool for Healthcare Smartphone Applications. Telemed J E Health 2015 October 01;21(10):831–837.
121. Essential medical statistics2nd ed. Malden, Mass.: Blackwell Science; 2003.
122. Wongpakaran N, Wongpakaran T, Wedding D, Gwet KL. A comparison of Cohen's Kappa and Gwet's AC1 when calculating inter-rater reliability coefficients: a study conducted with personality disorder samples. BMC Med Res Methodol 2013 April 29;13:61–61.
123. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics 1977 Mar;33(1):159–174.
124. Timonen J, Mannerstrom H, Vehtari A, Lahdesmaki H. Lgpr: an Interpretable Non-Parametric Method for Inferring Covariate Effects from Longitudinal Data. Bioinformatics 2021 July 27;37(13):1860–1867.

125. WMA General Assembly. WMA Declaration of Helsinki -Ethical Principles for Medical Research Involving Human Subjects.
126. Beauchamp T, Childress J. Principles of Biomedical Ethics: Marking Its Fortieth Anniversary. Am J Bioeth 2019 November 01;19(11):9–12.
127. Gillon R. Medical ethics: four principles plus attention to scope. BMJ 1994 July 16;309(6948):184–188.
128. Beauchamp TL. Methods and principles in biomedical ethics. J Med Ethics 2003 October 01;29(5):269–274.
129. Shea M. Principlism's Balancing Act: Why the Principles of Biomedical Ethics Need a Theory of the Good. J Med Philos 2020 July 29;45(4-5):441–470.
130. Beauchamp T, Childress J. Principles of Biomedical Ethics: Marking Its Fortieth Anniversary. Am J Bioeth 2019 November 01;19(11):9–12.
131. Marschik PB, Kwong AKL, Silva N, Olsen JE, Schulte-Ruther M, Bolte S, et al. Mobile Solutions for Clinical Surveillance and Evaluation in Infancy-General Movement Apps. J Clin Med 2023 May 20;12(10):3576. doi: 10.3390/jcm12103576.
132. Lincoln & Guba. Naturalistic inquiry Newbury Park: Sage; 1985.
133. Adde L, Aberg KB, Fjortoft T, Grunewaldt KH, Lade R, Osland S, et al. Implementation of remote general movement assessment using the in-motion instructions in a high-risk norwegian cohort. BMC Pediatr 2024 July 10;24(1):442–4.
134. Kwong AK, Eeles AL, Olsen JE, Cheong JL, Doyle LW, Spittle AJ. The Baby Moves smartphone app for General Movements Assessment: Engagement amongst extremely preterm and term-born infants in a state-wide geographical study. J Paediatr Child Health 2019 May 01;55(5):548–554.
135. Aagaard H, Uhrenfeldt L, Spliid M, Fegran L. Parents' experiences of transition when their infants are discharged from the Neonatal Intensive Care Unit: a systematic review protocol. JBI Database System Rev Implement Rep 2015 October 01;13(10):123–132.
136. Danks MT, Gray PH, Hurrion EM. Diagnostic accuracy of Ages and Stages Questionnaire, Third Edition to identify abnormal or delayed gross motor development in high-risk infants. J Paediatr Child Health 2024 November 01;60(11):709–715.
137. Marschik PB, Kwong AKL, Silva N, Olsen JE, Schulte-Ruther M, Bolte S, et al. Mobile Solutions for Clinical Surveillance and Evaluation in Infancy-General Movement Apps. J Clin Med 2023 May 20;12(10):3576. doi: 10.3390/jcm12103576.

Paper I

BMJ Open

In-Motion-App for remote General Movement Assessment: a multi-site observational study

Lars Adde ,[1,2] Annemette Brown,[3,4] Christine van den Broeck,[5] Kris DeCoen,[6] Beate Horsberg Eriksen,[7] Toril Fjørtoft,[1,2] Daniel Groos,[8] Espen Alexander F Ihlen,[8] Siril Osland,[2] Aurelie Pascal,[5] Henriette Paulsen,[9] Ole Morten Skog,[10] Wiebke Sivertsen,[7] Ragnhild Støen[1,11]

To cite: Adde L, Brown A, van den Broeck C, *et al*. In-Motion-App for remote General Movement Assessment: a multi-site observational study. *BMJ Open* 2021;**11**:e042147. doi:10.1136/bmjopen-2020-042147

► Prepublication history and supplemental material for this paper is available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2020-042147).

Received 26 June 2020
Revised 21 January 2021
Accepted 19 February 2021

For numbered affiliations see end of article.

Correspondence to
Dr Lars Adde;
lars.adde@ntnu.no

ABSTRACT

Objectives To determine whether videos taken by parents of their infants' spontaneous movements were in accordance with required standards in the In-Motion-App, and whether the videos could be remotely scored by a trained General Movement Assessment (GMA) observer. Additionally, to assess the feasibility of using home-based video recordings for automated tracking of spontaneous movements, and to examine parents' perceptions and experiences of taking videos in their homes.

Design The study was a multi-centre prospective observational study.

Setting Parents/families of high-risk infants in tertiary care follow-up programmes in Norway, Denmark and Belgium.

Methods Parents/families were asked to video record their baby in accordance with the In-Motion standards which were based on published GMA criteria and criteria covering lighting and stability of smartphone. Videos were evaluated as GMA 'scorable' or 'non-scorable' based on predefined criteria. The accuracy of a 7-point body tracker software was compared with manually annotated body key points. Parents were surveyed about the In-Motion-App information and clarity.

Participants The sample comprised 86 parents/families of high-risk infants.

Results The 86 parent/families returned 130 videos, and 121 (96%) of them were in accordance with the requirements for GMA assessment. The 7-point body tracker software detected more than 80% of body key point positions correctly. Most families found the instructions for filming their baby easy to follow, and more than 90% reported that they did not become more worried about their child's development through using the instructions.

Conclusions This study reveals that a short instructional video enabled parents to video record their infant's spontaneous movements in compliance with the standards required for remote GMA. Further, an accurate automated body point software detecting infant body landmarks in smartphone videos will facilitate clinical and research use soon. Home-based video recordings could be performed without worrying parents about their child's development.

Trials registration number NCT03409978.

Strengths and limitations of this study

- A cohort of families of high-risk infants frequently seen in neonatal infant care units follow-up settings.
- In-Motion-App standards for remote General Movement Assessment communicated through a simple and short animated video.
- Data from a motion tracking software on smartphone videos pioneering automatic and markerless infant motion capture.
- Study did not assess sociodemographic factors as reasons for families not to record or return videos.
- Study did not evaluate how markerless infant motion capture on smartphone videos can be used for prediction of cerebral palsy outcome.

INTRODUCTION

Cerebral Palsy (CP) is the most common physical disability in childhood. Diagnosis is typically set between 12 and 24 months corrected age.[1–3] Early developmental screening of high-risk infants to predict future neurological impairments is today a priority for clinicians and researchers, and most parents express interest in such neurodevelopmental screening.[3 4]

The General Movement Assessment (GMA) has been recommended in combination with MRI to achieve a CP diagnosis before 6 months corrected age in infants with newborn-detectable risk factors.[3] Early detection of CP has the potential to improve the organisation and resources used in follow-up screening at hospitals and reduce medical complications for children with CP. The fidgety type of general movements (GMs) observed at 9–20 weeks' corrected age has shown the highest predictive validity for later CP, compared with the writhing type of GMs observed before 9 weeks corrected age.[5–8] Video recordings for GMA must follow requirements for infant state, position

and clothing and are scored by certified and trained assessors.[9] Such trained GMA observers also have the expertise needed to ensure that video recordings fulfil the requirements for a valid GMA.[9]

Access to trained observers using the GMA in hospital-based follow-up programmes is limited by geographical constraints and lack of GMA expertise.[10] As healthcare and parents move into the digital age using smartphones to share videos via internet, opportunities to perform remote GMA have developed. Recently, the Baby Moves smartphone app was presented for remote GMA within research settings.[10 11] However, smartphone apps for health data capturing in clinical settings are rarely assessed and usability tested.[12] To be feasible in a clinical follow-up setting, home-based video recordings must fulfil basic GMA requirements without the need for comprehensive parental training or guiding.

Video recordings by hand-held smartphones introduce movement artefacts in the camera. Computer-based methods for objective detection of infant GMs[13 14] may be jeopardised by such artefacts. Our research group has recently presented a machine-learning model which predicted CP with high accuracy (sensitivity of 92%, specificity of 81%) performed by clinician using a stationary camera, comparable to observational GMA.[15] Important shortcomings of the method were the need for manual and time-consuming body point annotations, as well as the need for a stationary camera. Hence, an automated 7-point body tracker has been developed by our group and needs to be validated on recordings taken with hand-held cameras.

Provided that GMs can be assessed, and computer-based infant body point tracking can be performed on videos taken with a hand-held camera, it is possible to perform remote GMA as well as automated infant body point tracking for a computer-based model for the prediction of CP. Thus, the In-Motion instructional video has been developed so that parents can perform home-based videos with quality standards feasible for remote GMA and automated infant body point tracking. Feasibility of the In-Motion instructional video was assessed in a multi-site study including families of high-risk infants from Norway, Denmark and Belgium.

The main aims of the study are as follows: (1) to determine whether videos taken by parents with a hand-held camera were in accordance with the standards set in the instructional video, and whether the videos could be scored by a trained GMA observer; (2) to assess the accuracy of a 7-point body tracker software based on the same recordings; (3) to describe parents' perceptions of the instructional video and filming their baby in a home environment.

METHODS

Design

Multi-centre prospective observational study.

Patient and public involvement

The study protocol including the parental survey content was developed and designed collaboratively with representatives from The Norwegian Cerebral Palsy organisation and The Norwegian Premature Association.

Participants

Parents of infants admitted to one of five participating level III–IV neonatal infant care units (NICU) in Norway (3 hospitals including 13, 11 and 4 families, respectively), Denmark (1 hospital including 43 families) and Belgium (1 hospital including 15 families) from 2018 to 2019 (12 months recruitment period) were consecutively recruited at referral to the hospital follow-up programme before discharge from the NICU. Families were recruited based on willingness to participate and the infant being evaluated as at high-risk of CP. In Norway and Denmark inclusion criteria were (1) birth weight (BW) ≤1000 g (extremely low BW and/or gestational age (GA) <28 (extremely low GA), (2) neonatal arterial ischaemic stroke, (3) neonatal encephalopathy, (4) other significant risk factors. In Belgium, only infants with GA <32 weeks or with perinatal stroke were included.

