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Combined surveillance and treatment register for children with cerebral palsy: the protocol of the Netherlands CP register

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ABSTRACT

Introduction Cerebral palsy (CP) is a childhood onset, lifelong, condition. Early detection and timely treatment of potential problems during the child's development are important to prevent secondary impairments and improve function. Clinical management of children with CP requires a spectrum of multidisciplinary interventions, which have an impact on short-term and long-term outcomes. However, there is a lack of knowledge about a personalised approach in this heterogeneous population. Various CP registers with different aims have been developed worldwide, which has made an important contribution to our understanding of CP. The purpose of this protocol is to describe the unique design of a combined multidisciplinary surveillance and treatment register for children with CP in the Netherlands, which aims to improve quality of care and to enhance an individual treatment approach.

Methods and analysis The Netherlands CP Register combines a multidisciplinary surveillance programme with a standardised protocol for treatment registry. The register systematically collects real-life surveillance and treatment data of children with CP. The register contributes to daily care at the individual level by screening for potential secondary impairments using a decision-support tool, by visualising individual development using a dashboard, and by supporting goal setting and shared decision-making for interventions. The register provides a platform at the national level for quality of care improvement and a comprehensive database of real-life data allowing multicentre studies with a long-term follow-up. People with lived experience of CP, healthcare professionals from different disciplines and researchers collaborated in the development of the register.

Ethics and dissemination The Netherlands CP register was submitted to the Medical Ethics Review Committee of VU University Medical Center (Amsterdam, the Netherlands), who judged the register not to be subject to the Medical Research Involving Human Subjects Act. A scientific board reviews requests for dissemination of data from the register for specific research questions.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ We provide a model for a combined surveillance and treatment register.
⇒ Collecting patient-centred real-life data within a multidisciplinary surveillance programme and treatment register provides a national platform for quality of care improvement and a database for practice-based studies.
⇒ The Netherlands Cerebral Palsy Register was cocreated with people with lived experience.
⇒ Transparency about the development and design of registers will allow international alignment.
⇒ Implementation of the register in daily care is an ongoing process, in which structural funding and limiting registration load for healthcare professionals are the most important challenges.

INTRODUCTION

Cerebral palsy (CP) is a heterogeneous group of disorders of posture and movement that is the consequence of brain damage or malformations during early development,[1] affecting around 1 in 500 newborns worldwide.[2] In the Netherlands, a country with a population of 17 million, around 35 000 people have CP, of whom around 7000 are children. Neuromusculoskeletal and psychosocial impairments are common in CP, with a diverse clinical presentation due to heterogeneity in aetiology and pathophysiology.[1] A multidisciplinary approach is required to target the diverse aspects of functioning and improve quality of life. A wide range of interventions can be selected, including physical, occupational and speech/language therapy, assistive devices, medication and surgery.[3] Besides being affected by primary impairments directly caused by the brain damage, individuals with CP are at risk of developing various secondary impairments over time, such as hip dislocation, scoliosis, contractures, chronic pain and fatigue. Both primary and secondary impairments may affect daily

activities and participation, and vice versa. CP is a lifelong condition, and the majority of individuals with CP live at least until 58 years of age in a high-income country,[4] so adequate management in children with CP has a large impact on long-term care. Timely treatment in childhood can help prevent secondary impairments, and, thus, also reduce the burden of the disease in adult life.

Various CP registers with different aims have been developed worldwide[5–10] and have made an important contribution to our understanding of CP. However, there is still a lack of knowledge about a personalised approach in this heterogeneous population. Important aspects of the management of children with CP are (1) selecting optimal personalised data-driven treatment, (2) providing timely treatment and (3) following guidance by the individual goals.

