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An international survey of cerebral palsy registers and surveillance systems

Shona Goldsmith[1], **Sarah McIntyre**[1,2], **Hayley Smithers-Sheedy**[1], **Eve Blair**[2], **Christine Cans**[3], **Linda Watson**[2,4], and **Marshalyn Yeargin-Allsopp**[5] **on behalf of On Behalf Of The Australian Cerebral Palsy Register Group**

[1]Cerebral Palsy Alliance, The University of Sydney, Sydney, NSW, Australia

[2]Telethon Kids Institute, University of Western Australia, Perth, WA, Australia

[3]RHEOP–ThEMAS - Centre Hospitalier Universitaire de Grenoble, Grenoble Université, Grenoble, France

[4]Department of Health Western Australia, Perth, WA, Australia

[5]Developmental Disabilities Branch, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, GA, USA

Abstract

AIM—To describe cerebral palsy (CP) surveillance programmes and identify similarities and differences in governance and funding, aims and scope, definition, inclusion/exclusion criteria, ascertainment and data collection, to enhance the potential for research collaboration.

METHOD—Representatives from 38 CP surveillance programmes were invited to participate in an online survey and submit their data collection forms. Descriptive statistics were used to summarize information submitted.

RESULTS—Twenty-seven surveillance programmes participated (25 functioning registers, two closed owing to lack of funding). Their aims spanned five domains: resource for CP research, surveillance, aetiology/prevention, service planning, and information provision (in descending order of frequency). Published definitions guided decision making for the definition of CP and case eligibility for most programmes. Consent, case identification, and data collection methods varied widely. Ten key data items were collected by all programmes and a further seven by at least 80% of programmes. All programmes reported an interest in research collaboration.

INTERPRETATION—Despite variability in methodologies, similarities exist across programmes in terms of their aims, definitions, and data collected. These findings will facilitate harmonization of data and collaborative research efforts, which are so necessary on account of the heterogeneity and relatively low prevalence of CP.

Correspondence to Shona Goldsmith, Cerebral Palsy Alliance, PO Box 6427, Frenchs Forest, NSW 2086, Australia. sgoldsmith@cerebralpalsy.org.au.

A list of contributors is given in Appendix S1 (online supporting information).

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article:

Appendix S1: List of contributors.

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Cerebral palsy (CP) is a heterogeneous neurological condition with many aetiologies. Population-based surveillance programmes are considered the criterion standard for describing its changing birth and childhood prevalence and characteristics.[1,2] The earliest CP registers and surveillance systems have reported on trends since the 1950s.[1,3] However, the number of registers and population-based surveillance systems (hereafter referred to as 'surveillance programmes') is increasing[3] and currently nearly 40 exist worldwide.

Current collaborations between CP surveillance programmes that are geographically close allow not only comparisons between CP birth year cohorts but also pooling of data and greater statistical power for subgroup analyses. The first large network of CP surveillance programmes, the Surveillance of Cerebral Palsy in Europe (SCPE), was formed in 1998,[4] followed by the Autism and Developmental Disabilities Monitoring (ADDM) CP Network in the USA in 2002,[5] and the Australian Cerebral Palsy Register (ACPR) in 2008.[6] Collaborating internationally across even broader geographical areas would further facilitate specific subgroup research—a necessity for CP.[4]

The purpose of this survey was to describe CP surveillance programmes and identify similarities and differences across topics of importance for the relevance and sustainability of, and collaboration between, surveillance programmes. It is anticipated that results will (1) encourage and inform those establishing new programmes about the methods and data items collected by existing programmes; (2) inform health professionals and researchers of the existence of national and international surveillance programmes and the potential for population-based research and data linkages; and (3) assist existing surveillance programmes to investigate the potential for future collaborations.

METHOD

Representatives from 38 surveillance programmes were contacted by e-mail and invited to participate in the online survey. Surveillance programmes were identified by the study authors, and all participants were encouraged to forward the survey link to any other known surveillance programmes.

The survey, developed and constructed by the study authors, was available online via 'Survey Monkey' (https://www.surveymonkey.com) for 4 weeks in June to July 2014. Seventy-one questions related to issues of governance and funding, aims and scope, definition of CP, inclusion/exclusion criteria, ascertainment strategies, data collected, and research collaboration. A variety of question formats were used including open-ended and multiple choice. Participants were asked to supply a copy of their data collection sheet in English and a list of publications arising from their surveillance programmes. Non-responders to the initial invitation were prompted to participate one further time by e-mail.

