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CP-North: living life in the Nordic countries? A retrospective register research protocol on individuals with cerebral palsy and their parents living in Sweden, Norway, Denmark, Finland and Iceland

Ann I Alriksson-Schmidt,[1] Matti Ahonen,[2] Guro L Andersen,[3] Guðbjörg Eggertsdóttir,[4] Taru Haula,[5] Reidun Jahnsen,[6,7] Johan Jarl,[8] Ira Jeglinsky-Kankainen,[9] Gudny Jonsdottir,[10] Abdu Kedir Seid,[11] Tinna L Ásgeirsdóttir,[12] Bjarne Møller-Madsen,[13] Kirsten Nordbye-Nielsen,[13] Sanjib Saha,[8] Darina Steskal,[14] Lauri Sääksvuori,[5] Gunnar Hägglund[1]

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For numbered affiliations see end of article.

Correspondence to
Dr Ann I Alriksson-Schmidt; ann.alriksson-schmidt@med.lu.se

ABSTRACT

Introduction Cerebral palsy (CP) is one of the most common neurodevelopmental disabilities. Yet, most individuals with CP are adults. How individuals with CP fare in terms of health, quality of life (QoL), education, employment and income is largely unknown. Further, little is known about the effects of having a child with CP on the parents. The Nordic countries are known for their strong welfare systems, yet it is unknown to what extent the added burden related to disability is actually compensated for. We will explore how living with CP affects *health*, *QoL, healthcare utilisation, education, labour market outcomes, socioeconomic status* and *mortality* throughout the lifespan of individuals with CP and their parents. We will also investigate if these effects differ between subgroups, within and across the Nordic countries.

Methods and analyses *CP-North* is a multidisciplinary 4-year (1 August 2017 to 31 July 2021) register research project. The research consortium comprises researchers and users from Sweden, Norway, Denmark, Iceland and Finland. Data from CP registries and follow-up programmes, or cohorts of individuals with CP, will be merged with general national registries. All individual studies are structured under three themes: medical outcomes, social and public health outcomes, and health economics. Both case–control and cohort designs will be included depending on the particular research question. Data will be analysed in the individual countries and later merged across nations.

Ethics and dissemination The ethics approval processes in each individual country are followed. Findings will be published (open access) in international peer-reviewed journals in related fields. Updates on *CP-North* will be published online at http://rdi.arcada.fi/cpnorth/en/

Strengths and limitations of this study

- Population-based registry study including vast data from five countries, which will allow for greater generalisability than usual.
- The use of observational data (register) has the advantage of being less sensitive to study selection and allow for long-term follow-up.
- Multidisciplinary research with focus on medical, social and public health as well as health economics.
- Users and stakeholders are highly involved with the research.
- Application of advanced methods to reduce bias from unobservable factors and allow causal interpretation.

INTRODUCTION

Living with a disability does not need to be a negative experience. However, moving through life for individuals with disabilities is generally a different experience. How individuals with disabilities and their families fare in domains such as health, education and employment depends on a multitude of factors including type and severity of disability.[1 2] Yet, life does not occur in a vacuum and as emphasised in the *International Classification of Functioning, Disability and Health* outcomes related to activity and participation at different life arenas are greatly influenced by the interactions among body functions and structure, personal factors and environmental factors such as family support, social and public health policies, medical interventions (and access to these), interpretation and enforcement of laws, and societal attitudes.[3] In their *Report on Disability* in 2011, the WHO and the World Bank outlined a number of domains

where globally, and as a group, individuals with disabilities were at increased risk of adverse outcomes. According to this report, individuals with disabilities were some of the most marginalised in society with limited access to education, employment and financial resources.[4] While it is likely that individuals with disabilities are worse off in some settings it has not been sufficiently studied how individuals with lifelong complex disabilities fare in other settings with privileges like universal healthcare and university education free of charge, such as in the Nordic countries (NC).