Data collection procedure

Included participants were assisted by a research physiotherapist/paediatrician at the time of inclusion to download and instal the In-Motion-App by smartphone, containing the instructional video from Google Play or iTunes. They could ask any questions about the app and how to manage the software. They got information about the time window for performing two separate video recordings for their infant between 12^{+1}–13^{+6} and 14^{+1}–17^{+6} weeks post-term age (PTA).[11] The time points were defined to ensure GM videos from the fidgety movement's period. If no videos were returned from the families before 17^{+6} weeks PTA, the local study coordinator contacted the family by phone to ask the reason why they had not uploaded any videos. The app was linked to a secure online server hosted at St. Olavs Hospital in Trondheim, Norway, and was available for i-operating system and Android. After the end of the second time window, the families were contacted by email with a link to an online Norwegian University of Science and Technology (NYNU) survey to collect information about their opinions using the app and the In-Motion instructional video.

In-Motion-App and instructional video

The In-Motion-App and instructional video was designed by GMA trained personnel (LA, TF, RS, SO) at St. Olavs Hospital in Trondheim, Norway, for parents to give basic insight into recording standards needed for GMA and lighting and stability of camera. It was made as a short animation with simple drawn sequences containing a minimum of text. The instructional video was deployed to the parents by downloading the In-Motion-App developed for this study, and videos could be uploaded to be remotely assessed by a trained GMA observer.

After downloading the app and getting basic information from the local study coordinator, parents logged into the app with a username and a password. They typed in the first name of their child and the expected date of delivery (due date). The In-Motion-App generated two separate time windows between 12^{+1}–13^{+6} and 14^{+1}–17^{+6} weeks PTA[11] and visualised them in a graphical timeline to show when videos should be taken. A red dot illustrated today's date placed on the timeline, helping parents to plan when to perform the video recordings. In addition, a pop-up message reminded parents to prepare for videos a week before the beginning of each time window.[11] The In-Motion-App was constructed in such a way that the video recording automatically stopped after 3 min and asked the parents whether to upload the video or not.

The instructional video was 2 min and 47 s long. Before taking videos, parents were told to look through the In-Motion instructional video which was available from the app menu. They could watch the video as many times as they wanted until they felt confident performing the recording. The main themes aimed at ensuring quality standards for remote GMA included: (1) clothing of infant (just a diaper or a onesie), (2) surface/underlay for infant (single-colour blanket or rug), (3) lighting (enough light avoiding sidelight that can cause shadows), (4) state of infant (awake, alert, content, not disturbing baby, no pacifier), (5) positioning (baby on floor—stand next to the baby's feet, whole body must be visible) and (6) length of video (3 min). In addition, instructions were provided about how to keep the smartphone steady and ensure that the whole infant body was observable in the video image. Examples of some of the In-Motion instructional video themes are shown in figure 1. Parents were asked to consecutively upload videos to the server at St. Olavs Hospital in Norway.

Assessment of video quality for remote GMA

Videos were assessed by a certified GMA observer with respect to the following standards[9]: (1) *GMA standards:* active movements (not hypokinetic), supine position, correct state, adequate clothing (diaper or a onesie), no disturbances during recording. (2) *Additional In-Motion standards:* adequate light, whole body visible, feet of parent visible in video (ensuring correct position of smartphone camera, see picture to the right in figure 1) and camera stability. Based on these standards, a classification was made by the same certified GMA observer as either 'GMA scorable' if all standard criteria were fulfilled or 'GMA non-scorable' if one or more standard criteria were inadequate. In addition, all videos were observed by the same GMA expert who also categorised yes/no whether the hand-held video had optimal stability, events of abrupt displacement, was predominantly unstable, whether an adequate underlay was used (firm, comfortable, large enough) and whether overall video image quality was sufficient (blurred/very blurred).

Assessment of GMs

All videos classified as 'GMA scorable' were consecutively assessed by one certified and experienced GMA observer that had passed advanced GMs courses under the General Movement Trust (LA). The use of one observer was chosen due to the study design not focusing on GMA and prediction of outcome. The observer had no knowledge about the infant's clinical history. According to Prechtl's method of assessment of GMs,[9] fidgety movements were classified as continuous (FM++), intermittent (FM+), sporadic (FM+/−), abnormal (Fa) or absent (FM−).

In-Motion body point tracking

The infant motion tracker algorithm consists of a convolutional neural network trained on 7-body points on 14 900 video frames on high-risk infants that had participated in another study from our group.[8] For further technical details of the previous trained convolutional neural net, the reader is referred to Groos and Aurlien.[16] To evaluate the infant motion tracker, 5493 video frames was selected from a subset of 66 videos from 36 infants, recorded by the In-Motion-App by 19 September 2018. Eighty per cent out of the selected 5493 frames were selected by random. The other 20% were selected manually in order to include body part occlusions (eg, right wrist occluded behind left wrist) that may be challenging to track. The performance of the infant motion tracker was assessed and reported by the following three steps: first, the automatic motion tracking was performed to detect the position of 7-body points (nose, thorax (centre between shoulders), wrists, pelvis and ankles) in each of the 5493 video frames. Second, all 7-body points in the 5493 selected video frames was manually annotated.

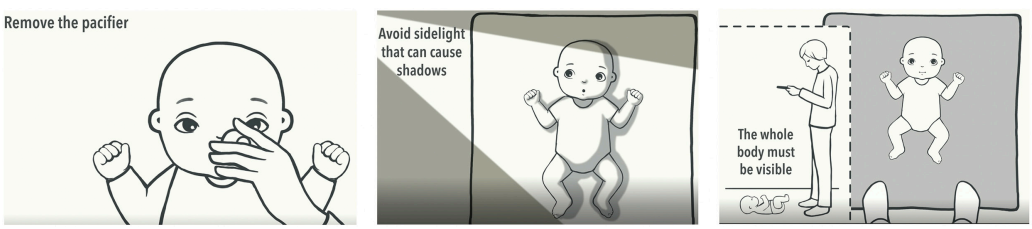


Figure 1 Screenshot of In-Motion instructional video showing examples of information about infant state, lighting and positioning of baby and person filming the baby.

	%
Mean	80.9
Nose	93.3
Thorax	93.9
Right wrist	74.4
Left wrist	83.1
Pelvis	63
Right ankle	79.5
Left ankle	79.3

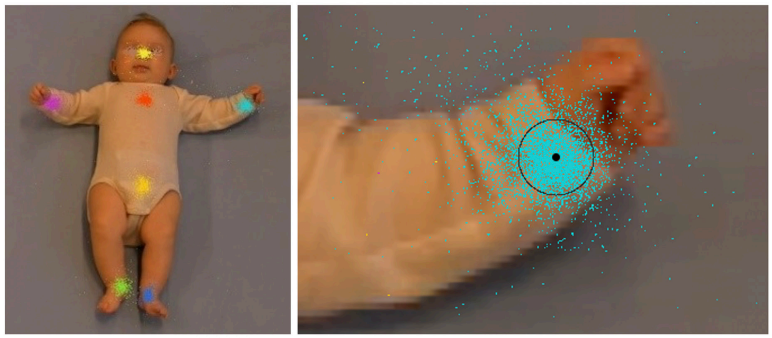


Figure 2 Accuracy of 7 estimated body points compared with manually annotated images. From left: table with proportions of correct detected body point; illustration of the computer-based detections according to 7-body points; the distribution of the left wrist body point detections (blue dots) relative to the manually annotated landmark (black dot) where 10% of the infant head size is used as a threshold (black circle).

These manually annotations are the ground truth for the evaluation of the infant motion tracker. Third, the performance of the infant motion tracker is reported as percentage of points within a circular area centred at the manually annotated body point for the 5493 frames. In accordance with the established metric for evaluating pose-estimation,[17] radius of the circular area was set to 10% of the infant head size and was normalised to adjust for different scaling (ie, video zoom) (figure 2).

Survey

Parents' opinions about the In-Motion-App and instructional video were collected using SelectSurvey V.4 software (ClassApps, www.classapps.com) in Norway, operated by NTNU. In Denmark, parents' opinions were collected using Smart Trails data management software (MEDEI ApS, www.medei.dk) and in Belgium the survey was collected by post. The survey was sent to the families by a link in an email within 1 week after the last video was returned. The survey questions were customised for the In-Motion-App based on a tool developed by Jin and Kim[18] and a survey used in a similar study on the Baby Moves App.[11] It contained questions based on forced-choice questions covering the themes: (1) In-Motion-App, (2) In-Motion standards for remote GMA and (3) parental worries. A statement was made, and the parents indicated agreement or disagreement with the statement on a 5-point scale (online supplemental appendix 1).

Data analysis

Data were analysed using SPSS statistics V.26.0 (IBM SPSS Statistics). The data are presented as numbers with proportion (%) or mean with SD and range. Differences between infants with returned and no returned videos were analysed using the Mann-Whitney U test for continuous variables and χ^2 test and Fisher's exact test for dichotomous variables. The accuracy of the 7-point body tracker was presented as the distribution of body point detections relative to the manually annotated body points, where 10% of the infant head size was used as a threshold.

RESULTS

In total, 86 infants/families were recruited and 17 (19.8%) out of them did not submit any video (figure 3), leaving 69 families with 130 videos for analysis.

Twenty-eight (32.6%) families were included from three different hospitals in Norway, 43 (50%) from one hospital in Copenhagen, Denmark and 15 (17.4%) from one hospital in Gent, Belgium. Infant/family characteristics are shown in table 1.

Video recordings

Two (1.5%) out of 130 videos were shorter than 3 min (1 min and 12 s and 2 min and 17 s). The mean PTA at video recording was 14.5 weeks (SD 2.28, range 8.1–23.6 weeks).

Fifteen (11.7%) families returned one recording, 49 (71%) two recordings, 4 (5.8%) three recordings and 1 (1.4%) six recordings. One-hundred and seventeen (90%) videos were returned within the expected time window between 12^{+1} and 17^{+6} weeks PTA. Two (1.5%) families returned two and three videos, respectively, which were all taken outside the time window (week 8, 10, and 21 and 23, respectively). Eleven families (8.5%) with videos from within the requested time window, had additional videos taken outside the expected time windows. Six videos from one family were taken at two different days; four videos in weeks 12 and two videos in week 14 PTA.