First, providing personalised management through evidence-based selection of the best type and dose of treatment for an individual child is important for optimal outcomes. However, often it is unclear what the best treatment for a child would be, attributable to the limited evidence for the clinical efficacy of many interventions.[3] Evaluation of treatment effects is challenged by the heterogeneity of the patient population and wide variation in treatment, resulting in small sample sizes in clinical trials.[11] Registering treatment characteristics and outcomes in a standardised way during usual care allows the development of a comprehensive database. The current treatment variation provides a starting point for understanding why treatment effects may differ between centres, which can be used for quality purposes. Moreover, such a treatment register allows the evaluation of treatment effects between subgroups of patients. Therefore, through such a register, practice-based evidence studies can be applied for comparative effectiveness research,[12 13] by comparing current treatments in large patient cohorts in longitudinal studies. Ultimately, by enabling personalised data-driven management in which the treatment is optimally tailored towards the individual child, a treatment register could prevent both undertreatment and overtreatment.

Second, providing timely treatment is important to prevent secondary impairments on the long term. Surveillance of children with a standardised follow-up programme may enable early detection, and, thus, timely treatment. For example, the Swedish CP Follow-Up Programme (CPUP) was proven effective in preventing hip dislocation.[14] Almost all Swedish children with CP are enrolled in CPUP, and are monitored by a standardised long-term follow-up of joint motion and musculoskeletal functioning.[5] This way, the incidence of hip dislocations was reduced from 9% to none.[14]

Third, incorporating an individual's wishes and goals in the treatment decision process is important for meaningful patient-centred care,[15 16] in which the patient's voice counts. Meaningful care can be achieved through individual goal setting and shared decision-making, which has been defined as 'an approach where clinicians and patients make decisions together using the best available evidence'.[17] Shared decision-making improves clinical and psychosocial patient-related outcomes through increased treatment adherence,[18] and improves patient understanding, satisfaction and trust.[19] Notably, this can be achieved without an increase in costs.[20] The importance of using patient-reported outcomes (PROs) for gaining better insights into patient functioning and involving patients in decision-making has also been acknowledged by the Cerebral Palsy Research Network (CPRN).[7]

Moreover, collecting and organising patient-centred data from children with CP on a national level during regular healthcare following a standardised protocol, could be a powerful approach to monitor and improve the quality of care provided to children within the Netherlands and provides a national database for practice-based studies. Therefore, we have developed a register for children with CP in the Netherlands that combines a surveillance and treatment register that aims to improve quality of care and to enhance evidence for individual treatment approach. The involvement of people with lived experience of CP was considered crucial in the development of the register. This paper describes the design of the Netherlands CP Register.

METHODS AND ANALYSIS

Process of development of the register

The Netherlands CP Register was set up in a collaboration between people with lived experience (ie, adolescents and adults with CP, parents/caregivers of children with CP), healthcare professionals of multiple disciplines (ie, rehabilitation physicians, orthopaedic surgeons, child neurologists, neonatologists, physical therapists, occupational therapists, psychologists, speech and language therapists, social workers) and senior researchers in the field. Organisations involved were patient association CP Nederland, the Netherlands Society of Rehabilitation Medicine and CP-Net, which is a network organisation involved in implementation of CP guidelines and improvement of care. The register was based on the Dutch guideline 'diagnosis and treatment of CP in children',[21] and on available standards of care. The Swedish follow-up register CPUP[5] was an important source for the register. Terminology followed the Surveillance of Cerebral Palsy in Europe guidelines for definitions and classifications.[22]

The register's structure was further developed by the collaborative partners. Core data sets describing patient and intervention characteristics, surveillance variables and treatment outcomes were developed for both the surveillance and treatment registries by expert groups, which consisted of healthcare professionals and researchers with expertise within the specific surveillance or treatment context. Outcome measures covered multiple domains of the International Classification of Functioning, Disability and Health (ICF) were validated, currently used in clinical practice, and considered to contribute to surveillance and/or treatment evaluation

and/or shared decision-making. The expert groups were advised by a panel of people with lived experience. Next, the core sets were approved by the Netherlands Society of Rehabilitation Medicine.