Given the negligible risk posed by the survey, exemption from ethical review was approved by the Cerebral Palsy Alliance Ethics Committee, a recognized National Health and Medical Research Council Human Research Ethics Committee (EC 00402). Informed consent of the participants was implied by survey completion. Participants were contacted by e-mail if clarification was required on specific responses.

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Descriptive statistics were generated throughout. For questions with response rates of at least 80%, relative frequencies (percentages) are reported. Absolute frequencies (raw counts) are otherwise reported. Inductive content analysis was used to analyse the qualitative data from open-ended questions. For items where multiple responses were possible, percentages can exceed 100%.

RESULTS

Twenty-seven surveillance programmes participated (response rate 71%), including three collaborations between surveillance programmes (SCPE, ADDM, ACPR). Participants represented 11 countries and three geographical regions (Australia, Europe, and North America). Two surveillance programmes reported that they have ceased operation in recent years owing to lack of funding. Non-responders included 10 European programmes and one programme from Australasia. All further results refer to the 25 operating programmes. Programmes varied greatly in the birth years included. The earliest data available are from the birth year 1954 (Table I). See the full report of this survey available online for detailed results and the full original survey (http://impact.cerebralpalsy.org.au/activities/research-activities/cp-register-and-surveillance).

Aims

There was considerable common ground about the aims of surveillance programmes, and most reported multiple aims. Responses could be grouped in five key domains: (1) resource for CP research (100%), for example identifying potential subjects, identifying CP as a long term outcome, and gauging representativeness of study samples; (2) surveillance (92%), for example monitoring prevalence, time trends, or survival by key characteristics; (3) prevention (68%), for example identifying aetiological pathways and reporting prevalence over time with the introduction of preventive strategies; (4) planning (48%), for example assisting with the planning of services for people with CP; (5) provide information about CP (20%), for example raising community awareness.

Definition

Five definitions of CP were used, with 46% of surveillance programmes using more than one definition. The SCPE definition was most cited (63%),[4] followed by that of Rosenbaum et al. 2007 (54%).[7]

Denominators

There was significant variability in demographic criteria determining eligibility (where they were born, where they currently reside, where their family resided at time of birth), with many programmes using multiple criteria. Denominators reported included live births (78%), children living in area at a specified age (35%), neonatal survivors (26%), 1 year survivors (9%), with some programmes having access to more than one denominator.

Funding

Funding for surveillance programmes was received from the government (health/education/research) (72%), not for profit/charitable organizations (12%), and other external sources

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(12%). Some groups reported multiple funding sources and one programme received no specific funding for CP surveillance activities.

Eligibility

To help improve precision in identification of cases, 55% of programmes used either of the papers by Badawi et al.[8] or Smithers-Sheedy et al.,[9] and 45% of surveillance programmes used the SCPE definition and decision tree.[4]

Surveillance programmes were specifically asked about several eligibility issues that have historically varied between programmes. Variation was still seen, with 44% of programmes stipulating a minimum age of survival (Table I) and 46% reporting minimum severity criteria for inclusion. Although 96% of programmes included, but differentiated, postneonatally acquired CP cases, the upper age limit varied for timing of postneonatally acquired brain injury (Table I). Hypotonic CP was included in 54% of programmes, all based outside Europe, and was not consistently defined. Criteria for inclusion as hypotonic CP used by the ADDM Network in the USA included ‘hypotonia’ and meeting ADDM criteria for CP or a diagnosis of ‘hypotonic CP’ made by a qualified examiner, for example a paediatric neurologist or developmental paediatrician. A review of cases of hypotonic CP as part of the ADDM Network was recently undertaken and the results are forthcoming.

Consent requirements and methods used to identify new cases

The consent requirements for collecting, recording, and maintaining the data set varied across surveillance programmes (Table I). Some surveillance programmes received permission from a government body, usually a health or education authority, whereas other programmes required individual/parent permission/consent. Several surveillance programmes used a combination of consent methods, each addressing different activities of the programme (Table I). Most (80%) surveillance programmes had provisions for allowing contact with registered individuals to invite them to participate in future research activities.

