

The impact of longitudinal surveillance of individuals with cerebral palsy in Norway; a 20-year quality registry and follow-up program perspective

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ABSTRACT

The Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP) has systematically collected data on individuals with cerebral palsy (CP) and been a driver of knowledge dissemination for over 20 years. NorCP data have increased the competence of health professionals in both the municipal and specialist healthcare services through publication of multiple scientific articles ranging from risk factors for CP to lifelong interventions, quality improvement projects, and training services. This has led to a streamlined process in the diagnosis and follow-up of children and youths with CP in Norway to ensure that they receive "the right treatment at the right time," regardless of where they live using evidence-based interventions based on needs that are revealed in the registrations.

NORSK SAMMENDRAG

Norsk kvalitets- og oppfølgingsregister for cerebral parese (NorCP) har systematisk samlet inn data om personer med cerebral parese og vært en pådriver for kunnskapsformidling i over 20 år. NorCP data har økt kompetansen til helsepersonell i både kommune- og spesialisthelsetjenesten gjennom publisering av flere vitenskapelige artikler om risikofaktorer for CP til livslange intervensjoner, kvalitetsforbedringsprosjekter samt kurs og kompetansetjenester. Dette har ført til økt kvalitet på diagnostisering og oppfølging av barn og unge med CP i Norge, som sikrer at de får «riktig behandling til rett tid», uansett hvor de bor i landet med bruk av evidensbaserte intervensjoner basert på behov som avdekkes ved registreringene.

Abbreviations: CP: cerebral palsy; CPHAB: Habilitation Trajectories, Interventions, and Services for Preschool Children with Cerebral Palsy; GMFCS: Gross Motor Function Classification System; HABU: pediatric habilitation center; HAVO: adult habilitation center; MACS: Manual Ability Classification System; MRI: magnetic resonance imaging; NorCP: Norwegian Quality and Surveillance Registry for Cerebral Palsy

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INTRODUCTION

Cerebral palsy (CP) is a lifelong condition that affects movement and posture, caused by a non-progressive injury to the immature brain (1). Although disturbances in motor function is the dominating criterion for the diagnosis of CP, individuals with CP often have associated impairments of hearing, vision, speech/communication, cognition, eating and epilepsy (1,2).

A diagnosis of CP is based upon clinical signs of motor disturbances and a history of known risk factors. Neuroimaging is also recommended to identify the brain injury, which is reported to be predictive of CP (3). CP is classified into subtypes based on the dominating motor function disturbances as well as which part of the body is affected, and confirmed at age five years (4). Gross and fine motor function is classified using the Gross Motor Function Classification System (GMFCS) and Manual Ability Classification System (MACS) five

level scales to provide clinicians and parents with a description of their child's current motor function and the prospective need for environmental adaptations and assistive devices for activity and participation (5-7).

In recent years, the birth prevalence of CP has declined in high-income countries to 1.5 per 1000 live births (8). The decline is attributed to advances in antenatal and neonatal care.

Cerebral palsy registers and follow-up programs systematically collect data on individuals with CP to identify and monitor variations in risk factors, prevalence, clinical manifestations and interventions over time. This, to provide up-to-date information to aid in the management of CP throughout an individual's journey in multidisciplinary care, because each individual with CP's development is unique and progresses at different rates. Their lifelong challenges need to be managed with evidence-based interventions that are aimed at optimizing function, reducing/preventing

NorCP protocols	Functional level	Age in years																	
		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
Physical therapy	GMFCS I																		
	MACS I																		
Occupational therapy	GMFCS II-V																		
	MACS II-V																		
Medical																			
Communication																			
Cognition (CPCog)																			
Hip x-ray	GMFCS I	None, provided clinical exam shows no evidence of hip dislocation																	
	GMFCS II																		
	GMFCS III-V	Assessed on individual-basis																	
Back x-ray	Not correctible/rigid scoliosis	When indicated per NorCP physical therapy, depending on age and function level																	
	Clinically moderate or pronounced scoliosis	When indicated per NorCP physical therapy, depending on age and function level																	
Surgery		When orthopedic, intrathecal baclofen pump or selective dorsal rhizotomy surgery has been performed																	

Figure 1. Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP) registration protocols and intervals, depending on age and functional levels; GMFCS=Gross Motor Function Classification System; MACS=Manual Ability Classification System.

complications and ensuring the best possible quality of life and participation (9). The objective of this article is to report the impact of the national Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP) during the past two decades.