Patient and public involvement

People with lived experience of CP were involved in the development and governance of the Netherlands CP Register at all stages. They contributed to the core sets that are incorporated in the register. Furthermore, people with lived experience are involved in all governance layers.

Patient inclusion

A child is eligible to be entered into the register when they have a clinical diagnosis of CP, when they are younger than 18 years of age, and when they attend medical specialist care, that is, rehabilitation medicine, neurology or orthopaedic surgery.

Potential children for the register are identified by healthcare professionals during regular consultation in one of the participating rehabilitation centres or hospitals. Recruitment to the register uses an opt-in process. Children with CP and their parents/caregivers receive oral and written information about the register, available in the most spoken languages in the Netherlands, that is, Dutch, English, Turkish and Arabic. An explanatory video is also available. All registered children and their parents/caregivers gave written informed consent. The register was submitted to the Medical Ethics Review Committee of VU University Medical Center (Amsterdam, the Netherlands), who judged the register not to be subject to the Medical Research Involving Human Subjects Act. The Netherlands CP register complies with the Dutch laws and privacy regulations.

Structure

The register combines a surveillance and treatment register (figure 1). The input to the register is standardised regarding the data that are entered and the time points which data are entered at. The data collection takes place entirely with usual care during regular consultations with healthcare professionals. Core data sets include outcomes across multiple ICF domains, and are provided in detail in online supplemental appendix 1. The child's characteristics are entered, including diagnosis, comorbidities and level of functioning in various domains. The patient's current treatment and treatment history, based on the medical record, are also entered and continuously tracked throughout childhood during follow-up consultations. Based on the patient characteristics, data that are irrelevant are disabled for input. For example, when a patient's GMFCS level is above III, no data about independent walking are requested. Patient characteristics are copied to every new consultation by default, and can be adjusted if needed.

Surveillance register

Follow-up consultations for surveillance take place at set time points and are part of usual care. A follow-up consult is planned every 6 months for a child younger than 7, and every 12 months for a child between 7 and 18. Two weeks before each consultation, the software automatically sends patient-reported outcome measures (PROMs) by email to the child and/or their parents/caregivers. The PROMs include questionnaires on pain, psychosocial functioning, participation and quality of life. During each consultation, clinical data from the physical examination and, where relevant, hip and spine imaging is entered by the clinician. Moreover, the current treatment, for example, orthoses, tube feeding and medication, is adjusted where relevant at each consultation.

Treatment register

The treatment register currently includes registries for botulinum toxin A, intrathecal baclofen and for orthopaedic surgery. Data of intervention characteristics, side effects, clinical outcome data and PROs are collected during regular consultations before the treatment, and 3 months (botulinum toxin, intrathecal baclofen), 1 year (orthopaedic surgery) and/or yearly (intrathecal baclofen) after the treatment. Treatment details are registered, such as the exact type and target of the treatment, as well as the provided aftercare and side effects. Core data sets include treatment-relevant clinical outcome data and PROs. There is an overlap in data between the surveillance and treatment register, such as the standardised physical examination. Data collected during follow-up consultations within 2 months before the treatment consultations are automatically copied into the treatment register, to avoid double measurement and unnecessary burden to the children and registration load for healthcare professionals. Outcome goals are set and evaluated through Goal Attainment Scaling (GAS) by the patient, parents/caregivers and clinician on both the activity as body functions level.

Dashboard

The register provides a dashboard for every patient, displaying the individual development (figure 2), which is available for the healthcare professional to use during consultations. The dashboard shows patient characteristics, clinical outcomes and PROs over time and an overview of the registered treatments. Separate pages can be viewed for different scenarios, that is, hip development, flexion gait pattern, spine and adduction/endorotation gait pattern, and for treatment details. An important aspect of the dashboard is the decision-support tool using a traffic light system. When a data point scores within thresholds of normative values, it is displayed in green, but when it approaches a threshold it gets orange, and when it is outside of normative values it is shown in red. Normative values are available for passive range of motion, as based on CPUP data, and for psychosocial screening using normative data of age-related general paediatric populations for the Strength and Difficulties Questionnaire.[23]