Remote GMA

Among the six videos returned from one family, the first one from each of the 2 days was selected for GMA analysis. Exclusion of the remaining four videos and additional four videos excluded due to PTA outside of the age

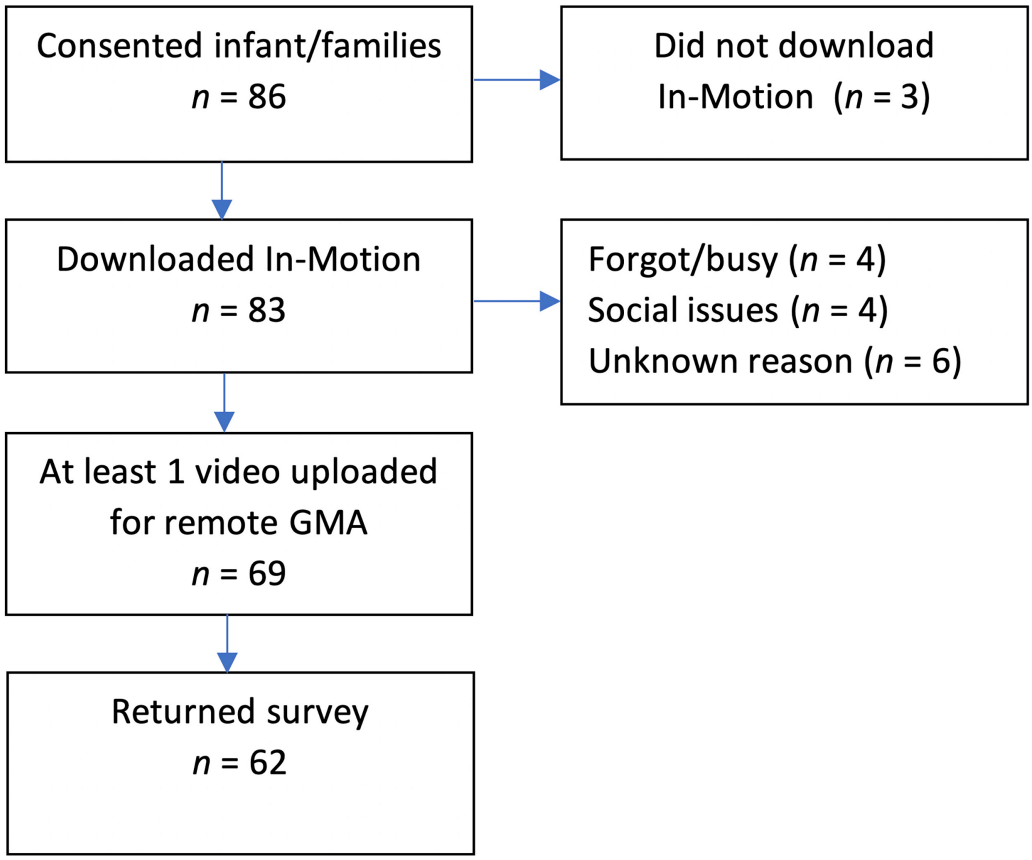


Figure 3 Flow chart of infant/families with reasons for non-upload of videos. GMA, General Movement Assessment.

required for assessment of FMs gave a total of 122 videos available for quality assessment.

One hundred and twenty-one (99%) out of 122 videos which were returned within the required time window were classified as GMA scorable. The video that was non-scorable had infant in side lying position. Details about compliance to the In-Motion standards are shown in table 2.

General Movement Assessment

Of the 121 videos classified as GMA scorable, 3 (2.4%) videos were classified with exaggerated (Fa), 3 (2.4%) with absent (FM−) and 7 (5.6%) with sporadic (FM+/−) FMs. Eighty-seven (69%) and 21 (16.7%) videos were classified with intermittent (FM+) and continuous (FM++) FMs, respectively.

Computer-based body point tracking

The proportion of correctly predicted left wrist key point from 5493 tested video images was 83.15%. Details of accuracy of 7-predicted body points and mean value for all points are shown in figure 2.

Parent responses

Survey responses were received from 64 (92.8%) families of the 69 families who returned at least one video. Fifty-four (84.3%) of them observed the instructional video one or two times before filming their baby. No families returned a video without training on filming their baby first.

The majority of the survey respondents found the In-Motion-App easy to use. All respondents agreed or strongly agreed that it was easy to understand how to stand and hold the smartphone during the filming. Details about family responses are shown in table 3. Fifty-seven (90.5%) families strongly disagreed, disagreed or neither disagreed nor agreed that they did become more worried about their child's development through using the In-Motion instructions.

Table 1 Summary of infant/family characteristics

	Total N (%) (n=86)	N (%) video responders (n=69)	N (%) no video responders (n=17)	P value
Demographics				
Boys, n (%)	51 (59.3)	42 (60.9)	9 (52.9)	0.32
Birth weight (BW), mean (SD), g	1952 (1107)	1915 (1124)	2105 (1055)	0.67
Gestational age (GA), mean (SD), weeks	32.4 (5.3)	32.3 (5.4)	33.4 (4.7)	0.43
Risk group				
BW ≤1000 g and/or GA <28	25 (29.1)	20 (29)	5 (29.4)	0.77
Neonatal arterial ischaemic stroke	11 (12.8)	4 (5.8)	7 (41.2)	0.001
Hypoxic ischaemic encephalopathy	20 (23.3)	17 (24.6)	3 (17.6)	0.06
Others	32 (37.2)	27 (39.1)	5 (29.4)	0.38
		Infant families (n=63)		
Sociodemographic data				
Mother relation (survey), n (%)		48 (76.2)		
Married/cohabitant family, n (%)		59 (93.7)		
Age mother/farther, mean (SD, range)		31.8 (5.5, 21–6)		
Age farther, mean (SD, range)		33.9 (6.9, 22–59)		
Single child, n (%)		32 (51.6)		
iOS vs Android				
iOS users, n (%)		41 (65.1)		

iOS, i-operating system.

DISCUSSION

In this study, more than 95% of families with high-risk infants filming their baby at home, returned at least one video that was in accordance with the In-Motion standards for remote GMA. Most families found the In-Motion-App easy to use and the instructions for filming easy to follow, and less than 10% of respondents became worried through using the In-Motion-App. Despite the use of hand-held smartphones introducing movement artefacts in the video image, our computer-based 7-point body tracker detected positions of the body points with high accuracy. To the best of our knowledge, this is the first automatic infant body point tracker that is tested on video recordings from hand-held smartphones.

This study has several strengths. First, it included families of high-risk infants frequently seen in NICU follow-up settings. We argue that this makes our findings robust and generalisable to comparable clinical settings. Second, the communication of In-Motion standards through a simple and short animated video, makes the instructions easily applicable to a broad range of different clinical settings. Furthermore, the accuracy of the 7-point body tracker software with the use of smartphone videos makes it pioneering in the field of automatic and markerless infant motion capture compared with other studies.[19 20] This facilitates further development of methods for early automated detection of CP based on smartphone videos. Finally, the design of the study using an experienced and

Table 2 Compliance to In-Motion standards (n=126)

	Active movements (not hypokinetic)	Supine position	Correct state	No disturbances during recording	Adequate clothing	Adequate light	Whole body visible	Feet of parents visible
N (%)	126 (100)	125 (99.2)	122 (96.8)	124 (98.4)	125 (99.2)	124 (98.4)	124 (98.4)	116 (92.1)*
		Optimal stability	Abrupt displacement	Predominantly unstable	Correct base of support		Image quality	
						Clear	Blurred	Very blurred
N (%)		80 (63.5)	26 (20.6)	22 (17.5)	119 (94.4)	114 (90.5)	11 (8.7)	1 (0.8)

*Three missing data.

Table 3 Parents' responses to the In-Motion-App and instructional video

	Strongly agree (%)	Agree (%)	Neither agree nor disagree (%)	Disagree (%)	Strongly disagree (%)
In-Motion-App					
The In-Motion-App was generally easy to use	58.7	33.3	3.2	4.8	0.0
It was easy to enter the information needed in the In-Motion-App	46.0	41.3	11.1	1.6	0.0
The reminders about when the child should be filmed were helpful	44.4	41.3	6.3	6.3	1.6
The number of reminders about when the child should be filmed was suitable	25.4	39.7	15.9	14.3	4.8
There were no technical problems with uploading and sending the videos	55.6	22.2	6.3	4.8	11.1
In-Motion standards for remote GMA					
It was easy to understand how I should stand and hold the telephone during the filming	60.0	40.0	0.0	0.0	0.0
It was easy to keep the telephone still while I was filming	16.7	46.7	30.0	6.7	0.0
It was easy to do the filming without disturbing the child	36.5	42.9	9.5	11.1	0.0
It was easy to understand how my child should be dressed when filmed	65.1	33.3	0.0	1.6	0.0
It was easy to understand how my child should be positioned and how the mat should be when I was going to film	63.5	28.6	4.8	3.2	0.0
It was easy to follow the instructions about how the lighting should be during the filming	36.5	38.1	14.3	11.1	0.0
Filming my child for 3 min went smoothly	39.7	39.7	19.0	1.6	0.0
Parental worries					
I felt safe about uploading video of my child	63.5	27.0	7.9	1.6	0.0
I became more worried about my child's development through using the In-Motion-App	1.6	7.9	28.6	22.2	39.7
Using the In-Motion-App made me more attentive to my child's development	7.9	36.5	46.0	4.8	4.8

GMA, General Movement Assessment.

certified GMA observer for evaluation of video quality and a survey with very high response rate, makes the study quality high and the results trustworthy.

There are also several limitations. First, almost 20% of the included families did not return any video. This study was not designed to evaluate reasons for not recording or returning videos. We can, therefore, only conclude on the quality of returned videos. The questions in our survey may also have limitations, mainly covering topics favourable to participants returning videos, participating in follow-up and smartphone usage, giving little or reduced information about responders with low mobile health technology usage. Hence, problems encountered by families who did not record or return any video need to be further explored. Our findings are in accordance with the study by Kwong *et al*,[11] where 24% of families did not return any video using the Baby Moves App. These findings indicate that home-based video recordings for remote GMA is not a solution for all families and that it might be difficult in a clinical setting to know beforehand which families will return a video or not. Furthermore, 13 (19%) families returned one or several videos outside the required time window needed for a valid GMA. More than 90% of respondents found the reminders in the app helpful, but one-fifth disagreed that the number of reminders were appropriate. These findings indicate a limitation in the design of the app reminders and lack of programmed filming windows parameters. These app functionalities need to be improved in a process involving the users.