NORWEGIAN QUALITY AND SURVEILLANCE REGISTRY FOR CEREBRAL PALSY (NORCP)

In Scandinavia, both quality registries and surveillance programs for CP are well established, and in more recent years often combined (9-11). The Cerebral Palsy Registry of Norway and Norwegian Cerebral Palsy Follow-Up Program were established as separate projects around 20 years ago at Vestfold Hospital in 2001 and Oslo University Hospital in 2006, respectively. The CP registry received status as a national medical quality registry by The Norwegian Directorate of Health in 2006 and has collected detailed medical data (i.e. CP subtype, associated impairments, congenital anomalies and cerebral magnetic resonance imaging (MRI) results in children with CP born 1996 onwards at three points in time; at diagnosis, age five years (when the diagnosis is confirmed), and at age 15-17 years (11). Surveys on mental health, quality of life and other factors important for transition to adulthood have been collected from youths and their parents. The CP follow-up program, which was modelled after the Swedish Cerebral Follow-Up Program (9), was officially approved in 2006 by the South-Eastern Health Trust. The CP follow-up program has recorded longitudinal physical and occupational therapy measurements and interventions, information on hip and back x-rays and orthopedic surgeries in children with CP born 2002 in South-East Norway and nationally, starting in 2010, from birth year 2006 onwards. During the first eight years, information was collected annually or biannually depending on the child's age and motor function (GMFCS/MACS)

levels. In 2015, the frequency of data collection was updated to annually or biennial depending on the child's age and functional level (11). This change was due to the experience that such a high frequency of data collection was not sustainable. All children and youths aged 0-18 years in Norway have been invited to participate (through informed consent) in the CP registry and/or follow-up program at one of the 21 pediatric habilitation centers (HABUs) nationwide.

In 2020, the CP registry and follow-up program were combined into the Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP). The NorCP is owned and operated by Vestfold Hospital, with a division at Oslo University Hospital. As of December 31 2022, over 3000 children and youths with CP born 1996-2022 and residing in Norway (ages 0-26 years) are registered in NorCP (12). The completeness of NorCP is 70% among young adults with CP ages 21-26 years (born 1996-2001), and 94% of children with CP born 2002-2016 (11,13). Figure 1 shows the NorCP protocols and registration intervals per January 1, 2022.

In addition to data collection, the NorCP provides networking and training for the multidisciplinary healthcare professionals who treat/follow-up children and youths with CP. Training includes courses in the standardized classification and evaluation tools that are included in the NorCP protocols, as well as courses related to evidence-based interventions. This is an important measure to increase knowledge and clinical competence.

Thereby, the aim of NorCP is to streamline the diagnosis and follow-up of children and youths with CP in Norway, and to ensure that they receive "the right treatment at the right time," regardless of where they live using evidence-based interventions based on needs that are revealed in the registrations.

As the population of children and youths in NorCP have grown older, the need for a follow-up program for

adults with CP has become clearer (14). Therefore, the NorCP, together with the Norwegian CP Association, are working on expanding NorCP for adults (15).