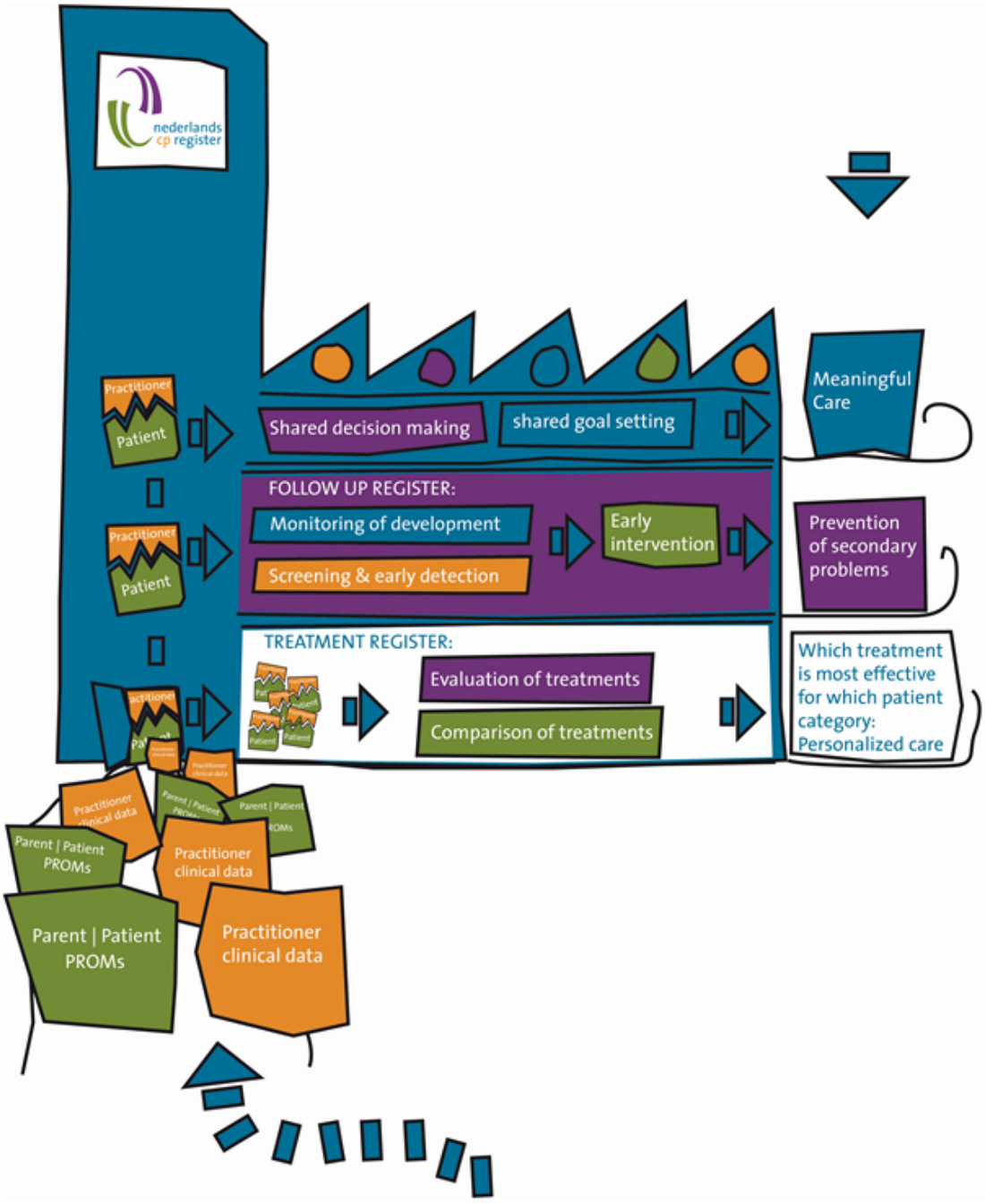

Figure 1 An overview of the structure and functionalities of the Netherlands Cerebral Palsy Register. Patient-reported outcome measures and clinical data that are entered at standardised time points are combined at three different levels: for shared decision-making, for follow-up registration and for treatment registration.