Second, our study comprised five different hospital sites in three different countries, and information provided to families when downloading the app may have differed. Additionally, there is a risk that the research personnel could have given more information and assistance to families than will be common in an ordinary clinical setting. Our study setting could therefore be in slight contrast to an ordinary clinical setting, where adapted and flexible family information is needed due to challenges in reduced participation in neurodevelopmental follow-up[21] and racial and socioeconomic differences in mobile health technology usage.[22]

Third, even though almost 20% of the hand-held videos in our study were classified as predominantly unstable, the GMA expert considered the videos to be GMA scorable. There is a risk that more videos might have been classified as non-scorable by another GMA observer with less training and experience or if there had been several GMA experts observing the same videos. To the best of our knowledge, there is only one study protocol planning to assess the predictive validity of GMA from videos taken with hand-held smartphones for CP outcome.[10] Hence, further studies on the use of smartphones for GMA are needed.

Finally, our computer-based 7-point body tracker showed accurate estimations compared with manual annotations on the video image. However, further studies must explore how selection of body points, tracked body point accuracy and movement artefacts in camera will influence a machine-learning model for prediction of CP from smartphone video recordings.

This study facilitates and contributes to the use of smartphone technology for video recordings and remote GMA. Consequently, it will contribute to giving high-risk infants and their families equal access to GMA as an accurate method for early identification of CP, without geographical constraints. The use of early remote medical assessment will improve the organisation and resources used in follow-up screening at hospitals and have the potential to reduce medical complications for children with CP due to early detection. A clinical feasible computer-based movement analysis with equal accuracy as GMA, will greatly reduce the need for specialised GMA observers and provide an innovative resource-effective diagnostic measure.

Author affiliations
[1]Department of Clinical and Molecular Medicine, Norwegian University of Science and Technology, Trondheim, Norway
[2]Clinic of Clinical Services, St. Olavs Hospital, Trondheim University Hospital, Trondheim, Norway
[3]Department of Health Sciences, Lund University, Lund, Sweden
[4]Department of Pediatric and Adolescent and Department of Neurology and Physiotherapy, Copenhagen University Hospital, Nordsjællands Hospital, Hillerød, Denmark
[5]Department of Rehabilitation Sciences, Ghent University, Ghent, Belgium
[6]Department of Neonatology, University Hospital Ghent, Gent, Belgium
[7]Department of Pediatrics, Møre og Romsdal Hospital Trust, Ålesund Hospital, Ålesund, Norway
[8]Department of Neuromedicine and Movement Science, Norwegian University of Science and Technology, Trondheim, Norway
[9]Department of Physiotherapy and Rehabilitation, Vestfold Hospital Trust, Tønsberg, Norway
[10]Habilitation Center, Vestfold Hospital Trust, Tønsberg, Norway
[11]Department of Neonatology, St. Olavs Hospital, Trondheim University Hospital, Trondheim, Norway

Acknowledgements We would like to thank all the families that participated in this study. We acknowledge the support from St. Olavs Hospital, The Liaison Committee between the Central Norway Regional Health Authority and the Norwegian Open AI-Lab, Norwegian University of Science and Technology, Trondheim, Norway. Thanks also to Mia Ortved Bjerager consultant neonatologist and the neonatal ward staff at Nordsjællands Hospital in Denmark for their valuable contribution to this study.

Contributors Conceptualisation: LA, RS, HP, OMS, TF, SO, WS, BHE, CvdB. Data curation: LA, RS, EAFI, DG. Formal analysis: LA, RS, EAFI, DG. Funding acquisition: LA, RS. Methodology: LA, RS, EAFI, DG, TF, SO. Project administration: LA, BHE, HP, AP, AB, CvdB, RS, KD. Resources: LA, TF, SO, AB, AP, HP, OMS, BHE, WS, KD. Writing-original draft: LA, RS, EAFI, DG. Writing-review and editing: LA, RS, EAFI, DG, TF, SO, BHE, WS, AB, AP, CvdB, HP, OMS, KD.

Funding This work was supported by grants from St. Olavs Hospital, Trondheim, Norway and The Liaison Committee between the Central Norway Regional Health Authority and the Norwegian University of Science and Technology, Trondheim, Norway (SO: 90056100). In Denmark the study was supported by grants from Nordsjællands Hospital, University Hospital of Copenhagen, Hillerød (PSP E-20231-18-01).

Competing interests None declared.

Patient consent for publication Obtained in all participants.

Ethics approval All infant/families provided written informed consent and ethics was approved by the regional committee for medical and health research ethics (REC Central-Committee 2017/913) in Norway. The study sites in Denmark and Belgium also had approvals from their local Institutional Review boards.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available. Data from this study are not available for sharing due to ethical approval requirements. Researchers interested in collaboration should contact the corresponding author with their expression of interest.

ORCID iD

Lars Adde http://orcid.org/0000-0001-5532-0034

REFERENCES

1 Granild-Jensen JB, Rackauskaite G, Flachs EM, *et al*. Predictors for early diagnosis of cerebral palsy from national registry data. *Dev Med Child Neurol* 2015;57:931–5.
2 Hubermann L, Boychuck Z, Shevell M, *et al*. Age at referral of children for initial diagnosis of cerebral palsy and rehabilitation: current practices. *J Child Neurol* 2016;31:364–9.
3 Novak I, Morgan C, Adde L, *et al*. Early, accurate diagnosis and early intervention in cerebral palsy: advances in diagnosis and treatment. *JAMA Pediatr* 2017;171:897–907.
4 Dorner RA, Boss RD, Burton VJ, *et al*. Parent preferences for neurodevelopmental screening in the neonatal intensive care unit. *Dev Med Child Neurol* 2020;62:500–5.
5 Kwong AKL, Fitzgerald TL, Doyle LW, *et al*. Predictive validity of spontaneous early infant movement for later cerebral palsy: a systematic review. *Dev Med Child Neurol* 2018;60:480–9.
6 Bosanquet M, Copeland L, Ware R, *et al*. A systematic review of tests to predict cerebral palsy in young children. *Dev Med Child Neurol* 2013;55:418–26.
7 Darsaklis V, Snider LM, Majnemer A, *et al*. Predictive validity of Prechtl's method on the qualitative assessment of general movements: a systematic review of the evidence. *Dev Med Child Neurol* 2011;53:896–906.
8 Støen R, Boswell L, de Regnier R-A, *et al*. The predictive accuracy of the general movement assessment for cerebral palsy: a prospective, observational study of high-risk infants in a clinical follow-up setting. *J Clin Med* 2019;8. doi:10.3390/jcm8111790. [Epub ahead of print: 25 10 2019].
9 Einspieler C, Prechtl HF, Bos A, *et al*. *Prechtl's method on the qualitative assessment of general movements in preterm, term and young infants*. London: Mac Keith Press, 2004.
10 Spittle AJ, Olsen J, Kwong A, *et al*. The Baby Moves prospective cohort study protocol: using a smartphone application with the General Movements Assessment to predict neurodevelopmental outcomes at age 2 years for extremely preterm or extremely low birthweight infants. *BMJ Open* 2016;6:e013446.
11 Kwong AK, Eeles AL, Olsen JE, *et al*. The baby moves smartphone APP for general movements assessment: engagement amongst extremely preterm and term-born infants in a state-wide geographical study. *J Paediatr Child Health* 2019;55:548–54.
12 McCartney M. How do we know whether medical apps work? *BMJ* 2013;346:f1811.
13 Marcroft C, Khan A, Embleton ND, *et al*. Movement recognition technology as a method of assessing spontaneous General movements in high risk infants. *Front Neurol* 2014;5:1–9.
14 Cabon S, Porée F, Simon A, *et al*. Video and audio processing in paediatrics: a review. *Physiol Meas* 2019;40:02TR.
15 Ihlen EAF, Støen R, Boswell L, *et al*. Machine learning of infant spontaneous movements for the early prediction of cerebral palsy: a multi-site cohort study. *J Clin Med* 2019;9. doi:10.3390/jcm9010005. [Epub ahead of print: 18 12 2019].
16 Groos D, Aurlien K. Infant body part tracking in Videos using deep Learning-Facilitating early detection of cerebral palsy: NTNU 2018.
17 Groos D, Ramampiaro H, Ihlen EAF. EfficientPose: scalable single-person pose estimation. *Applied Intelligence* 2020;190.
18 Jin M, Kim J. Development and evaluation of an evaluation tool for healthcare smartphone applications. *Telemed J E Health* 2015;21:831–7.
19 Sciortino G, Farinella GM, Battiato S, *et al*, eds. *On the estimation of children's poses. International conference on image analysis and processing*. New York: Springer, 2017.
20 Hesse N, Bodensteiner C, Arens M, eds. *Computer vision for medical infant motion analysis: state of the art and rgb-d data set. Proceedings of the European conference on computer vision (ECCV)*. Munich, Germany: Springer, 2018.
21 L Orton J, McGinley JL, Fox LM, *et al*. Challenges of neurodevelopmental follow-up for extremely preterm infants at two years. *Early Hum Dev* 2015;91:689–94.
22 Hamilton EC, Saiyed F, Miller CC, *et al*. The digital divide in adoption and use of mobile health technology among caregivers of pediatric surgery patients. *J Pediatr Surg* 2018;53:1478–93.

Paper II

Elevate Series

ANNALS OF MEDICINE
2024, VOL. 56, NO. 1, 2309606
https://doi.org/10.1080/07853890.2024.2309606

RESEARCH ARTICLE

Parents' lived experience of early risk assessment for cerebral palsy in their young child using a mobile application after discharge from hospital in the newborn period

Annemette Brown[a,b,c], Åsa B. Tornberg[a] and Inger Kristensson Hallström[a]

[a]Department of Health Sciences, Faculty of Medicine, Lund University, Lund, Sweden; [b]Department of Pediatrics and Adolescence Medicine, Nordsjælland University Hospital, Capital Region of Denmark, Denmark; [c]Department of Neurology and Physiotherapy, Nordsjællands Hospital, Capital Region of Denmark, Denmark

ABSTRACT

Introduction: General Movement assessment (GMA) is considered the golden standard for early identification of infants with a high risk of developing cerebral palsy (CP). The aim of this study was to explore parents' lived experience of early risk assessment for CP using a mobile application for home video recording after discharge from hospital stay in the newborn period.