Cerebral palsy

To study 'disability' as a pooled heterogeneous group is justified at times,[1] and in some cases there is as much heterogeneity within diagnoses as between. However, it is not always appropriate because certain disabilities manifest so differently that the short and long-term ramifications vastly differ for the individuals and their families. At a prevalence of 2–3 per 1000 live births,[5 6] cerebral palsy (CP) is one of the more common early-onset disabilities. CP is lifelong and associated with painful and progressive musculoskeletal complications and reduced participation in society.[7–9] Studies on CP have not shown large sex differences, although the number of males with a diagnosis of CP is slightly higher, and there are no known sex differences on gross motor function.[10 11] The causal brain damage is non-progressive, however, many associated secondary conditions, which per definition are preventable, develop and worsen over time.[12] Levels of function and comorbidities vary greatly; some individuals with CP function independently, whereas others experience severe limitations and require full-time assistance. Numerous treatments and medical procedures are used to maximise physical function such as physical and occupational therapies, orthoses, medications and orthopaedic surgeries.

Little is known about the effects of CP on social and health economic outcomes. Knowledge is scarce also regarding medical outcomes, particularly in the long term for adults with CP. Some challenges associated with complex disabilities are shared virtually globally. Transitions from childhood to adulthood and from paediatric to adult healthcare are examples of such challenges.[13] The tradition of a well cared for paediatric population that 'age out' of childhood in the late teens into uncharted territories in adulthood is a problem in many parts of the world, including the NC. In childhood, multidisciplinary clinics or habilitation units with broad expertise is the predominant model to treat and monitor complex conditions, with school and family providing social scaffolding outside of the medical world. The same cohesive level of care and expertise are generally not available in adulthood, and it is startling how little is known about adults with CP.[14] While certain medical centres, educational settings and workplaces are experienced in how to treat and include individuals with CP, many such places cluster in specific geographical regions. Varied outcomes within and across geographical regions might reflect differences in infrastructures, interpretation of policies and laws, or procedures that need to be modified. From a societal standpoint, this is important in determining how interventions and services should be prioritised, organised and implemented.

To have an income and be self-supporting are goals for most people. Despite ambitious political efforts and integration policies, individuals with disabilities still do not have the same access to work life as their peers without disabilities, irrespective of the severity of the disability.[5] Only around 10% of individuals with disabilities in Sweden who receive social services have a connection with or experience from the labour market.[15] In Norway, 43% of individuals with disabilities have been reported to be employed, compared with 74% in the total population.[16]

Research shows that people with disabilities are more likely to be poor and to find it challenging to survive on a disability pension than those without a disability. Financial and social struggles create insecurity, anxiety and stress which are associated with negative physical and psychological health.[17 18] Healthcare and social systems are under financial strain and to learn from each other in terms of what has worked—and importantly, what has not—as far as including individuals with disability in the labour market can facilitate sustainability of health and social systems.

Parents of individuals with CP

The implications of caring for a child with severe CP can be far reaching. In contrast to parents of typically developing children (TDC) the caretaking might become a lifelong commitment and implies extended care responsibilities that parents of TDC are generally not exposed to. Parents of children with CP have been found more likely to struggle financially and to report higher levels of stress and depression than their counterparts with TDC.[19–23] Being a close relative to someone with a serious health problem (eg, Alzheimer's disease) is associated with reduced health, lower quality of life (QoL) and reduced labour market income.[24 25] Similar findings have been observed in small non-Nordic studies on CP. It is not clear if this is the case in the context of the NC, where governmental benefits and support (to different degrees) are available for those with eligible diagnoses and their families to financially compensate and facilitate continued work attachment. The physical and emotional demands, as well as the logistical complexities of taking care of family members with multifaceted disabilities can be multiple. Anxiety regarding the children's health and well-being, bureaucracy or full-blown battles to receive support, worries over how to cover steep out-of-pocket expenditures and concerns about what the future will hold for their children can put significant strain on the entire family units. Moreover, parents may be affected differently. Mothers are more likely than fathers to take parental leave and to stay home from work when children are ill. This might have a spillover effect in that mothers