Many different methods were used to identify new cases, with 68% of surveillance programmes using four or more different methods and 84% using five or more different data sources (Table II). Medical professionals were the most commonly reported source of data (100%).

Data collection

Age at data collection varied greatly between the surveillance programmes, ranging from birth/first diagnosis to older adulthood, depending on the programme’s purpose and geographical region. Ascertainment was generally considered complete between 5 and 8 years of age. Forty-six per cent of surveillance programmes had a procedure for assessing the completeness of population ascertainment. Six programmes reported comparing rates with long-standing population surveillance programmes anticipated to have similar rates of CP, three compared with other surveillance programmes/health care sources, and two used capture–recapture techniques: however, short of house-to-house surveys,[10] there was no criterion standard.

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Classification of CP subtypes

Significant geographical variation existed in classification of CP based on the type/s and topographical pattern of the movement disorder, reflecting the different definitions used for CP. Within spastic CP subtypes, all European programmes used as a minimum ‘unilateral’ and ‘bilateral’ to classify topography. In Australia, monoplegia/hemiplegia/diplegia/triplegia/quadriplegia were used consistently, which can be grouped to match European categories when required. Most North American programmes used both systems.

Aetiology

Eighty-seven per cent of surveillance programmes collected information about aetiology of cases not postneonatally acquired, with many collecting this as free-text.

Congenital anomalies

Seventy-five per cent of programmes collected data on congenital anomalies, most categorizing by International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) codes and/or free text. The upper age limit for recognition of congenital anomalies varied from at birth to no restriction. Sixty-seven per cent of programmes reported that a congenital anomalies register existed serving the same population as their CP surveillance programme; seven programmes had performed linkages with these registers.

Cerebral imaging

All programmes collected either (1) whether imaging had been performed (79%, of which 63% recorded where imaging was performed), and/or (2) clinical reports of imaging findings (54%), and/or (3) the original images (13%). Ninety-six per cent of all programmes collected data pertaining to cranial magnetic resonance imaging (MRI), 67% to cranial ultrasound, and 54% to cranial computed tomography.

Fourteen programmes reported the imaging classification system used by their surveillance programme to interpret and record images; seven programmes had not yet adopted a formal classification system. Seven programmes classified imaging based on clinical reports of neuroimaging findings, one programme classified scans by re-reading original images, and three used a combination of reports and rereading images. Imaging was classified by more than one person for seven programmes, and usually by a single person for three programmes. Classifications were made by a broad range of medical professionals (radiologist, neuropaediatrican, paediatric neurologist, neuroradiologist, paediatrician, paediatric neuroradiologist), other clinicians, and by surveillance programme staff.

Multiple births

Ninety-two per cent of programmes collected information on the plurality of the pregnancy, and 88% collected birth order. Only a few surveillance programmes systematically collected information on death of a co-multiple at <20 weeks’ gestation (17%), death of a co-multiple at >20 weeks’ gestation (17%), timing of death of a co-multiple (13%), health outcome of co-multiples (13%), zygosity (13%), or chorionicity/amnionicity (8%). Seventy-three per

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cent did not consider a survivor as a multiple if their comultiple(s) died before 20 weeks' gestation.

Assisted conception

Fifty-five per cent of programmes recorded some aspect of assisted conception, with most recording whether in vitro fertilization was used for the pregnancy.

Follow-up after verification

Twenty-one per cent of programmes systematically completed follow-up of children after they had been verified as having CP. Age at follow-up and frequency varied widely, from annually, to 5 years, 10 years, and/or at 15 to 17 years of age.

Interventions

Seventy-two per cent of programmes collected information on interventions received, including surgeries (56%), spasticity medications (48%), assistive devices (including orthotics and equipment) (48%), and therapies (36%). Four programmes had a longitudinal follow-up programme for secondary impairment prevention (CPUP Sweden, Danish National Cerebral Palsy Register, The Cerebral Palsy Register of Norway, NSW and ACT Cerebral Palsy Register Australia).

Data sheets

Data collection forms were available for 22 operating programmes. Overall, 38 items were collected by at least half of the programmes, with 10 collected by all programmes. Six of these items were collected in the same way across programmes. It was clear that there was some common ground for key data items but also considerable variation in additional data items and methods of collection (Table III).