Methods: An inductive qualitative design using a hermeneutical phenomenological approach was chosen, and fourteen parents with children at risk of CP were interviewed at home. The hermeneutical phenomenological approach describes humans' lived experiences of a specific phenomenon with a possibility of deeper understanding of the expressed statements. The interviews were analyzed using the fundamental lifeworld existential dimensions as guidelines for describing the parents' lived experience.

Results: The overall understanding of the parents' experience was 'Finding control in an uncontrolled life situation'. During the often-long hospitalizations, the parents struggled with loss of control and difficulty in understanding what was going on. The use of the mobile application followed by a swift result made them feel in control and have a brighter view of the future.

Conclusions: The findings suggest that the mobile application did not seem to worry the parents. Instead, it provided the parents with a sense of active participation in the care and treatment of their child. The mobile application should be accompanied with clear instructions and guidelines for the parents and details about how and when the result is given.

KEY MESSAGES

1. For the first time, parents' experiences concerning early assessment for cerebral palsy using a mobile application are profoundly explored.
2. Early risk assessment for cerebral palsy performed by parents at home using a mobile application did not seem to increase the parents' worry; instead, it gave them a sense of control.
3. Involving parents in the care and treatment of their child is vital to increase parental participation and control.

ARTICLE HISTORY
Received 28 February 2022
Revised 19 December 2023
Accepted 15 January 2024

KEYWORDS
Cerebral palsy; experiences; general movements; mobile application and parents

Introduction

Globally, infants with perinatal brain injury represent more than nine million years lived with disabilities [1]. Functional consequences of perinatal brain injury will often appear months or even years later, which will delay therapeutic intervention and result in uncertainty about the child's health status for a long period. Around 15–20% of Danish children born very preterm (<32 weeks of gestation), are diagnosed with a broad range of neurodevelopmental impairments [1], and approximately 5% have the characteristics of cerebral palsy (CP), some children are not diagnosed until the age of five years [2]. CP defines as 'a non-progressive neurological disorder affecting multiple motor systems as muscle control and tone, feeding and swallowing difficulties as well as balance and coordination' [3]. In Denmark, 125–150 [4] children are diagnosed annually with CP. Clinically the diagnosis is first established when the children show firm signs of CP. In Denmark 52% of the children are diagnosed at the age of 18 months, and a small share of them are diagnosed between the ages of 4 and 5 years [2,5,6].

There is a growing body of evidence that early intervention improves functional outcomes of infants at risk of neurodevelopmental impairment [4,7]. However, it is a challenging task to identify children

CONTACT Annemette Brown annemette.brown@regionh.dk

who are at the highest risk of neurodevelopmental impairment at an early age [8]. General movement assessment (GMA) is a non-invasive observational method used to describe the infant´s spontaneous gross motor motility in relation to the maturation of the brain. General movements are observable from fetal life to approximately 5 months post term age [9]. The accuracy is highest when GMA is performed during the fidgety movement period at 10 to 20 weeks post-term age [10]. The method is based on Gestalt perception [10] and is a non-invasive method in which the child's spontaneous motor movements are recorded on video, after which a GM observer [10] classifies the quality of GM movements in different categories. These movements are a strong marker for later developmental disabilities, CP, especially seen in the so-called 'Absent Fidgety Movements' that occur when the child is aged 9–20 weeks post term. It is important to emphasize that using GMA for early risk assessment for CP is not an assessment for CP diagnosis but only a risk estimate and therefore the assessment should be handled with caution [8,11,12].

In person GM assessment is time-consuming for the child, its parents, and GMA trained personnel, and the method requires the parents to travel with their young and fragile child to the hospital for testing [12]. Mobile technologies have made it possible to develop mobile applications that could be available for many people independent of region, country, and continent. Free et al. 2013 [13] demonstrated that mobile technology interventions, such as mobile applications, improved healthcare delivery and had an advantage over other communications technologies. A broader use of home-based video recording to be objectively analyzed and processed by newly developed software as the Baby Moves mobile application [14] may make it possible to focus hospital follow-up resources and provide targeted interventions at an early age to those infants at the highest risk of developing CP in a regional, national, and global context. Hence a recent multicenter international feasibility study testing home-based video recording using a mobile application has demonstrated that home-based video recordings are feasible for 97% of families [15].

Giving birth to a healthy child is a life event for the parents and their family. Giving birth to an unexpectedly sick or premature child often replaces excited emotions with anxiety, distress, and worry [16]. Children born with severe complications and/or prematurity are admitted to neonatal intensive care units, which is extremely stressful. The parents worry about whether their child is going to survive and later they worry about their child's future life [17]. Introducing new technology such as a mobile smartphone application to screen for risk of CP in infants with a complicated start in life might however concern the parents in both the short and the long term. Parents' experience, as demonstrated by Kwong et al. [14], showed that they appreciated being able to video record their child at home instead of in a hospital setting. So far, however, no research has explored parents' experience of early risk assessment of using GMA in a home setting.

Therefore, the aim of this study was to explore parents' lived experience of early risk assessment for CP using a mobile application for home recording after discharge from hospital stay of the newborn period.

Method

Design

A descriptive inductive design with a hermeneutic phenomenological approach based on van Manen [18,19] was used to describe parents' lived experience. Hermeneutic phenomenology is a descriptive methodology where lived experience is recollected after it is passed or lived through. The hermeneutic phenomenological approach is to go beyond what is said and to understand the underlying experience of what has been lived through by transforming the lived experience into a textual expression of its essence [18,19]. As described by van Manen the four fundamental lifeworld existentials; 'lived body', 'lived space', 'lived time', and 'lived others' were used to describe, clarify and deepen the understanding of the participants' lived experiences [18,19].

Procedure

The study took place in the northern part of the Capital Region of Copenhagen in Denmark. Qualitative interviews in the homes of the parents were performed from 15 March 2018 until 21 February 2019.

Fourteen Danish parents were strategically selected from the multicenter feasibility study 'In-Motion-App for remote General Movement Assessment: a multi-site observational study' [15], based on socioeconomic background, civil status, age, and academic background. The parents were asked prior to discharge if they were willing to participate in an interview concerning their experiences of early risk assessment for CP using the In-Motion mobile application after they have used the device. Inclusion criteria for the study were: Parents of infants with high-risk of perinatal brain injury based on [1] Birth weight ≤1000 g and/or

gestational age < 28 weeks [2]; Neonatal arterial ischemic stroke [3]; Neonatal encephalopathy [4]; Other significant risk factors such as intrauterine growth retardation, perinatal hypoglycemia and infants born with withdrawal syndromes.

In-motion mobile application

The In-Motion mobile application was developed for parents and health care personnel to record a video of the infant's spontaneous movements during the fidgety period [15]. Each infant was given a unique ID, and the infant's date of birth and expected date of birth were registered in the app. In the application the parents got an instruction video in Danish providing information and brief instructions on positioning of the infant, how to use their smartphone, and how to upload the video.

The parents were instructed to video record their child twice. The first time when the child was between 12 + 1 to 13 + 6 weeks post term and the second time between 14 + 1- and 17 + 6-weeks post term age. They were reminded by notifications from the study coordinator when to record the videos. When the video was uploaded successfully, they received a message through the application [15].

Participants

All invited fathers and mothers agreed to participate. The parents included two single mothers and 12 mothers and 12 fathers living together, with a total of 18 children. 13 parents were under the age of 30, 11 were between 30 and 49 years of age, and two parents were over 50 years. Seven parents (four fathers and three mothers) had an academic background of 12 years of education, 17 parents (seven fathers and 10 mothers) had an academic background of more than 12 years of education, and the remaining parents had less than 12 years education and 11 parents were first-time parents. Eight children were born before gestational age of 28 weeks and six children were twins, with a birthweight below 1000 g and they spend more than 2 months in neonatal intensive care unit (NICU). Four children were born before 32 weeks and with a birthweight of less than 1500 g, they spend less than six weeks in NICU. Four children born at full term where three children had neonatal encephalopathy and underwent hypothermia and one child suffered neonatal arterial ischemic stroke, all four had a birthweight above 3500 g and were discharged within two weeks. Two children were born at full term, one with symptomatic perinatal hypoglycemia and one child was born with growth retardation more than 50% with a birthweight below 1500 g. These two children spend a month at the NICU before being discharged.

Data collection

Prior to the interview the parents had received their child's GMA result in person by their local neonatal physiotherapist. The result was given to the parents within 14 days from the day they uploaded their second video. Within 14 days after they had received the GMA result, they were given an appointment with the child's neonatologist and pediatric physiotherapist at the developmental outpatient clinic of the local hospital.

The first author interviewed the parents at a time suitable for them; 13 interviews were performed in Danish and one in English. Efforts were made to ensure that both parents (if relevant) could be present during the entire interview.

An interview guide with open-ended questions based on earlier research associated with perinatal and early infant screening was used [8]. The first two interviews were used as pilot interviews before continuing with the rest of the interviews. As no major changes were made to the interview guide the pilot interviews were included in the analyses. Before the interview started, the interviewer used some conversation time to make the parents feel at ease. Each interview started with the parent/parents being asked to narrate in their own words the birth and their stay in hospital by the question: 'How did you experience the birth of your child and the following stay at the neonatal ward? ' Questions such as 'Can you explain further? ', 'Can you explain how that made you feel? ', and 'Can you please elaborate on that particular emotion? ' were asked for clarification and to get the perspectives of both fathers and mothers and to create space for both parents to express themselves. The next questions asked were: 'How did you experience the information of the mobile application? In particular, what did you think of the use of the word cerebral palsy in the information leaflet? ', 'How did it make you feel? ' and 'How did it make you feel to record and send the video *via* the mobile application? ' Finally, parents were asked about receiving the result from the video and the waiting time; 'How did it make you feel when you had the video for assessment? ', 'How did you experience the waiting time for the result? '

The interviews took 60–90 min and lasted until the parents themselves stated that they had nothing further to add. All the interviews were audiotaped on an iPhone mobile application, transcribed verbatim by the

first author, and stored on a secure server at Nordsjællands Hospital, Denmark.

After each interview the interviewer wrote field notes about emotions during the interview, eye contact, unrest, changing focus and other emotional manifestations. Each interview was given an identification number, and names, places, and professionals appearing in the interviews were pseudonymized. Quotes were used to illustrate the parents' lived experience and professionals as well as family members were anonymized in the text and described as nurse, physician, sibling, or midwife.

Data saturation seemed to appear after 12 interviews but additional two interviews were made to assure that no new information appeared.