might be more likely to reduce their work hours to care for their children with CP.[26] Children with CP undergo many surgeries, which require a parent to stay home during the recovery period. Absence from the workforce, even for shorter periods, affects salary, opportunities for promotion and retirement benefits. Whereas parents of TDC might stay home or reduce their workload in the first and second years of their children's lives, children with highly involved CP need extra involvement from the parents for years on end, if not for life. This affects parents financially and we hypothesise that mothers are disproportionally affected. The response of society and the extent to which social security compensates for loss of income and keeps the household out of financial insecurity and poverty is important, but also how this response is distributed across the population. Potential inequalities in access to and levels of disability-related benefits as well as differences in exposure to financial deprivation will be studied herein as well as differences in these across the NC.

Objectives

The overall purpose of *CP-North* is to explore how individuals with CP, and their parents, are affected at the individual, family and societal levels. Areas of study include how living with CP affects health, QoL, healthcare utilisation, medical intervention outcomes, education, labour market outcomes, socioeconomic status and mortality throughout the lifespan, and how outcomes differ based on disability-specific factors (eg, severity), personal factors (eg, sex), socioeconomic status and environmental factors (eg, geographical regions, policies).

The specific aims are to investigate the following:

1. What are the effects of CP on education, employment and income, and how do disability-specific factors such as degree/severity and comorbidity affect the outcomes
   A. For adults with CP?
   B. For parents of children with CP?
2. How, and to what degree, do social/disability-specific programmes and benefits offset economic vulnerability in the case of CP
   A. For adults with CP?
   B. For parents of children with CP?
3. Are the disability-specific benefits equally distributed in relation to disability-specific functioning, demographics (eg, sex, age, region of residence) and socioeconomic status?
4. What are the effects of severe permanent disability (CP) in terms of health (eg, pain, medical complications, utilisation of drugs and healthcare), QoL and mortality
   A. For children with CP?
   B. For adults with CP?
   C. For parents of children with CP?
5. Are there strategies of secondary prevention to reduce secondary conditions (eg, hip dislocations, scoliosis, fixed joint contractures) and to maximise health and function in individuals with CP in the NC, and are these associated with improved outcomes (eg, reduced pain, increased QoL)? What are the strategies?
6. Do patterns of healthcare contacts change over time? Is there a shift from preventive, planned care to more unplanned acute care as adolescents with severe disabilities 'grow out' of the paediatric healthcare system? If so, is this related to higher healthcare costs and reduced (worse) health outcomes?

METHODS

CP-North is a 4-year (1 August 2017 to 31 July 2021) population-based, multidisciplinary project consisting of cross-sectional and longitudinal registry studies in Sweden, Norway, Denmark, Finland and Iceland. The research in Iceland has been somewhat postponed, and Iceland will join the project later. However, the information on Iceland is included in this research protocol. The research consortium consists of researchers and clinicians with broad areas of expertise including physiotherapy, orthopaedics, psychology, health economics, public health and paediatrics. Secondary analyses will be performed on pre-existing data available in national quality registries (or cohorts) on CP and general national registers. Both case–control and cohort designs will be included depending on the particular research question. The five countries differ in how the healthcare is structured for individuals with CP: Sweden, Norway, Denmark and, to some extent, Iceland use similar systematic follow-up programmes, whereas Finland does not.

CP-North comprised numerous studies and it is beyond the scope of this protocol to provide details of each individual study. In line with the purpose and aims, the work has been divided into three main themes: (1) medical outcomes, (2) social and public health outcomes, and (3) health economics. Each theme has an assigned research team dedicated to carry out the work entailed. During the first 2 years focus will primarily be on individual national studies, and in the final 2 years more collaborative studies across countries will be undertaken, at which time data will be pooled across countries.

Patient and public involvement

A reference team which comprised users and family members will provide input and feedback throughout the project. An Icelandic researcher heads the reference team; however, users from all five countries participate in the reference team. This research protocol includes input from users, who specifically highlighted the need for research on pain, family members and transition.