Research collaboration

All programmes reported an interest in collaborating with other surveillance programmes. Forty-eight per cent of programmes have had a linkage/collaborative relationship with other surveillance programmes serving the same denominator group for research purposes, for example perinatal data sets/newborn quality register, regional and national death indexes, intervention services/health databases, congenital anomalies registry, CP follow-up program. Sixty-seven per cent reported a linkage/collaborative relationship with similar CP surveillance programmes serving other denominator groups.

Eighty per cent of programmes were able to send ad hoc, de-identified individual data to be used in collaborative studies with appropriate ethics approval. Thirty-three per cent had access to controls through a variety of methods including national health care registers, sampling of birth certificates, and as invited study participants.

Current research themes being investigated by the surveillance programmes included aetiology (68%), participation (48%), evaluation of interventions (40%), and survival (32%). Fifty-two per cent of programmes reported trends that they would like to discuss with other programmes, such as the decrease in birth prevalence of CP in extremely preterm infants,

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increase in the proportion of unilateral CP, and the increase in the proportion of hypotonic CP, all of which were reported by more than one programme.

DISCUSSION

CP surveillance programmes, like the people with CP that they represent, are heterogeneous. Although differences in methodologies existed across various geographical regions, there was some consistency in aims, definitions, and data sets. Some differences in important areas such as inclusion/exclusion criteria have recently been reported in the paper by Smithers-Sheedy et al.[9] and this survey confirmed those findings.

Although several data items were collected by the majority of programmes, the manner in which each was collected was not always comparable, particularly for items referring to aetiological risk factors, neonatal history, and associated impairments. For example, 34 different data items referring to vision were used across the data collection forms received. Professionals working with surveillance programmes need to decide if these common data elements are sufficiently important to warrant taking further steps to facilitate harmonization internationally. Himmelmann and colleagues recommended that the collection of CP register data be updated in line with emerging knowledge in the field,[2] but meeting this proposal may have implications for the identification of time trends. In the future, systematic collection of biomarker data or linkage with existing bio-banks (e.g. genetic testing and placental pathology) will be important. Additionally, extending systematic collection of data related to comorbidities, functioning, participation, and management into middle childhood, adolescence, and adulthood would extend our understanding of the breadth of the condition on a population basis across the lifespan.

The publication of the Gross Motor Function Classification System (GMFCS)[11] in 1997 represented a new era in the classification of gross motor function in CP. It is encouraging that all current surveillance programmes are using the GMFCS (Table III). On the other hand, geographical differences exist in classification systems for upper limb function, with most Australian and North American programmes using the Manual Ability Classification System (MACS), and European programmes using the Bimanual Fine Motor Function classification.[12,13] Classification systems for communication, speech, and dysphagia are not in universal use, although potentially useful classifications have recently been developed.[14–17] Working towards valid and reliable classification systems and incorporating these into surveillance programmes over time is essential to allow (1) comparison with data from other programmes and (2) monitoring the severity of CP over time.

Where numbers of cases are small, collaborative research efforts are of paramount importance. All participating CP surveillance programmes reported an interest in collaborating with other programmes and, with ethics approval, most (80%) were able to provide ad hoc, de-identified individual data. Barriers to collaboration identified by survey respondents included funding difficulties, problems with harmonization and comparability of data (definition, inclusion/exclusion criteria), and with negotiating common ground and priorities for research. International collaborative research networks such as IMPACT for

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Cerebral Palsy (International Multidisciplinary Prevention and Cure Team) have been established to further encourage collaboration between groups.

Although systematic reviews and randomized controlled trials of interventions are considered the ‘criterion standard’ for evaluating effectiveness of interventions, surveillance programmes also have a role, particularly for heterogeneous conditions such as CP. Four surveillance programmes included an individual, longitudinal follow-up programme aiming to prevent secondary impairments. Such programmes have been shown to significantly decrease musculoskeletal complications such as hip dislocation,[18,19] and some are expanding to include functional outcomes across domains including communication, mobility, self-care, and social interaction.[20,21] Surveillance programmes are also vital for evaluating the ‘real world’ outcomes of new interventions deemed effective in research settings.