NEW KNOWLEDGE GENERATED FROM NORCP

Etiology and risk factors

The injury to the developing brain that causes CP is most likely the result of a combination of events that occurs during pregnancy (prenatal), labor/delivery (perinatal) or shortly after birth (postneonatal) (16,17). There are several known pre/perinatal risk factors such as a congenital brain anomaly, intrauterine growth restriction, preterm birth, maternal infection, trauma (i.e. hypoxic ischemic encephalopathy), as well as other complications (16). Recently, studies on the impact of genetic variants have also shed new light on potential causes of some individuals with CP, especially in those born at term without specific neuroimaging findings (18). Some common postneonatal causes are cerebrovascular events, head injuries/other accidents and infections (19). Through yearly linkage to the Medical Birth Registry of Norway as well as linkage to other national health registries, NorCP has published numerous studies on risk factors for CP.

Delivery/gestational age

In children born 1996-1998, Andersen et al. reported that breech delivery was a risk factor for CP, with a four times greater risk for CP among singletons born at term by vaginal delivery (20). Bjellmo et al. later repeated the study using data from a larger cohort of children born 1999-2009, and concluded that breech delivery was indeed not associated with an increased risk for CP, but for a composite outcome of CP, neonatal mortality and stillbirth. Therefore, the authors recommended a vaginal breech delivery, assuming precautions are taken accordingly (21). In another study, Bjellmo et al. found that a previous caesarean section was associated with increased risk for stillbirth and perinatal death compared with a previous vaginal delivery in children born 1996-2015, and a marginally increased risk of CP in children who survived the first month of life (22). Using the data on children born 1996-1998, Elkamil et al. found an increased risk for bilateral CP in term born children after induction of labor (23). This, while Stoknes et al. reported that CP in children born at term were more likely due to injuries to the brain during pregnancy and by a singular cause, while children born preterm more often had a combination of multiple risk factors during pregnancy, birth or directly after birth (17).

Preeclampsia/placenta

Using data on children born 1999-2008, Strand et al. found that preeclampsia in pregnant mothers was a risk factor for CP, but mainly mediated through preterm birth and being small for gestational age (24). In another study, Strand et al. found that placental dysfunction (small or large placenta) was considered to increase the

risk of severe CP. This was interpreted as a risk factor included in the combination of events leading to severe CP (25).

Congenital anomalies

Jystad et al. reported that one of four singleton children with CP born 1999-2009 at term or preterm had at least one congenital anomaly (26). Children with CP and congenital anomalies often had more severe gross motor dysfunction and associated impairments than children without congenital anomalies. The authors noted the importance of neuroimaging in the diagnosis of CP, as a majority of the congenital anomalies were located in the central nervous system (26). Building upon this study, NorCP was a partner in an international multi-center collaboration of CP registers in Europe and Australia, together with the European Surveillance of Congenital Anomalies. Data on children with CP born 1991-2009 were pooled and grouped into prenatal/perinatal CP and postneonatal CP. This study confirmed that nearly one of four children with prenatal/perinatal CP had at least one congenital anomaly, primarily cerebral anomalies. Children with CP and congenital anomalies also had more severe motor function and associated impairments. It was concluded that the presence of congenital anomalies is a risk factor in the combination of events leading to CP in children born as singletons near term/term (27). One in four children with postneonatal CP had congenital anomalies, primarily cardiac anomalies. Although, the causes of postneonatal CP varied greatly between those with and without congenital anomalies, no differences were found in severity of motor dysfunction and associated impairments. Postneonatal CP caused by surgeries related to the anomalies may be further prevented by improvements in care (28).

Invasive Group B streptococcus infection

In a study by Mynarak et al. in children born 1996-2012, the authors found that although an invasive Group B streptococcus infection in the newborn period and up to age one year was uncommon, it was associated with a high risk of mortality and CP. The authors suggested that improvements in prevention strategies are needed (29).

In all the aforementioned studies, there is agreement on the continual need for improvements in monitoring and treating risk factors for CP during the perinatal, prenatal and postneonatal period to minimize or prevent the impact they may have on the pathway leading to CP. Yet, the etiology behind these risk factors for CP needs further investigation.