National quality registries and cohorts included

The Cerebral Palsy Follow-Up Program (CPUP) originated in Sweden in 1994. As a secondary prevention programme used by the habilitation services, CPUP was mainly designed to detect and treat early signs of musculoskeletal deterioration.[27] The healthcare delivery model is coordinated across professional disciplines and includes

orthopaedic surgeons, hand surgeons, physical therapists (PT), occupational therapists (OT), psychologists and neuropaediatricians. Other professionals are involved on an 'as needed' basis. In 2005, CPUP became a national quality registry, nationwide data collection was initiated and CPUP has served as a dual follow-up programme and registry ever since. Data are routinely collected on a number of variables such as gross motor function, mobility, hand function, range of motion, degree of spasticity, hip displacement, pain and scoliosis (see www.cpup.se for a complete list). Gross motor function is classified using the Gross Motor Function Classification System Expanded & Revised Version (referred to as GMFCS in this report), which replaced the original GMFCS system in 2007 and expanded the age range to also include 12–18 year-olds.[28] The GMFCS is a five-level classification system that describes gross motor function of children and youth with CP based on gross motor performance in daily life.[29] GMFCS V indicates more severely affected gross motor function whereas GMFCS I indicates the least affected gross motor function. Similarly, the Manual Ability Classification System is used to classify manual abilities, and more recently, the Communication Function Classification System has been included to classify communication.[29] Adults with CP are eligible to participate; however, the adult cohort in CPUP does not comprise the total population. The assessment schedules differ based on GMFCS level and age, and based on those parameters CPUP assessments are recommended annually or biannually (figure 1).

The Cerebral Palsy Registry of Norway (CPRN) is a consent-based national medical quality registry that has systematically recorded detailed clinical information on all children with CP in Norway born 1996 and onwards. The purpose of the registry is to collect data on children and youth with CP in Norway and to follow prevalence, specifically causes and risk factors, increase knowledge and monitor the status of treatments and habilitation, ensure systematic, equal and predictable follow-up of children and youth with CP, regardless where they live, and to suggest measures to improve treatments, function, QoL and participation. The CPRN registers children with CP at three stages: at the time of diagnosis, at 5 years and at 15–17 years of age. The completeness of the CPRN has been ascertained by linking the CPRN with the Norwegian Patient Registry using the 11-digit personal identification number unique to each resident in Norway.[30]

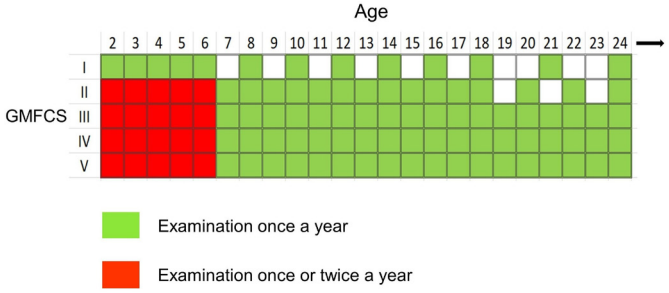

Figure 1 Follow-up schedule by physical therapists (PT) and occupational therapists (OT). GMFCS, Gross Motor Function Classification System.

The Cerebral Palsy Follow-up Program (CPOP) was established as a project in South-eastern Norway in 2006, funded by the Norwegian Directorate of Health, and implemented nationally in 2010. CPOP uses the same protocol as CPUP, and works in close collaboration with CPRN. Multidisciplinary teams in 21 habilitation centres conduct the assessments of the children according to the CPOP protocol. For quality purposes, and to contribute to equal treatment nationwide, CPOP runs a network of local health professional coordinators in the habilitation centres and their collaborating municipalities. Together, CPRN and CPOP facilitate the identification of prevalence, causal pathways and the need for habilitation interventions for all individuals with CP, and thereby contribute to the knowledge base needed to guide the prioritising of health services for individuals with CP and childhood-onset disabilities.[27]