It was not considered valid to report a combined prevalence of CP calculated across surveillance programmes because of the variability in methods of obtaining those estimates. Variations in estimated prevalence across surveillance programmes are considered to be at least partly accounted for by methodological differences (such as inclusion criteria, particularly whether postneonatally acquired cases are included, minimum age of survival, consent requirements, and type of denominator). The length of time a surveillance programme has been operating is also an important determinant. After commencement, it takes some years to build ascertainment as surveillance programme workers increase knowledge of locally appropriate ascertainment techniques and both medical and affected communities become aware of the existence of the surveillance programme. It is possible that variations in proportion reported with CP are due primarily to methodological differences and resulting variations in ascertainment proportion rather than to underlying differences in prevalence of the condition. Time trends should therefore only be assessed from proportions estimated by the same methods over time.[22]

This survey had several limitations. Although attempts were made to identify and invite all known CP surveillance programmes, there are at least 11 currently operating programmes that did not participate, and a further three did not contribute their data collection forms. The programmes that did participate were mostly based in Europe and Australia, and developing countries are not represented. Although this may represent a true lack of surveillance programmes in developing countries,[3] relevant studies and surveys are known to have been completed in such countries.[23,24] As the prevalence and aetiological profile of CP are known to vary by socioeconomic status,[25] as well as by perinatal care conditions (e.g. preterm birth), this presents an important area for future research. This survey did not address the topic of participant/parent involvement in the functioning of surveillance programmes. Although beyond the scope of this survey, we are aware of multiple programmes across Europe and Australia that have participant/parent advisory groups informing the work of the CP surveillance programme.

Two surveillance programmes have closed in recent years owing to lack of funding, highlighting the continuing difficulties programmes face in a global climate of financial constraints. In this era of increased research into the possibilities for prevention of CP and

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achieving better outcomes for those with CP, surveillance programmes will play a vital role in the pragmatic evaluation of treatments that have been found to be efficacious or effective in a research setting. It is important that existing programmes are able to report not only trends in prevalence but also severity, and compare these across different geographical regions, particularly those that differ in their approaches to perinatal care and CP management.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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ABBREVIATIONS

ACPR	Australian Cerebral Palsy Register
ADDM	Autism and Developmental Disabilities Monitoring
IMPACT	International Multidisciplinary Prevention and Cure Team
MACS	Manual Ability Classification System
SCPE	Surveillance of Cerebral Palsy in Europe

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What this paper adds

- CP surveillance programmes aim to be a resource for research and surveillance.
- Methods vary significantly, however all surveillance programmes are committed to collaboration.
- Seventeen core data items identified should be included in new surveillance programmes.

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Table I

Cerebral palsy surveillance programmes

Name of register/surveillance group (city)	First birth year cohort registered	Approximate number of live births per year	Minimum age of survival for inclusion (y)?		Postneonatal injury age limit (y)	Consent model
Australia						
1. Australian Cerebral Palsy Register (ACPR) (Sydney)	1993	298 900	No		2	N/A
2. NSW and ACT Cerebral Palsy Register (Sydney)	1993	102 300	No		2	C, O
3. Northern Territory Cerebral Palsy Register (Darwin)	1993	3700	No		2	C
4. Queensland Cerebral Palsy Register (Brisbane)	1993	63 000	No		2	C
5. Tasmanian Cerebral Palsy Register (Hobart)	1993	6100	No		2	C
6. The South Australian Cerebral Palsy Register (Adelaide)	1993	20 200	No		2	M, L, C
7. Victorian Cerebral Palsy Register (Melbourne)	1970	70 000	No		2	L
8. Western Australian Register of Developmental Anomalies – Cerebral Palsy (Perth)	1956	33 600	No		5	M
Europe						
9. C 28 RCP-HR Register of Cerebral Palsy SCPE-NET Project (Zagreb)	2003	28 400	Yes	5	2	C
10. CPUP (Lund)	1990	113 600	Yes	2 (for incidence)	3	C
11. Danish National Cerebral Palsy Register (Copenhagen)	1960	64 500	Yes	1 in case of death before inclusion age 4	Not included	L
12. Northern Ireland Cerebral Palsy Register (NICPR) (Belfast)	1997	25 300	Yes	16	5	L
13. North of England Collaborative Cerebral Palsy Survey (NECCPS) (Sunderland)	1991	30 500	No		10	C
14. Registre des Handicaps de l'Enfant en Haute-Garonne (Toulouse)	1986	16 000	Yes	4	5	O
15. RHEOP (Grenoble)	1980	30 000	No		5	O
16. Slovenian Register for Cerebral Palsy (Ljubljana)	2001	19 800	No		2	L
17. Surveillance of Cerebral Palsy in Europe (SCPE) (Grenoble)	1976	350 000	Yes	2	No limitation	N/A
18. Surveillance program: Epidemiology	1987	7000	No		5	C