Genetics

As stated above, CP is associated with prenatal, perinatal and postneonatal risk factors. It has however been hypothesized that much of the unknown pathophysiology of CP may be genetically caused. Until recently, studies have only been conducted on single genes (30, 31). Lien et al. found that the presence of APOE ϵ 4 was not neuroprotective in children with CP born 1996-2003 (32). However, when exploring six genetic variants in

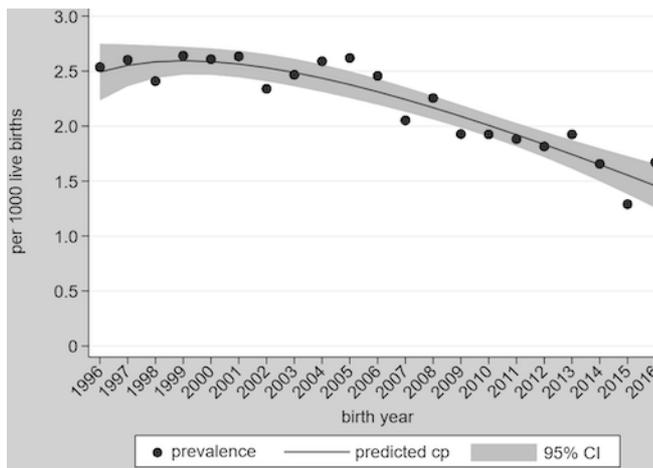


Figure 2. The birth prevalence of cerebral palsy (CP) in Norway. Each point shows the actual prevalence. The line represents predicted CP prevalence using logistic regression with fractional polynomials, and the shaded area denotes 95% confidence intervals (CI).

the sequences that regulate the expression of the APOE ϵ 4 gene, one was associated with a severe CP outcome, and certain combinations of genetic variants in both the APOE and TOMM40 genes may explain differences in CP outcomes. They concluded that genetics might also play a role in the combination of events leading to CP due to “differences in individual susceptibility to injury” (33,34).

Prevalence and clinical characteristics

NorCP has reported that the birth prevalence of CP in Norway has decreased from 2.5 per 1000 livebirths in 1996 to 1.6 in 2016 (Figure 2) (12,35).

Additionally, the severity of CP has decreased over time (35). The prevalence of spastic bilateral CP has decreased, mainly in children with spastic diplegic CP. This, concurrent with a decrease in mothers with pre-eclampsia during pregnancy, or decrease in multiple births due to improved assisted fertilization techniques. There was also a reduction in children with spastic quadriplegic and dyskinetic CP from birth year 2007 onwards, which corresponds with national guidelines for therapeutic hypothermia treatment for children born at term with hypoxic ischemic encephalopathy. At the same time, there was also a decrease in the proportion of children with CP with severe motor dysfunction and associated impairments (35). The decrease in prevalence and improvements in clinical outcomes are regarded as being related to improvements in obstetric and neonatal care.

On the other hand, Hollung et al. reported that nearly all children and youths with CP born 1996-2010 and recorded in the Norwegian Patient Registry had at least one associated impairment, and often multiple associated impairments regardless of CP subtype (2). The authors noted the importance of identifying them in order to minimize/prevent any negative impact they may have on quality of life and participation.

As previously mentioned, neuroimaging is recommended for all children under evaluation for CP. This is to rule out progressive conditions and identify the location and size of the brain injury. NorCP records neuroimaging findings using the MRI Classification System developed by the SCPE (36). Eighty-six percent of Norwegian children born 2002-2014 have had neuroimaging. Figure 3 shows neuroimaging results per CP subtype. Injury to gray and/or white matter is, as expected, dominant in children with spastic or dyskinetic CP, as these areas contain nerve cells and nerve pathways that control motor movements. Almost 35% of children with ataxia had normal neuroimaging (12).

Evidence-based treatments and interventions

Recently, there has been a growing emphasis on the importance of evidence-based methods to promote early diagnosis and interventions for children with CP in order “to optimize neuroplasticity and functional outcomes” (37-39). Using data from NorCP, many studies on gross and fine motor function, empowerment, participation, as well as services provided to children with CP and their parents have supported the efforts to encourage evidence-based interventions.