The Danish CPOP, currently under development, also serves as a joint follow-up programme and national quality registry. It was developed to monitor and improve healthcare and QoL for children with CP. Similar to CPUP and CPOP-Norway, the children in the five regions included are offered systematic assessments by multidisciplinary teams of professionals. Denmark differs from Sweden and Norway in that it does not use habilitation units. Children with CP are followed in hospitals by orthopaedic surgeons, hand surgeons and paediatric neurologists, PTs, OTs and psychologists throughout the 98 municipalities. Six quality indicators are used based on radiographic examination of the hip, gross motor function, manual ability and diagnosis.[31]

Two institutions in Iceland, Æfingastöðin (since 2012) and Endurhæfing-þekkingarsetur (since 2014), offer their clients access to the Icelandic CP Follow-Up Program (CPEF). Æfingastöðin specialises in children and youth, whereas Endurhæfing-þekkingarsetur specialises in adults 18 years of age or older. Both institutions are in the capital area of Reykjavik, and only a small number of individuals from other regions in the country are included. CPEF is largely based on CPUP and the data are hosted on the same platform as CPUP in Sweden, which has been approved by the Icelandic Data Protection Authority. CPEF is not designated as a national quality registry. Recruitment to CPEF is underway and more individuals will be recruited, in particular during the first 2 years of *CP-North*.

Finland has no national CP registry and will serve as a comparison. For longitudinal follow-up, *the 1987 National Birth Cohort* will be used. The main purpose of the development of this cohort was to study the impact of childhood on health and well-being later on in life. The cohort includes all children entered in the 1987 Medical Birth Registry, including all live births >500 g or a gestational age of >22 weeks.[32] In total, the cohort includes over 60 000 individuals of which 229 have CP. Birth data have

Table 1 National quality registries and cohorts included in *CP-North*

Sweden	Norway	Denmark	Iceland	Finland
CPUP Children and adolescents aged 0–18 years n=3700 Adults n=1000	**CPRN** Children and adolescents aged 0–22 years n=2350 Adults n=100 **CPOP** Children and adolescents aged 0–16 years n=1500	**CPOP** Children and adolescents aged 0–15 years n=761	**CPEF** Children and adolescents aged 0–18 years n=100 Adults n=100	**1987 National Birth Cohort** Children and adolescents aged 0–25 years n=229

CPEF, Icelandic CP Follow-Up Program; CPRN, Cerebral Palsy Registry of Norway; CPUP/CPOP, Cerebral Palsy Follow-Up Program in Sweden and Norway, respectively.

been combined with data from several other registries, including data on social and socioeconomic status, health status and educational level of the cohort members and their parents.[33] The cohort has been followed to the age of 25 years. Additionally, data from several different databases will be used and combined to answer the research questions. To be able to answer research question 5, data from medical charts at two university hospitals will be collected. A summary of the national quality registries and cohorts included is summarised in table 1.

National registries

Data from CPUP/CPOP-CPRN/CPOP/CPEF and the Finnish 1987 cohort will be merged with data from national registries in the five countries. Individuals with diagnoses of CP (cases; International Classification of Diseases 10th Revision G80 code) will be identified in the respective national quality registries, when applicable, and cross-referenced with the national registries that contain medical diagnoses (eg, national patient and medical birth registries) in the respective countries. A control group from the general population will be identified at a 5:1 ratio, matched on sex, birth year, country and municipality excluding any siblings to cases. The parents of the identified cases/controls will also be included using multigenerational registries. Staff at one of the national registries will perform the merging of data and the researchers in *CP-North* will only have access to unidentified matched data on the variables of interest. Examples of the registries to be used in the respective countries, as well as examples of variables that will be accessed from each registry are summarised in table 2.