Ethical considerations

The study was approved by the Danish Committee System on Health Research Ethics, reg.no. 170117778 and by the Danish Data Protection Agency. NOH-2017-025, I-Suite no. 05988. The study followed international guidelines outlined in the Declaration of Helsinki [20]. Written consent was obtained from all parents. Confidentiality was explained in an information leaflet and orally prior to consent. Parents were told that they could withdraw from the study if they wanted. To avoid any obligation on the part of the parents, a designated nurse at the neonatal ward included the parents in the study. All parents could be referred to the ward counselor for talks if necessary.

Data analysis

By active listening and reflecting during and after each interview a thematic analysis guided by van Manen's (1997) [18,19] hermeneutic phenomenological approach started in parallel with the data collection by the first author. Each transcribed interview was read by all the authors to get a naïve understanding and to capture the overall meaning of the parents' lived experience. Thereafter the first and last author read six interviews independently, and the second author read four, scrutinizing every sentence and asking what it showed about the parents' lived experience. Discussions were held when the first and last authors reflected upon their understanding of the parents' lived experience. The first author then read the remaining eight interviews independently in the same thorough way and reflected on the meaning of the parents' lived experience. Key sentences revealing the parents' lived experience were highlighted and color-coded to describe the four fundamental dimensions of lived body, lived time, lived space, and lived human relations in all interviews. The four fundamental dimensions were used to explore the parents' lived experience as it appeared when the parents gave their narratives by an inductive approach. The analysis moved between the four lifeworld existentials, (the parts), and the overall understanding (the whole) through reflective writing and rewriting as described by van Manen [18,19] to transform the essence of the participants' lived experience into text.

Through close collaboration, reading of interviews, attention to field notes and discussions between the first and third authors [18,19] preliminary subthemes emerged describing the parents' experience. Thereafter, the second author read the coded material, and discussions between all three authors were used to develop a nuanced description of the parents' lived experience based on the four lifeworld existentials. The field notes were used to gain an in-depth understanding of the parents' experiences of home-based early risk assessment for CP by means of a mobile application. During reflections it became evident that the parents' experience of the risk assessment was only one part of the parents' experience. To describe the uniqueness and significance of the parents' experience it was important to also include their overall experience of their child's birth and transition to home. The first and second authors then continued the reflective writing and rewriting process according to the hermeneutical phenomenological process [18,19] which included regular discussions between all authors about the parts and the whole. As subthemes and themes emerged, they were organized and refined within each lifeworld existential ending in an overall theme and three subthemes describing the parents' lived experience [18,19].

Only the first author coded all the interviews. Then the second author coded four interviews and the last author coded six interviews, to validate the latent interpretation of manifest transcripts of the first author by triangulation.

No themes were derived in advance. Instead, the themes were constructed during the analysis process and according to the phenomenological hermeneutic methodology. After the subthemes were identified a theme summarizing the parents' overall experience was described.

Results

The overall understanding of the parents' lived experience was described in one essential theme, 'Finding control in an uncontrolled life situation', based on three themes and nine subthemes (see Table 1). The parents found themselves in an alien situation and

had no previous experiences of what they were facing. For long times they were in shock, scared, worried, and unhappy. The early risk assessment for CP using a mobile application was described as a small and simple task that strengthened them in the endeavor to overcome past difficulties. The parents described struggling with a challenging start to their parenthood, which formed the first theme 'A challenging start to parenthood'. During the often-long hospitalization they felt as if they were living beside reality, which formed the second theme, 'Living in a bubble'. The parents indicated that they did not feel in control of their lives until they came home from the hospital, and this formed the third theme, 'Getting control in a safe environment'. Then they saw that their child made improvements, and by means of the app believed in their own ability to see their child's progress.

'A challenging start to parenthood'

This theme describes a challenging start to the parents' parenthood. Unprepared, they were thrown into an uncontrolled life situation, which often started with a complicated pregnancy followed by traumatic delivery. When the child was born, they suffered from their child's unstable medical condition and the uncertainty of not knowing whether their child would survive. They found it difficult to bond with their newborn child when struggling to cope and find control in the highly specialized care their child ended up in. When they learned to deal with the routines in the highly specialized setting, they were moved to their local neonatal hospital with new routines and new uncertainties. Slowly, they felt that they got to know their child, became parents, and could start their parenthood.

Difficult pregnancy and delivery

The parents described with great emotions the – in many ways – difficult and traumatic start of their parenthood. They described challenges during many years of longing and failing to become pregnant, with miscarriages and repeated and difficult artificial In-Vitro-Fertilization (IVF) treatments. These treatments were hard for both parents and affected their mental and physical health. This almost made them give up their dream of becoming parents, and then they experienced it as a miracle when an artificial IVF treatment actually worked. They described complication during pregnancy with long periods of bedrest for the mother, for weeks to months at home or in hospital to prevent premature labor, which made them feel anxious and out of control.

> I knew it was my last chance of becoming a mother, I had already decided that this was my last IVF treatment, when the pregnancy became complicated, I prayed that it was going to be okay (ID 5209).

Uncomplicated pregnancies sometimes became complicated when the mother felt less intrauterine life and ended up with acute cesarean section or when the pregnancy resulted in an acute delivery with a premature birth. Complicated delivery resulted in the child being taken for intensive treatment, which made the parents anxious and fear for the child's survival. One or both parents were separated from the child for shorter or longer periods due to the severity of the child's condition. Mothers found the time after the delivery traumatizing when they lost contact with their newborn child and their partner, when their child was moved to intensive care. They experienced the time alone, waiting and lacking comfort from anyone.

> This was the wildest rollercoaster I have ever been on. At first it made me physically sick, I had to go to the restroom to collect myself. The staff got very anxious, thought I was doing drugs, but I just had to collect myself and get the strength to be there for my child and wife (ID 5209).

Difficulty in coping with highly specialized care

In the highly specialized care, the parents felt anxious, angry, and powerless. These feelings increased when different staff members gave different information and communication about their child's state and development. They lacked information about how to care for their child as parents, which made them feel helpless and not know what was expected of them, like spectators in their own play. The parents described a difficult time as their sick child was moved between different wards and highly specialized and local hospitals. They lacked information about the transfer and what was expected for the care of their child. When they were unfamiliar with the child's treatment plan, they became nervous and anxious.

Table 1. Overall theme, themes and subthemes.

Finding control in an uncontrolled life situation		
A challenging start to parenthood	Living in a bubble	Getting control in a safe environment
Difficult pregnancy and delivery	Difficulty in processing emotions	Feeling safe at home
Difficulty in coping with highly specialized care	Difficulty in processing information	Can see that the child is developing
Separation and difficulty in bonding with the newborn child	Handing over responsibility to the experts	The app gives control and security

> Being admitted to neonatal intensive care hospital was extremely daunting because you follow how all the admitted children were by looking at the monitor in the room. When we were there, two children died on the same day, and I saw it all on the screen. After that we never left our child alone with the staff (ID 5522).

Separation and difficulty in bonding with the newborn child

The parents felt that their life situation became difficult as their child was fragile and often in an incubator, closely monitored by highly specialized technology and needing help to breathe. The separation from their child felt unbearable and it was hard for them to believe that their critically sick child would survive when they could not be physically close to their child.

> My child was critically ill; I didn't get a chance to hold her. The child needed emergency hypothermia treatment and was transferred to the neonatal intensive hospital. My husband accompanied the child, and I followed hours later. Due to treatment, I was unable to hold my child and my distress was immense as I believed the child would not survive or would get serious brain damage, I was crying non-stop (ID 9913).

'Living in a bubble'

The parents felt as if they were living in a world of their own. Having to stay there for months, the hospital room became their home. Being tired, sad and confused, it was difficult for them to process their emotions and the information given by the professionals. Confidence in the healthcare system and the support from the healthcare staff saved them from total despair.

Difficulty in processing emotions

Feeling insecure and without control made it difficult for the parents to deal with their emotions. Parents found it difficult to see their child connected to technical equipment, not knowing if their child was alive. They had difficulties following the progress of their child and they did not comprehend or understand their child's progress. They saw their child as fragile and critically ill even though the discharge day was getting closer.

When they were able to be physically close and hold their child, they were insecure and did not know if they handled their child in the right way. They felt happy as they could be close skin-to-skin and scared of doing something wrong and putting the child at risk. Mothers spoke of a need for their usual life pretending that they had given birth to a healthy child.

> I felt that I was going mad, I needed normality. One of the nurses recommended me to go for a walk, I went downtown for a coffee, making believe that I had not been admitted with my newborns, it felt good but at the same time I felt guilty leaving my children (ID 2629).

Difficulty in processing information

Parents described that it was difficult for them to process information they received about their child, and they felt that they sometimes did not have the strength to ask relevant questions. They had difficulty taking in information, and even if the medical staff told them about the risks, they did not comprehend or refused to believe that their child would not develop normally. When the staff told them that their child was doing well and in recovery, they found it hard to believe.

It was difficult for them to leave their child and go for a walk or take lunch, not knowing which nurse would take care of their child. They preferred to stay at the hospital and look after their child. When the time for discharge came, they became almost terrified and worried about what to do if they suddenly needed hospital support.

> I just couldn't process the information given by the physician, it was too much information and as soon as they told us there could be a risk of brain damage, I switched off, and just saw my little newborn, thought for myself that it couldn't be true (ID 4183).

Trusting the health care system

Becoming parents of a critically sick child started an emotional turnover for the parents. A way of coping for them was their confidence in the professionals and the health care system. They described how they tried to live day by day and tried not to worry about the future. Parents said that they left the responsibility to the experts to cure their child. The confidence they felt in the health care system gave them the necessary room to grow as parents and they became relieved when they did not have to worry all the time. Trusting the health care system, information and knowledge was necessary for the parents to keep their faith that the health care system was doing everything possible to heal their child.

As time passed by, the parents became acquainted with the medical monitors, test results, and procedures at the hospital. They even thought they became experts themselves in their child's treatment. This was experienced as challenging for them and the staff, and trustful communication was vital.

> At one stage my child was critically ill, it was touch or go if he was going to survive but I did not at any time doubt that he was in the best possible hands. I felt informed and taken care of during the entire crisis (ID 6314).

'Getting control in a safe environment'

Parents very much looked forward to going home with their child and becoming a family. But at the same time, they had a daunting feeling about taking on the full responsibility for their child with no backup from the hospital. Once at home they started to feel safe and then they also were able to see their child and the progress the child made. The mobile application was described as a tool that gave them a sense of being in control and an active participant in the follow-up of their child.