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Name of register/surveillance group (city)	First birth year cohort registered	Approximate number of live births per year	Minimum age of survival for inclusion (y)?		Postneonatal injury age limit (y)	Consent model
of Cerebral Palsy in Kaunas County (Kaunas)						
19. The Cerebral Palsy Register of Norway (Tønsberg)	1996	61 100	Yes	1	2	C
20. The CP Register of Western Sweden (Göteborg)	1954	24 600	Yes	2	2	L
North America						
21. Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) (Atlanta)	1983	45 000–50 000 Children age 8 residing in area	Yes	8	8	L
22. The Autism and Developmental Disabilities Monitoring (ADDM) Network (Atlanta)	1994	130 000–150 000 Children age 8 residing in area	Yes	8	8	L
23. The Canadian Cerebral Palsy Registry (Montreal)	1999	194 400 Children age 2 residing in area	Yes	2	2	C
24. The Cerebral Palsy Research Registry (Chicago)	N/A	3 941 000	No		5	C
25. Weinberg Family Cerebral Palsy Centre, Columbia Cerebral Palsy (CP) Registry (New York)	1977	239 200	No		No limitation	L, C

Two additional programmes that are no longer operational participated in the survey: 4 Child – Four Counties Database of Cerebral Palsy, Vision Loss and Hearing Loss in Children (Oxfordshire, Berkshire, Buckinghamshire, and Northamptonshire); and the Merseyside Cerebral Palsy Register. N/A, not applicable; C, require individual consent to collect data; O, other: (2) NSW and ACT Cerebral Palsy Register: opt-off consent model; (14) Registre des Handicaps de l'Enfant en Haute-Garonne: after gaining individual no objection to collect the data; (15) RHEOP: individuals are informed individually but do not have to confirm whether their data can be used; M, as part of a mandatory reporting process; L, in line with specific legislation or legal agreements that allow data collection without individual consent.

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Table II

Data sources

Data sources	Programmes reporting this method (*n*)
Medical professionals	25
Disability service providers	19
Hospital inpatient records	19
Hospital outpatient records	17
Allied health staff	16
Birth register/certificates	12
Parents	12
Death register/certificates	10
Self-reporting	10
Routine child health surveillance	9
Diagnostic registers	7
Midwives data system	7
Education records	6
Research partnerships	4
Morbidity data system	3
Health visitors	1
Tax register	1
Other: for example prospective registrations within secondary prevention programme, administrative organization providing funding to families, disability financial support providers, administrative local authority for children with disabilities, website	8

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Table III

Data items common to most surveillance programmes

Items collected by all programmes	Items collected by ≥80% of programmes	Items collected by ≥50% of programmes
Date of birth[a]	Vision	Number previous live births/stillbirths to mother
Sex[a]	Hearing	Order of birth (multiple births)
Birthweight	Plurality	NICU/SCN admission
Gestational age[a]	Intellectual function	Neonatal seizures
GMFCS[a]	Mother's year of birth/age at delivery	Aetiology of main deficiency if known
Diagnosis/motor type	Place of delivery	MACS[a]
Postneonatal cause/timing[b]	Communication: understanding and expression	Age/date at diagnosis
Epilepsy/seizures		Education level of parents
Syndromes/ congenital malformations		Date of death[a]
Magnetic resonance imaging		Apgar
		Indigenous status/ethnicity of parents
		Strabismus
		Cranial ultrasound in neonatal period
		Drug treatment for hypertonia
		Paediatrician/health professional details
		Assistance with conception
		Ventilation in neonatal period
		IQ
		Feeding difficulties
		Computed tomography scan
		Orthopaedic surgery

[a]Data item collected in same way across all surveillance programmes.

[b]If included in surveillance programme. NICU, neonatal intensive care unit; SCN, special care nursery; GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System.