Information from a number of national registries will be linked to the identified individuals (cases and controls including parents) using the unique personal identification numbers available in the NC. Using Swedish registries as an example (although corresponding and additional registries from other NCs will also be used), school performance will be linked from the Registry of Grades from mandatory and secondary school, labour market outcomes and social security benefits from the Longitudinal Integration Database for Health Insurance and Labour Market Studies, demographic information from the Registry of the Total Population, healthcare utilisation and medical diagnoses from the National Patient Registry, pregnancy-related factors from the Medical Birth Registry and mortality information from the Cause of Death Registry. Disability-specific information for the cases will be extracted from CPUP (not available in Finland, where additional data collection will be necessary). Healthcare utilisation data will also be extracted from regional healthcare utilisation databases, which include more detailed information compared with the National Patient Registry (eg, healthcare episodes in primary care, costs and activity codes). To the extent possible, all identified persons will be followed from 1990 (or birth) until 2015 (or death), that is, a maximum of 25 years for each person.

All national registries have strict procedures that must be followed to access and use the data. These procedures pertain, for instance, to how the data must be stored and who can access them, which is also generally specified by the ethical review boards. The practical management of the data will be handled through the Nordic Microdata Access Network (NordMAN). NordMAN is an ongoing collaboration project between the Nordic National Statistical Institutes to facilitate for researchers in applying for and accessing data from Nordic registries. The data will be managed, analysed, presented and archived in compliance with national regulations, European Union directives (when applicable), Good Epidemiological Practice and the requirements posed by the ethical review boards.

Data analysis plan and statistical considerations

In general, the data will be analysed using standard regression techniques such as ordinary least squares, logistic regressions and selection models. The maximum likelihood Heckman selection model will be used when it is only possible to observe an outcome for a restricted, non-random sample. This type of model is appropriate, for example, when estimating a healthcare cost equation where many observations generally have no healthcare visits during a specific time period, or when estimating a wage equation (wage is dependent on employment). Disability-specific factors will be used to identify the models. Additional regression techniques and estimation methods

Table 2 National registries to be used

Examples of registries to be used and examples of relevant variables in the registries

Sweden	Norway	Denmark	Iceland	Finland
Statistics Sweden (SCB) *LISA:* employment, unemployment, absenteeism, income (eg, work income, pensions, benefits), education and immigration status. *Register of the Total Population:* demographic information (eg, country of birth, region of residence).	**Statistics Norway** Demographic information, family relations, education. **FD-Trygd** Work, income, social insurance and demographics.	**Statistics Denmark** Information corresponding to the Swedish registers is available from Statistics Denmark although not organised into named registers.	**Statistics Iceland** *Tax register* *Education registry* *Registers Iceland* Benefits and allowances are available from the **Social Insurance Administration**.	**Statistics Finland** *Finnish Longitudinal Employer-Employee Data (FLEED)* *Causes of death* Benefits and allowances are available from the **Social Insurance Institution (KELA)**, some also from the **National Institute of Health and Welfare**. Employment and pension are also available from the **Finnish Centre for Pensions**.
National Board of Health and Welfare *National Patient Register*: frequency/duration of inpatient care, ICD codes, number of healthcare visits and operation codes. *Cause of Death Registry:* dates and causes of death.	**Norwegian Institute of Public Health** **Norwegian Directorate of Health** **Norwegian Patient Registry** Cause of Death Registry Norwegian Neonatal Network Medical Birth Registry of Norway	**Sundhedsdatastyrelsen** *Civil Registration System National Patient Registry* *Register on Causes of Death* *Cancer Registry* *Psychiatric Central Research Register* *Medical Birth Registry*	**The Directorate of Health** *Birth registry* *Causes of death registry* *Inpatient care registry* *Primary care visits registry* *Specialists' clinic registry*	**National Institute of Health and Welfare** *Medical Birth Register* *Care Register for Health Care* *Register of Primary Health Care Visits (2011–)*
Drug Registry: medical prescriptions and eligible supplies filled at the pharmacies and the associated costs.	*The Norwegian Prescription Database*	*Lægemiddelstatistikregisteret*	**The Directorate of Health** and **Icelandic Health Insurance** *Drug Registry*	**KELA** Drug utilisation
County councils *Healthcare utilisation databases:* healthcare utilisation including diagnoses, activity codes and associated costs.				