Outcomes

Outcomes of the surveillance and treatment register, as presented through the dashboard, are useful at multiple levels (figure 1). The standardised evaluation of treatments in the treatment register can enable personalised care. Data from this treatment register provide a national platform for quality of care improvement. Furthermore, the data can be used in research to evaluate and compare treatments through comparative effectiveness research, with the goal of finding out which treatment is most effective for which patient.

The standardised monitoring of a patient's development through the standardised follow-up by the surveillance register can prevent the occurrence of secondary impairments. Screening for upcoming problems, as facilitated by the traffic light system within the dashboard, allows early detection of potential problems. This way, timely treatment can be provided to reduce the risk of developing secondary impairments.

The register's dashboard will support meaningful care, as it invites patients, their parents/caregivers and clinicians to collaborate. The dashboard with traffic light

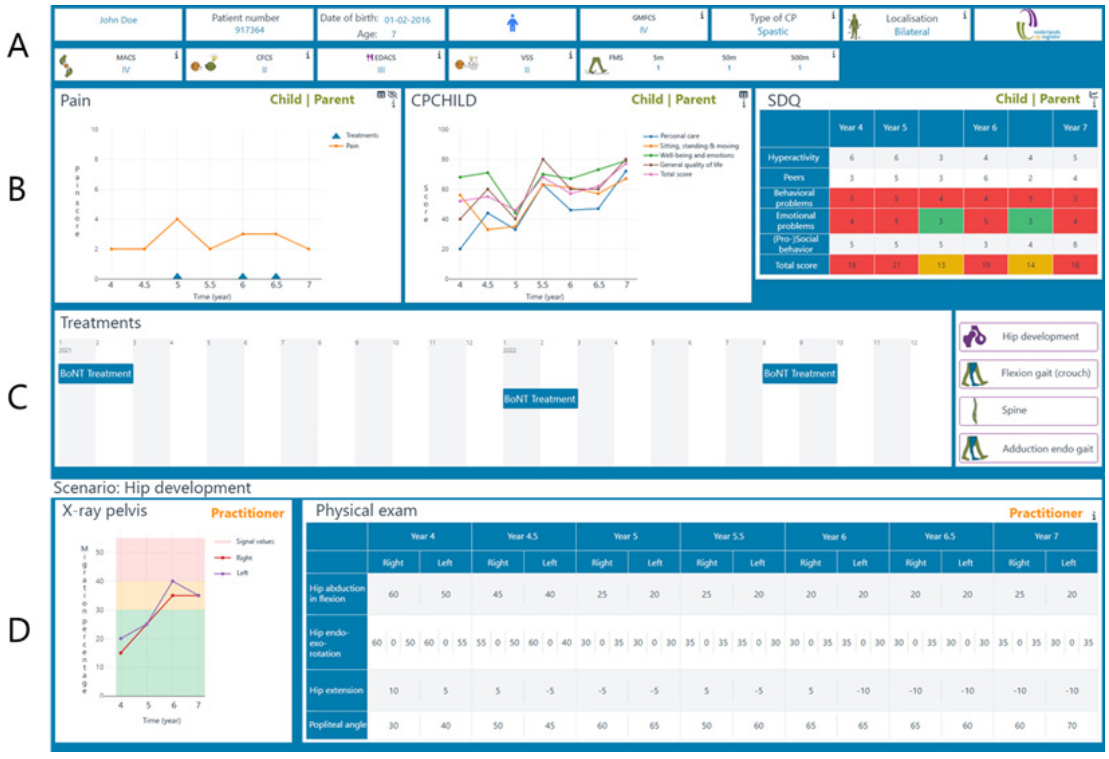

Figure 2 An example of the register's dashboard for a fictitious child. (A) displays child characteristics, (B) displays outcomes of patient-reported outcome measures over time, (C) displays when interventions took place and (D) displays outcomes of clinical measures, in this case hip development, over time. CP, cerebral palsy; SDQ, Strength and Difficulties Questionnaire.