Feeling safe at home

Parents felt an ultimate joy when they finally were discharged from the hospital together with their child, being able to go home to a safe and familiar environment after months in hospital. Now they could focus on their child, each other, and their new family. The child was stable and growing/developing. Getting the possibility of taking control at home in a safe environment gave the parents a feeling of overseeing their child. This was what they wished for all those months in the hospital. Their past experiences were still in the back of their minds but being surrounded by family and friends made them feel safe.

> Finally, being at home after two months in hospital, I felt safe and almost ecstatic that we reached the goal of going home with our child. It also gave me the courage to develop as a mother and wife. Away from the hospital, being able to care for my child without the interference of nurses day and night, gave me a feeling of safety, it was a strange feeling but it was probably due to familiar smells and sounds that were very different from what was experienced at the hospital (ID 2896).

Can see that the child is developing

Coming home with their child meant a new start for the parents. Suddenly, they realized that their child was doing well, slept normally, ate well, and thrived. This brought great comfort and confidence to the parents and they sometimes they even forgot that they had had a difficult start. For some moments they even could forget about what might lie ahead. They simply looked at their child and were comforted.

> After just three weeks at home I could see that my child was developing, he was now eating all his food by himself, no tube feeding, what a joy. Then a week later I got the first smile, now for sure he was developing, no doubt about it (ID 1030).

The app gives control and security

Parents described how the app gave them a possibility of a risk assessment for CP. Parents felt that it was better to know about the risk, and their burden was eased when they knew about their child's risk of CP. The information leaflet about the risk of CP together with the mobile application gave them clear information. They understood that the risk was real. Understandable information helped them to deal with the uncertainty and they appreciated being able to participate in the assessment. They felt empowered in being involved and performing the assessment video, especially the fact that they themselves chose which videos were optimal for assessment, as they saw their child every day and they knew what was normal for their child.

> We felt so much in control, being able to select a video that was a true picture of our child's abilities for clinical assessment. To be honest we took five videos before uploading the video showing the true movements of our child (ID 6209).

When waiting for the result they felt anxious, describing it as a normal response when waiting for a test result. They understood it was the first stop on the recovery journey, and what was waiting for them were two roads: the low-risk road and the high-risk road. Knowing was described as better than not knowing. They had prepared themselves for both answers and were ready to deal with the result of the assessment. All parents, without exception described that they felt secure during the waiting time and that they felt fully informed about how and when they were going to be informed about the result. They were aware of the direct line to the principal investigator, which meant that they could get advice during the waiting time for the result. Not knowing was described as worrying. Not if the result would be 'high-risk' or 'low-risk'.

By having the In-motion app on their smartphone, the parents were able to talk to their family and friends about their child's follow-up, which gave them confidence and prepared them for their upcoming outpatient meetings with the neonatologist and physiotherapist. They were able to prepare questions in advance and thereby get a more profound understanding of how their child's future would be.

> For the first time I felt as an active partner in the treatment of my child. I was well prepared for the outpatient appointment with my child's doctor and physiotherapist and felt that the treatment plan for the future was just as much my plan as the plan decided by the medical professionals. I've got answers to all my questions; what lovely sentiment (ID 2896).

Discussion

Qualitative interviews with parents showed that the early risk assessment for CP using a mobile application did not seem to worry the parents but gave them

instead a kind of security. The risk assessment they performed by themselves through the mobile application was experienced as rewarding and helpful to them after the strain caused by the long stay in the hospital. During their hospitalization they experienced no control and had to cope with different information from a variety of health care professionals at all hours of the day. Being at home, the parents appreciated the concise information about how to use the application and they appreciated being involved in the plan after discharge when they knew what was expected of them.

The parents' experiences during their hospital stay are similar to what is described in earlier research [21]. Contradictory information and guidelines from different healthcare professionals and information they did not understand or could not cope with worried the parents and gave them a sense of an uncontrolled life situation. Kowalski et al. [22] likewise found that although the parents were informed about risk factors, 20–30% of all parents said they were not sufficiently informed about the risk of permanent neurological damage. The communication between parents and healthcare professionals is vital for parents to cope when they are hospitalized with a severely ill preterm born child. Parents in earlier studies described the communication as either positive or negative, depending on how much they felt that the information helped them to cope with the situation [23]. Several other studies have also shown the need for transparency for parents to feel safe and empowered [24–26].

The discharge for which parents prepared themselves in our study was both a long-awaited day and a day associated with worry, knowing that they would have to care for their child themselves. Most of all it felt like a happy day, going home, and settling into their own routines, and trying to find control in their lives at home. For the first time they felt as a family, finally being able to grow as a family on their own accord. The successful discharge and the easily understood information for the app was important for their use of the application at home and for their sense of security in using the application. The application entailed that the same information was given to all parents, both orally and visually through an instruction video and written information with links to evidence-based medical research. They knew exactly when and how to record the video and why they had to record their child's movement. Giving parents scientific knowledge makes them strong as parents and an equal partner to the health care professionals in the follow-up of their child [22,23]. On the other hand, Wigert et al. [27] showed that the lack of accurate communication could give the parents feelings of loneliness, abandonment, or unwanted responsibility.

Communication about early diagnosis or high risk for CP is vital for both parents and health care providers; however, some parents find healthcare providers overall pessimistic [23,28]. Parents request information and education surrounding their child's early risk assessment or early diagnosis [23,29,30]. In that context our study shows strong elements of communication and education as the parents were receiving information both orally and written; besides that, they had a lifeline where they could get in contact with a health professional.

We used the In-Motion app developed in Norway. The Baby Moves app is similar [14] to the one used in our study. The two apps are similar, the main difference between the two is that the In-Motion app has an instruction video that the parents must watch prior to recording their child with the app. The In-Motion was likewise designed to be used in connection with computer-based GM assessment, which demands that the video is recorded in a specific way [15]. However, both apps are only available for research.

By using the application, the parents in our study decided when and which video recording was going to be used for the assessment. This meant that the parents were more likely to record their child in the right behavioral state which is required by the GMA method [10]. Parents knew what was going to happen at the follow-up appointment and described that for the first time they had a plan to stick to. Engaging the parents actively in the follow-up of their child empowered them in their further engagement in their child's care and treatment. Lakshmanan et al. [31] showed that parents emphasized that mobile health technology would be helpful in preparing for both discharge and follow-up; they explained that all the information about the follow-up was gathered in one device which made life so much easier, besides which they could do it without going into hospital. Transferring the video recording for early assessment for cerebral palsy from the hospital to a safe home environment may help parents to feel empowered and gain control over their child's follow-up. However, it is important to find technical solutions that are both easy and safe to use for all involved, easily accessible for families, and efficient to use for the professionals. When developing and evaluating new eHealth solutions, the participation of end users is vital [14,15].

In our study, information about GMA, CP and parents support groups and local services is part of the Danish healthcare system for all infants. The parents in our study were pleased using the In-Motion app for early risk assessment for CP and by knowing that they could contact health professionals until they received

the result from the videorecording which probably increased their feelings of security. Early diagnosis or early risk assessment for CP is considered golden standard [8]. Research demonstrates that there is overall agreement between parents and healthcare providers that early diagnosis or early risk assessment is vital for long-term outcome and facilitates an open dialogue about the future of the child [32]. Parents also request written material regarding CP, support groups and local services [29,30] to support them.

Strengths and limitations

Qualitative interviews and a hermeneutic phenomenological approach as described by van Manen [18,19] is proved to be well suited to elucidate parents' lived experience. The authors all came into the study with a different preunderstanding which is considered a strength. The first author, Annemette Brown, is a pediatric physiotherapist with many years' experiences in the field of early prediction of adverse neurological development in children with high risk, and in working with parents in stressful situations like this. She was working at one of the neonatal wards where the infants were cared for but was not involved in the care of the infants. The second author, Åsa B. Tornberg, is an associate professor of physiotherapy with many years' experiences in clinical research. The last author, Inger Kristensson Hallström, is a professor of pediatric nursing with extensive experience of sick children and their families as well as in qualitative research and especially with-in the hermeneutic phenomenology by van Manen. The authors' preunderstanding was discussed and made explicit throughout the analyses and writing processes so that their preunderstanding did not influence the results in a subjective way.

To support the arguments for early intervention, our project planning, data and interpretations were dealt with at seminars arranged with fellow researchers having a multidisciplinary background as recommended by van Manen [18,19]. To ensure confirmability and let parents' voices be reflected in our findings, the study aimed to represent their lived experiences as gained first-hand, without any reflection or analysis [18,19]. The subjective and unique experience of each parent is shown by quotations in the text. Dependability was ensured by adopting a line-by-line approach, a systematic presentation of data and arrangement of the study process, and by having three researchers with different backgrounds analyze the data [33].

A limitation of the study was the homogeneity of the parents; they were either Danish or English speaking and none came from non-western countries. Further, all the parents came from one health region in Denmark. This implies that the results might not be transferable to parents in other contexts or other health regions and countries.

We followed the recommendations from van Manen [18,19], and parents did not review the transcribed manuscripts, nor did they get a chance to comment on the themes and subthemes. However, the parents' views could have strengthened the trustworthiness of the results.

Conclusion

After giving birth to a child at risk of CP parents struggle with loss of control and anxiety about the future. By using a mobile application for video recordings by the parents at home at a time which suits the child and the family it is possible to empower and involve parents in the care of their newborn child. In the future, remote video recording for general movement assessment in clinical practice is a means to ensure early identification of the risk of developing cerebral palsy in a high-risk population and thereby enable early interventions. However, a digital platform that can be used in clinical practice for safe transmission of videos is needed. A platform where parents additionally can get information of the newest research and the possibility of communicating with healthcare personnel or get in touch with parent support groups.

Acknowledgement

The authors wish to thank the parents for participating in interviews in their own home as well as nurses and physicians at the neonatal ward at Nordsjællands Hospital for recruiting families for the study.

Consent to publish

The parents have given their written consent to publish the information obtained. Consent to publish details has been obtained from both parents, and all efforts have been made to anonymize the participants.

Authors contributions

The corresponding author, physiotherapist and PhD student Annemette Brown, had primary responsibility for the protocol development, patient screening, enrollment, interviewing the parents, preliminary data analysis and writing the manuscript.

The second author associated professor Åsa B. Tornberg and the third author, Professor Inger Kristensson Hallström, participated in development of the protocol, supervised the

design and execution of the study, and participated in the analytical framework of the study, and contributed to writing of the manuscript and the final data analysis. All authors reviewed and approved the final manuscript and agree to be held accountable for all aspects of the work.