ICD, International Classification of Diseases.

that will be employed include regression discontinuity analysis, difference-in-difference estimations and fixed effects models, with the objective of estimating causal effects.

When studying the effects of CP on the parents of the individuals with CP it is plausible that parental factors are correlated both with the likelihood of the child having CP and parental outcomes. Causes of CP are often not known, nevertheless certain parental health-related behaviours are known to influence both parental outcomes and the risk of giving birth to a child with CP (mediated through, for example, prematurity and low birth weight). Socioeconomic factors, directly or indirectly, are associated with increased disease risk and future parental outcomes. Thus, standard regression techniques might produce biased results for parents.[34] We will therefore control for the potential non-random selection using, for example, 'average treatment effect models'. Using propensity scores based on the estimated likelihood of giving birth to a child with CP, observable differences between the groups can be accounted for. These types of models can easily be extended to survival and time-to-event estimations.[35] However, it is only possible to adjust for observed differences between groups and this is why it is necessary to have access to extensive longitudinal data including medical, socioeconomic and demographic data.[25] The statistical analyses will be performed using SAS, Stata and R.

ETHICS AND DISSEMINATION

Sweden, Norway and Finland have ethics approvals for the overall *CP-North* research programme (Sweden: Regional Ethics Board, Lund, 2018/1000; Norway: Regional Committees for Medical and Health Research Ethics 2017/2457 REK sør-øst D; Finland: Helsinki University Hospital Ethical Committee IV (HUS 3640/2017)). The ethics review processes in Denmark differ for registry research and a waiver has been obtained. The approval from the Icelandic Bioethics Committee has been obtained (18-144). However, an approval from the Icelandic Data Protection Authority is still pending and is required before full approval can be granted. No research will be performed without the appropriate ethics approvals in the individual countries.

There will be an active dissemination throughout the whole project. A dissemination and communication team has been created with the purpose to plan and carry out the dissemination as planned. The overall goal is to disseminate the results of *CP-North* to a wide audience including the scientific audience and stakeholders (eg, persons with CP, their families and governmental agencies), policymakers in the NC, healthcare administrators, the general public, user organisations as well as higher education students. Different tools will be used to disseminate the process as well as results. Additionally, results

will be presented at meetings or in scientific journals related to CP, and at more generic meetings, workshops, webinars and public journals. Updates on *CP-North* will be published online at the *CP-North* website at http://rdi.arcada.fi/cpnorth/en/

Author affiliations
[1]Orthopedics, Department of Clinical Sciences, Skåne University Hospital, Lund University, Lund, Sweden
[2]Department of Pediatric Surgery, Helsinki Children's Hospital, Helsinki University Central Hospital and University of Helsinki, Helsinki, Finland
[3]The Cerebral Palsy Registry of Norway, Habilitation Center, Vestfold Hospital, Tønsberg, Norway
[4]SLF's Rehabilitation Center–Æfingastöðin, Reykjavík, Iceland
[5]Centre for Health and Social Economics, National Institute for Health and Welfare, Helsinki, Finland
[6]Cerebral Palsy Follow-up Program, Department of Neurosciences for Children, Oslo University Hospital, Oslo, Norway
[7]Faculty of Medicine, Research Center of Habilitation and Rehabilitation Models and Services (CHARM), University of Oslo, Oslo, Norway
[8]Health Economics Unit, Department of Clinical Science (Malmö), Lund University, Lund, Sweden
[9]Department of Health and Welfare, Arcada University of Applied Sciences, Helsinki, Finland
[10]Endurhaefing, Rehabilitation Centre of Excellence, Kopavogur, Iceland
[11]Centre for Alcohol and Drug Research, Aarhus Universitet, Aarhus, Denmark
[12]Faculty of Economics, University of Iceland, Reykjavik, Iceland
[13]Department of Children's Orthopaedics, Aarhus Universitetshospital, Aarhus, Denmark
[14]Uni Research Rokkan Centre, Bergen, Norway

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