system provides a tool to the clinician to inform the patient and their parents/caregivers about their own development and functioning. Therefore, it can help patients and their parents/caregivers with understanding their progress, when treatment may be needed, and with evaluation of treatment. For clinicians, the comprehensive overview of outcomes across multiple ICF domains, including PROMs and GAS outcomes, can be helpful in getting a complete image of the patient. Combined, this allows shared decision-making, and shared goal setting and evaluation.

Data management

To collect the data, the register uses an open source web-based software application using GemsTracker (Generic Medical Survey Tracker; https://gemstracker.org/). The software application automatically saves patient data over two separate databases: (1) a database storing person identifying data (ie, name, date of birth, email address) and (2) a database storing pseudonymised clinical data. Healthcare professionals have access to data of their patients from both databases, as they will need both person identifying data and clinical data. For quality purposes and for research, only clinical data from the pseudonymised database is used. Both databases are hosted by an ISO 27001, ISO 9001 and NEN 7510 certified fully managed-hosting provider, making data storage compliant with the international standards for data security in healthcare.

A data management plan for information security and quality procedures, based on Dutch legislation and regulations, has been established. This plan describes, among other things, what kind of data is collected, how that data are stored and managed, and who will have access to the data. Furthermore, a Privacy Impact Assessment was carried out. Based on this, potential risks of data leaks have been described and the measures taken to prevent this.

Governance

All participating centres as well as the patient organisation CP Nederland, the Netherlands Society of Rehabilitation Medicine and network organisation CP-Net are collectively represented in the Netherlands CP Register consortium. People with lived experience of CP have been involved in the development of the Netherlands CP Register at all stages and the patient organisation is involved in all governance layers. The Netherlands CP Register consortium is governed by the steering board and the following bodies: expert groups, a register panel and local coordinators. The steering board is co-led by the patient organisation CP Nederland. The steering board is responsible for the coordination and decision-making within the register, meeting at least four times per year to take decisions regarding the register progress and development. Expert groups meet every year to evaluate core data sets and compare them to existing guidelines and literature. If needed, a core set is updated. The register

panel is formed by people with lived experience, and meets for advice about specific topics. Each participating centre has a local coordinator that is responsible for the local support base, implementation and logistics. All local coordinators are supported by an implementation coordinator, and they meet at least twice a year.

Initially, when the register started in January 2020, eight rehabilitation centres and five university medical centres were involved, providing a structured starting point on which could be built further. Currently, 21 centres, including 6 university medical centres, throughout the Netherlands participate in the register, providing nationwide coverage.

DISSEMINATION

Clinicians have access to the data of their patients through the registry database. Aggregated data on centre level can be used for quality improvement processes and enables benchmarking between centres. Researchers may access a specific dataset after approval of the register scientific board. Due to the richness of the data obtained by the register, we anticipate that multiple scientific studies can be based on the database, resulting in series of papers published in international peer-reviewed scientific journals.

DISCUSSION

This paper presents the protocol of the Netherlands CP Register, which is a comprehensive national, multicentre, patient-centred register for children with CP. The register combines surveillance and treatment registry. People with lived experience are actively involved in setting up and steering the register. Patient functioning is monitored at standardised consultations, and development is displayed through a dashboard with traffic light system. As such, the register supports surveillance and shared decision-making. Furthermore, a comprehensive database enables benchmarking between centres for quality purposes and comparative effectiveness research. Therefore, the register contributes to improving quality of care for children with CP, by providing personalised care, preventing secondary impairments and providing meaningful care.