Dislcosure statement

The authors declare no conflict of interest. Nor had the funders any role in the design of the study; in collection, analyses, or interpretation of the data; in writing of the manuscript; or in the decision to publish results.

Funding

Swedish Research Council for Health, Working Life and Welfare [2018-01399]. Grants from Nordsjællands Hospital, University Hospital of Copenhagen, Hillerød, Denmark PSP E-20231-18-01.

Data availability statement

The data are not publicly available due to the nature thereof: the interviews are very personal, and access is therefore restricted due to confidentiality. We summarized the data of the participants in the manuscript text. The data of the findings in this study can be provided from PhD student Annemette Brown on reasonable request.

References

[1] Ravn SH, Flachs EM, Uldall P. Cerebral palsy in Eastern Denmark: declining birth prevalence but increasing numbers of unilateral cerebral palsy in birth year period 1986-1998. Eur J Paediatr Neurol. 2010;143:1–11.

[2] Granild-Jensen JB, Rackauskaite G, Flachs EM, et al. Predictors for early diagnosis of cerebral palsy from national registry data. Dev Med Child Neurol. 2015;57(10):931–935. doi:10.1111/dmcn.12760.

[3] Centers for Disease Control and Prevention. What is cerebral palsy? 2023. https://www.cdc.gov/ncbddd/cp/facts.html

[4] Hoei-Hansen CE, Laursen B, Langhoff-Roos J, et al. Decline in severe spastic cerebral palsy at term in Denmark 1999-2007. Eur J Paediatr Neurol. 2019;23(1):94–101. doi:10.1016/j.ejpn.2018.08.010.

[5] Herskind A, Greisen G, Nielsen JB. Early identification and intervention in cerebral palsy. Dev Med Child Neurol. 2015;57(1):29–36. doi:10.1111/dmcn.12531.

[6] Skiöld B, Eriksson C, Eliasson A-C, et al. General movements and magnetic resonance imaging in the prediction of neuromotor outcome in children born extremely preterm. Early Hum Dev. 2013;89(7):467–472. doi:10.1016/j.earlhumdev.2013.03.014.

[7] Spittle A, Orton J, Anderson PJ, et al. Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. Cochrane Database Syst Rev. 2015;201511: CD005495.

[8] Novak I, Morgan C, Adde L, et al. Early, accurate diagnosis and early intervention in cerebral palsy: advances in diagnosis and treatment. JAMA Pediatr. 2017;171(9):897–907. doi:10.1001/jamapediatrics.2017.1689.

[9] Einspieler C, Prechtl HF. Prechtl's assessment of general movements: a diagnostic tool for the functional assessment of the young nervous system. Ment Retard Dev Disabil Res Rev. 2005;11(1):61–67. doi:10.1002/mrdd.20051.

[10] Einspieler C. Prechtl's method on the qualitative assessment of general movements in preterm, term and young infants. London:; Somerset: mac Keith Press; John Wiley & Sons, Incorporated Distributor; 2008.

[11] Adde L, Rygg M, Lossius K, et al. General movement assessment: predicting cerebral palsy in clinical practise. Early Hum Dev. 2007;83(1):13–18. doi:10.1016/j.earlhumdev.2006.03.005.

[12] Brown AK, Greisen G, Haugsted U, et al. Formal training in general movement assessment is required to effectively evaluate infants with perinatal asphyxia in outpatient settings. Acta Paediatr. 2016;105(9):1056–1060. doi:10.1111/apa.13491.

[13] Free C, Phillips G, Watson L, et al. The effectiveness of mobile-health technologies to improve health care service delivery processes: a systematic review and meta-analysis. PLoS Med. 2013;10(1):e1001363. doi:10.1371/journal.pmed.1001363.

[14] Kwong AK, Eeles AL, Olsen JE, et al. The baby moves smartphone app for general movements assessment: engagement amongst extremely preterm and term-born infants in a state-wide geographical study. J Paediatr Child Health. 2019;55(5):548–554. doi:10.1111/jpc.14240.

[15] Adde L, Brown A, van den Broeck C, et al. In-Motion-App for remote general movement assessment: a multi-site observational study. BMJ Open. 2021;11(3):e042147. 2020-042147. doi:10.1136/bmjopen-2020-042147.

[16] Heringhaus A, Blom MD, Wigert H. Becoming a parent to a child with birth asphyxia-From a traumatic delivery to living with the experience at home. Int J Qual Stud Health Well-Being. 2013;8(1):1–13. doi:10.3402/qhw.v8i0.20539.

[17] Breivold K, Hjaelmhult E, Sjöström-Strand A, et al. Mothers' experiences after coming home from the hospital with a moderately to late preterm infant - a qualitative study. Scand J Caring Sci. 2019;33(3):632–640. doi:10.1111/scs.12656.

[18] Manen MV. Researching lived experience: human science for an action sensitive pedagogy. 2 udgave ed. London, Ont.: althouse Press; 1997.

[19] van Manen M, van Manen M. Doing phenomenological research and writing. Qual Health Res. 2021;31(6):1069–1082. doi:10.1177/10497323211003058.

[20] WMA General Assembly. WMA Declaration of Helsinki -Ethical Principles for Medical Research Involving Human Subjects. Available at: http://www.wma.net/en/30publications/10policies/b3/index.html.pdf?print-media-type&footer-right=[page]/[toPage].

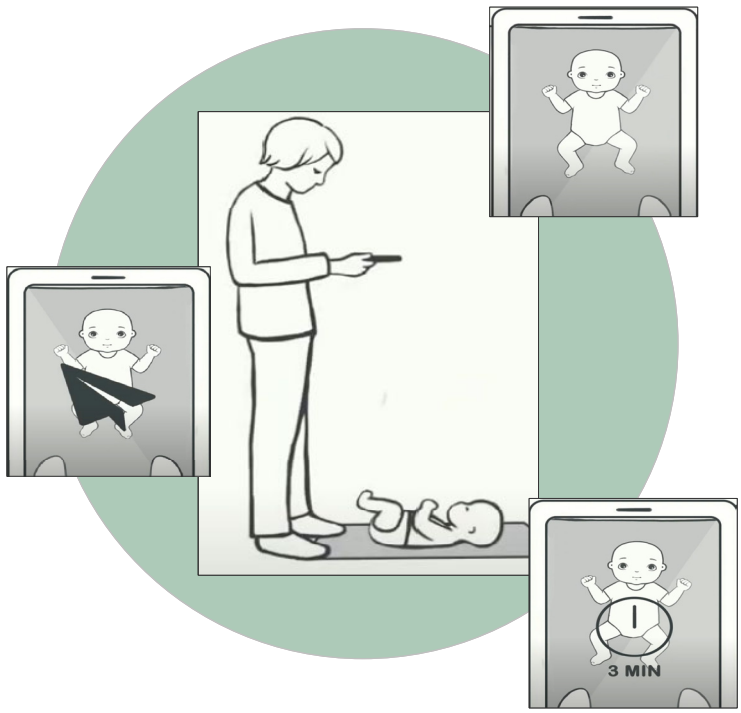
[21] Lundqvist P, Weis J, Sivberg B. Parents' journey caring for a preterm infant until discharge from hospital-based neonatal home care-A challenging process to cope with. J Clin Nurs. 2019;28(15-16):2966–2978. doi:10.1111/jocn.14891.

[22] Kowalski WJ, Leef KH, Mackley A, et al. Communicating with parents of premature infants: who is the informant? J Perinatol. 2006;26(1):44–48. doi:10.1038/sj.jp.7211409.
[23] Weis J, Lundqvist P. Parent experiences of communication with healthcare professionals in neonatal intensive care units: a qualitative systematic review protocol. JBI Database System Rev Implement Rep. 2016;14(8):12–18. doi:10.11124/JBISRIR-2016-003053.
[24] Gallagher K, Shaw C, Aladangady N, et al. Parental experience of interaction with healthcare professionals during their infant's stay in the neonatal intensive care unit. Arch Dis Child Fetal Neonatal Ed. 2018;103(4):F343–F348. doi:10.1136/archdischild-2016-312278.
[25] Arockiasamy V, Holsti L, Albersheim S. Fathers' experiences in the neonatal intensive care unit: a search for control. Pediatrics. 2008;121(2):e215-22–e222. doi:10.1542/peds.2007-1005.
[26] Heermann JA, Wilson ME, Wilhelm PA. Mothers in the NICU: outsider to partner. Pediatr Nurs. 2005;313(176-81):200.
[27] Wigert H, Dellenmark Blom M, Bry K. Parents' experiences of communication with neonatal intensive-care unit staff: an interview study. BMC Pediatr. 2014;14(1):304. 304-014-0304-5. doi:10.1186/s12887-014-0304-5.
[28] Guttmann K, Flibotte J, DeMauro SB. Parental perspectives on diagnosis and prognosis of neonatal intensive care unit graduates with cerebral palsy. J Pediatr. 2018;203:156–162. doi:10.1016/j.jpeds.2018.07.089.
[29] Baird G, McConachie H, Scrutton D. Parents' perceptions of disclosure of the diagnosis of cerebral palsy. Arch Dis Child. 2000;83(6):475–480. doi:10.1136/adc.83.6.475.
[30] Novak I, Hines M, Goldsmith S, et al. Clinical prognostic messages from a systematic review on cerebral palsy. Pediatrics. 2012;130(5):e1285-312–e1312. doi:10.1542/peds.2012-0924.
[31] Lakshmanan A, Kubicek K, Williams R, et al. Viewpoints from families for improving transition from NICU-to-home for infants with medical complexity at a safety net hospital: a qualitative study. BMC Pediatr. 2019;19(1):223. 223-019-1604-6. doi:10.1186/s12887-019-1604-6.
[32] McIntyre S, Morgan C, Walker K, et al. Cerebral palsy–don't delay. Dev Disabil Res Rev. 2011;17(2):114–129. doi:10.1002/ddrr.1106.
[33] Guba EG, Lincoln, YS. Competing paradigms in qualitative research. In: Denzin NK, Lincoln YS, editors. Handbook of qualitative research. SAGE; 1994. p. 105–117.

Paper III

Paper IV

Printed by Media-Tryck, Lund 2025
NORDIC SWAN ECOLABEL 3041 0903



LUND UNIVERSITY

FACULTY OF MEDICINE

Department of Health Sciences

Lund University, Faculty of Medicine
Doctoral Dissertation Series 2025:65
ISBN 978-91-8021-718-7
ISSN 1652-8220