Gross motor function

As of 2021, more than 90% of children with CP recorded in the NorCP had regular physical therapy interventions, varying between the HABUs from 68% to 100% (12). Nearly all (96%) children on GMFCS levels III-V had regular physical therapy, followed by 89% on GMFCS level II and 72% GMFCS level I (12). Stør vold and Jahnsen reported that physical therapy interventions mainly consisted of goal directed functional training (40). In fact, studies by Stør vold et al. also demonstrated that intensive training periods or increased physical therapy frequency enhances gross motor function (41,42). Among children with CP born 2006-2020, 18% participated in an intensive training program. Yet, 33% of children born 2015 onwards participated in an intensive training program, varying from 0% to 100% between the HABUs (11).

Fine motor function

During 2012-2016 NorCP participated in The Habilitation Trajectories, Interventions, and Services for Preschool Children with Cerebral Palsy (CPHAB) research program. Clinical data on children with CP were collected from both the NorCP and HABUs. Parent-reported data on children’s health and participation, caregiver priorities, family empowerment and quality of life, their perceptions of services and interventions, and how children benefited from these were collected by questionnaires.

Klevberg et al. explored trajectories in bimanual performance across MACS levels in young children (ages 18 months to 6 years) with unilateral CP (Assisting Hand Assessment) versus bilateral CP (Both Hands Assessment) (43). They concluded that although both children with unilateral and bilateral CP improved hand

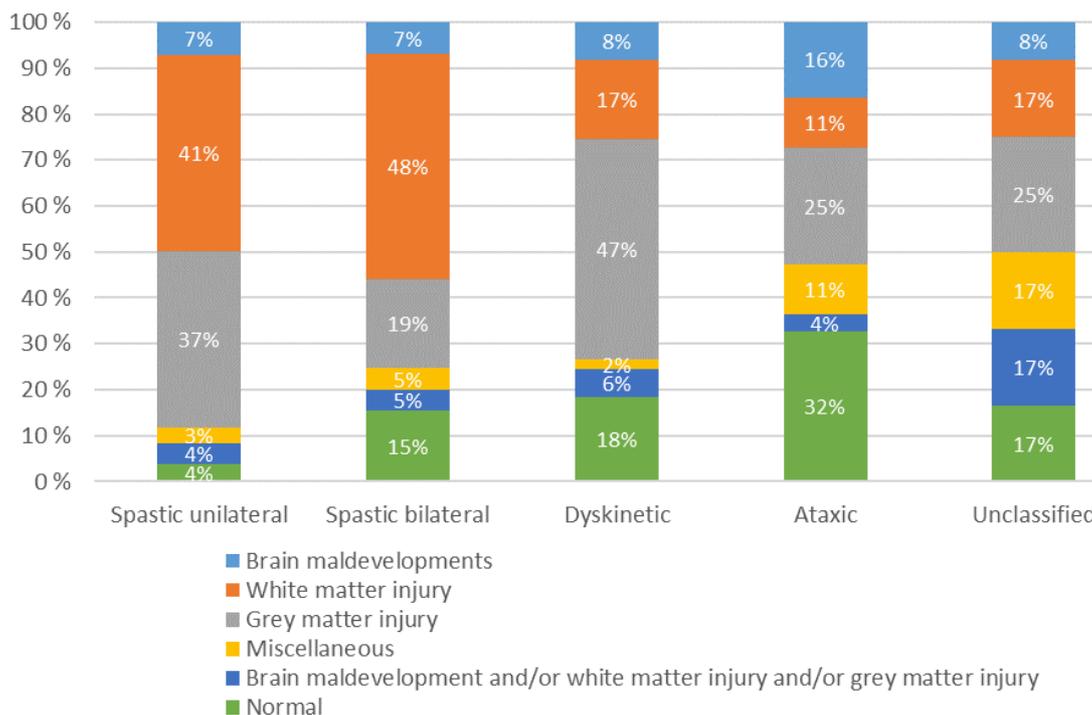


Figure 3. MRI classification system (MRICS) results per cerebral palsy subtype in children registered in the Norwegian Quality and Surveillance Registry for Cerebral Palsy (NorCP).