The register development is unique in various aspects. Persons with CP and parents/caregivers of children with CP were directly involved in the register development. For example, this group suggested to add psychosocial factors to the surveillance programme. Also, patients reported a high value for participation outcomes,[7] highlighting the importance of not only focusing on the ICF level of function, but also on the ICF levels of activity and participation. Following this, PROMs on those aspects of functioning were incorporated in the core data sets. Furthermore, the register combines multiple levels of reporting. It provides information on the level of the individual patient to monitor their development enabling surveillance, on the national level to provide benchmarking between centres, and for research purposes to evaluate treatments. Commonly, registers only focus on either surveillance (ie, CPUP[5] and CPIP Scotland[6]) or research (ie, CPRN,[7 8] Canadian CP Registry[9] and Australian CP Register[10]). Another unique aspect is that it is a patient-centred register, instead of a medical specialists-centred register such as, for example, the cardiology-focused Netherlands Heart Registry.[24] Multiple disciplines are combined within the register, since rehabilitation physicians, orthopaedic surgeons, child neurologists, neonatologists, physiotherapists, occupational therapists, psychologists, social workers and speech therapists are all involved.

The register is designed for implementation in clinical practice, and implementation has started at most centres. Face-to-face and online schooling is provided for local coordinators and clinicians of new centres to facilitate the implementation process. New participating centres follow a stepwise inclusion process, choosing a specific age category or treatment trajectory to start with. Even though the consultations are standardised in timing and in performance, circumstances within clinical practice may result in missing data. For example, PROMs are completed on a voluntary basis, and, therefore, not available from every patient at every consultation as intended. Nevertheless, the implementation in clinical practice allows comparison and evaluation of treatment as provided in current care. This may strengthen evidence for effectiveness of treatments.[3] An advantage of such comparative effectiveness research is that real-world results are provided,[12] as opposed to randomised controlled trials with often strict patient inclusion criteria and a highly controlled setting.

Multiple steps are being undertaken to further implement, improve and expand the Netherlands CP Register. In the near future, more treatments can be included in the treatment register, such as for selective dorsal rhizotomy, spinal surgery, tone medication, motor training and psychosocial interventions. The register's infrastructure is designed to accommodate easy addition of new treatment registries once decided on the core data set. The cost efficacy of the register will also be evaluated. Since a more predictive, preventive, personalised and participatory ('P4 medicine') approach can be applied through the register, its use is expected to result in more cost-effective medicine.[25] Furthermore, prediction models will be added to the dashboard, further enabling personalised clinical management. This way, surveillance and treatment can be personalised through a 'patients-like-me' principle. Also, implementation is further strengthened through closer collaboration with CP-Net, by facilitating implementation of best evidence, including the incorporation of recommendations from the Dutch CP guideline. Finally, transparency about the development and design of registers will allow international alignment. This may enable worldwide collaboration with even larger data sets, and the application of the register's model to other clinical populations.

The process of national implementation is an ongoing process. The most important challenges to ongoing implementation in daily care are structural funding and limiting the registration load for healthcare professionals. The register has been developed with external funding and grants. To achieve long-term national implementation in healthcare, structural funding is needed to ensure sustainability. National funding of quality registries may provide a way to reach long-term financial security. Additionally, reducing registration load is a primary focus point. Linkage between the electronic patient record system and the web-based software programme of the Netherlands CP register is an essential step towards this. Nevertheless, the high level of stakeholder engagement provides a strong foundation for sustainable implementation of the register in daily care.

We have described the protocol for the Netherlands CP Register, which is developed in co-creation with people with lived experience. The register combines surveillance and treatment registry, and supports shared decision-making. This way, personalised, data-driven care can be achieved through comparative effectiveness research, secondary impairments can be prevented and meaningful care can be provided. Ultimately, the use of the register is expected to result in improvement of quality of care, and thus improvement of participation and quality of life of persons with CP.

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