function over the study period, children with bilateral CP had a somewhat lower level of improvement (44). They also described developmental trajectories of bimanual performance at age 18 months and reported the importance of efficient early grasping ability in the affected hand among children with unilateral CP (44). These results were supported in a later study (45) and underscore the importance of classifying and measuring hand function early to introduce interventions that ensure the best long-term performance. In a study describing parent-reported interventions to enhance hand function, Klevberg et al. reported that most preschool aged children with CP performed hand training that was integrated into everyday activities and settings, complying with recent theories of motor learning (46).

Empowerment, participation and services

Kalleson et al. studied the importance of parental empowerment in raising a young child with CP. Results showed that parents consistently felt competent and empowered with issues in family and service situations, but less so in community situations. Additionally, families that had a multidisciplinary healthcare team felt more empowered than parents without, indicating the potential to strengthen parental empowerment over service situations and their ability to influence them (47). Kalleson et al. also explored participation in familial and recreational activities, indicating that child participation is context dependent and complexly influenced by more than just motor function. This calls for innovative thinking about how to develop service systems facilitating participation in meaningful contexts for children and families (48). Lastly, Kalleson et al. described the comprehensive family and child-based

services available in Norway, revealing that coordination and continuity in service provision appears to be areas in need of quality improvement (49).

QUALITY IMPROVEMENT

Information in medical quality registers can be used to describe variations in healthcare practices. Hence, a main aim of the NorCP is to reduce unwanted variation and promote best practice. The follow-up and treatment of children and youths with CP is aimed at improving, maintaining and optimizing function. Even if the aim of the treatment is improved body function, for example spasticity treatment or the installation of a gastrostomy tube to improve nutrition, the desired effect is usually improved activity and participation (50). Therefore, NorCP instituted 12 structural, process and outcome quality indicators for the diagnosis and follow-up of individuals with CP (12).

Increase the proportion of children formally tested for cognition

A NorCP process quality indicator is to increase the proportion of children who have been formally tested for cognition. This, because children with CP are known to be at risk of cognitive impairments, and the results of a cognitive assessment aid in individualized-based interventions. A study by Stadskleiv et al. showed that it is indeed possible to assess cognition in most children with CP, even in those with the most severe motor and associated impairments, by adapting the response method (51). NorCP has reported wide variations in practices in the proportion of children with CP who have had a cognitive assessment, and as a result, performed a

quality improvement project from 2019 to 2020 (52). Representatives from all HABUs in Norway successfully implemented local procedures and increased the number of children given formalized cognitive assessments. The proportion of children with CP who were cognitively tested increased significantly from 34% in 2018 to 62% in 2020, with variations in each HABU ranging from 9-54% in 2018 to 25-84% in 2020 (52). To aid in efforts to further increase the proportion of children with CP cognitively assessed, NorCP officially launched an updated cognitive protocol (CPCog) on January 1, 2022.

Number of new children with hip dislocation

A NorCP result quality indicator is to keep the number of new children with CP with hip dislocation at a minimum, preferably at zero. Individuals with CP have an increased risk of developing hip dislocation, which is painful, has major consequences for function and quality of life, and thus requires extensive and costly orthopedic surgery with long-term rehabilitation (53). Research from the Swedish CP Follow-Up Program shows that systematic follow-up and early intervention contributes to prevent hip dislocation and severe contractures (53,54). In Norway, registration of hip X-ray assessments has been a challenge, where only 48% of children had a registered hip x-ray in 2020/2021, according to protocols (12). The median age of the first hip X-ray is 5 years (range 1-9 years). According to the reported data, no new children who have been followed systematically in NorCP have had hip luxation since 2016 (12). In all, 23 children with CP have been registered in NorCP with hip luxation, of whom ten have had orthopedic surgery, five died, three were in too poor of a condition to be operated, while the parents of three children did not wish for their child to have surgery, and two are not recorded with information (12).

In addition to the quality indicators, NorCP also has reported on wide variations in the use and dosage of Botulinum toxin A for reduction in spasticity in Norway, (55) as well as the use of Botulinum toxin A, selective dorsal rhizotomy and intrathecal baclofen therapies in northern Europe (56).

NATIONAL GUIDELINES

There are currently no national clinical guidelines for CP in Norway. Therefore, in 2021 NorCP began work on developing a knowledge-based guideline for the diagnosis and follow-up of individuals with CP. A project plan was drawn up and both a steering and reference group were established. Clinical experts in the field (pediatricians, orthopedic surgeons, orthoptist-prosthetists, physiotherapists, occupational therapists, nutritionists, psychologists, among others) have been recruited and are currently participating in the work. The Norwegian CP Association is also an essential partner, participating at a strategic level, including a central role in the establishment of a user panel.

Existing international clinical guidelines, summa-

rized literature and systematic overview identified in a literature search will form the basis for the evidence-based descriptions and recommendations in the guideline. Descriptions and recommendations will follow the structure and terminology from World Health Organization's International Classification of Functioning, Disability and Health framework with emphasis on activity, participation and environmental factors (50). The guideline will focus on diagnosing CP and the follow-up of individuals with CP within key functional areas. The overall aim is to contribute to better and equal treatment of individuals with CP, as well as to increase competence and promote quality development of services nationwide. The primary target group is therefore professionals who provide services to individuals with CP within the municipal and specialist healthcare services, but will also be relevant to other sectors (i.e. training and Labour and Welfare Administration). The guideline will also be of interest for parents, caregivers and persons with CP. The plan is to publish the guideline late 2023 on the Method Books for Health Services website (<https://metodebok.no>).

ADULT FOLLOW-UP

Another current project is the development of a systematic follow-up for adults with CP. In March 2019, a national work group (user representatives, multidisciplinary professionals from municipal and specialist healthcare services, Norwegian CP Association and NorCP) submitted a report to the Norwegian Ministry of Health and Care on the need for follow-up of adults with CP (15). Yet, despite several inquiries to the Ministry, a mandate to develop a follow-up program for adults with CP has not been given. For over 20 years, research has documented the need for follow-up of adults with CP (15,57-59). In a recent survey carried out by the Norwegian CP Association, only 50% of individuals with CP over the age of 18 had follow-up in the specialist healthcare services in the last three years, and only 30% had follow-up at an adult habilitation center (HAVO). Of those who had not received follow-up, 70% reported a desire for follow-up (60). For comparison, a similar survey among parents of children with CP showed that 96% of the children had received follow-up at a HABU (61). NorCP continually receives feedback from its network of professionals in HABU, HAVO and the municipal healthcare services about the limited follow-up services for individuals with CP over 18 years. A survey of transition routines between HABU and HAVO in 2022 carried out by NorCP, showed that only five HABUs transfer their patients with CP to HAVO, while six transfer some, and six transfer none (unpublished).

CONCLUSION

Throughout the past 20 years, NorCP has developed into not only a high-quality medical quality registry, but also a follow-up program with multiple longitudinal

protocols for individuals with CP that are now fully integrated into the Norwegian municipal and specialized healthcare services. NorCP data have increased the competence of health professionals working with individuals with CP, through the publication of multiple scientific articles ranging from the diagnosis of CP to lifelong interventions, and training services. This, to ensure that all children and youths with CP in Norway are given the opportunity to be evaluated using international, standardized classification tools, and to pro-

mote "the right treatment at the right time," regardless of where they live.

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