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UKCP: a collaborative network of cerebral palsy registers in the United Kingdom

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ABSTRACT

Cerebral palsy (CP) is a relatively rare condition with enormous social and financial impact. Information about CP is not routinely collected in the United Kingdom. We have pooled non-identifiable data from the five currently active UK CP registers to form the UKCP database: birth years 1960–1997. This article describes the rationale behind this collaboration and the creation of the database. Data about 6910 children with CP are currently held. The mean annual prevalence rate was 2.0 per 1000 live births for birth years 1986–1996. Where type is known, 91 per cent have spastic CP. Where data are available, nearly one-third of children have severely impaired lower limb function, and nearly a quarter have severely impaired upper limb function. As well as describing the range and complexity of motor and associated impairments, the pooled data from the UKCP database provide a platform for studies of aetiology, long-term outcomes, participation and service needs. The UKCP database is an important national resource for the surveillance of CP and the study of its epidemiology in the United Kingdom.

Keywords cerebral palsy, collaborative research, epidemiology, UKCP

Background

In the United Kingdom, as in other developed countries, there have been increasing rates of preterm births and increasing survival of these early births over recent decades.[1] Such preterm survivors, and especially those from multiple pregnancies, have a significantly greater risk of cerebral palsy (CP).[2]

Infants with CP have an impact on families and how they cope with what may be a considerable change in their lifestyle and financial circumstances, on services necessary to support the children and their families and on the National Health Service (NHS) through claims for compensation. The rate of such claims across the United Kingdom is variable, and the overall cost to the NHS is increasing.[3] Obstetrics accounts for some 60 per cent of the NHS litigation bill,[4] £446 million in the year 2001/2002.[5] Recent individual CP-related settlements have been as high as £6 million, and even unsuccessful claims can cost the NHS up to £0.5 million in legal costs. The majority of settlements relate to adverse events around birth and to children with CP.

With the increasing survival and a shift in emphasis from mortality to morbidity, concern has focused on the quality of life of children with CP. The need to participate in the activities of daily life for children with CP and their families is as important as for all families.[6] Increased dialogue between families and those involved in research will enhance knowledge in this area.

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The UK Collaborative Network of Cerebral Palsy Registers and Surveys (UKCP) was formed in 1999. This article describes the establishment, characteristics and potential of the UKCP database as a national information and research resource for CP. The data analysis presented is for the purpose of describing the data held by UKCP, rather than describing the epidemiology of CP that will be reported elsewhere.

The cerebral palsy registers, databases and surveys

The collaboration comprises five active CP registers, databases and surveys in the United Kingdom, which will all be referred to as registers. The registers cover the birth populations of Northern Ireland and Scotland and the three former English health regions of Mersey, Northern and Oxford, around 15 per cent of England and Wales (Fig. 1). Each register has ethics committee approval.

All registers use multiple sources of ascertainment including child health systems, assessment centres, other registers, paediatricians, physiotherapists, death registration and periodic requests for notification. Capture–recapture analysis has been used by one register to assess ascertainment.[7] Methods of monitoring data quality include validation carried out by Surveillance of Cerebral Palsy in Europe (SCPE)[8] and by UKCP, double data entry and resolution of differences, inbuilt computer algorithms to identify values outside the expected range and data checking for reports and research studies.

As the registers were set up at different times (Table 1), with some collecting data retrospectively and some collecting data about newly diagnosed children, there is a variability in the completeness of data over time. Records of children in all registers are 'flagged' for death notification with the National Health Service Central Records System (NHSCR), the Registrar General for Scotland or the Central Services Agency for Northern Ireland as appropriate.

Merseyside and Cheshire Cerebral Palsy Register

Merseyside and Cheshire Cerebral Palsy Register (MCCPR) has been largely concerned with monitoring trends in the birth prevalence of CP, life expectancy and cause of death and the aetiological implications of those trends, with particular interest in multiple births.[9,10] Births during 1966–1977 formed a retrospective cohort, and prospective data collection was from 1978. Having identified the cases, clinical information is then abstracted from obstetric and paediatric case notes. The original ethics approval specifically precluded any contact with parents, but clinicians' concerns about providing access to information without informed consent (following the Alder Hey enquiry[11]) led to reduced ascertainment and data collection ceasing in 2000. Consent-based data collection has restarted with Department of Health funding to 2008.

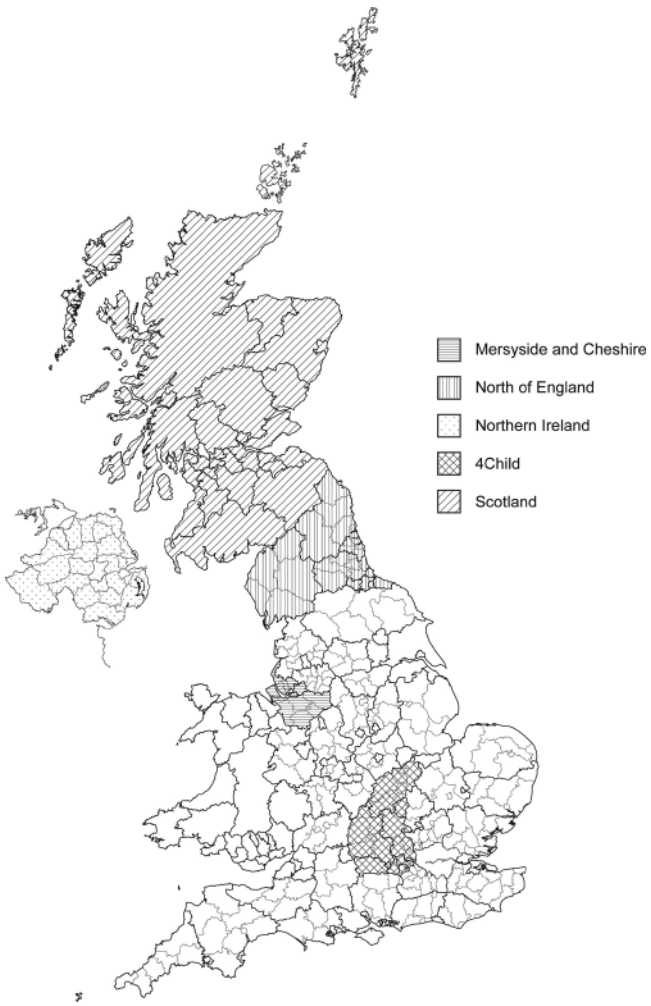

Fig. 1 Location and coverage of the five collaborative UKCP registers.

North of England Collaborative Cerebral Palsy Survey

North of England Collaborative Cerebral Palsy Survey (NECCPS) focused on the development of the assessment[6] of lifestyle and the quality of life. It has also studied differences over time in the pattern of severity and demonstrated how severity thresholds influence the completeness of ascertainment.[12] Retrospective searches were carried out in 1980, 1985 and 1995 for the survey of births between 1960 and 1990 for three districts. Consent was sought when children

Table 1 Characteristics of the UK collaborative cerebral palsy registers

Registers, databases and surveys	*Population size (million)*	*Number of live births per year**	*Birth years reported*	*Year register started*	*Number of children on the UKCP database*	*Geographical area*
1. Merseyside & Cheshire Cerebral Palsy Register	2.5	25–30 000	1966–1996[†]	1980	2384	Cheshire and Merseyside
2. North of England Collaborative Cerebral Palsy Survey	3.1	10 000	1960–1990	1979	1289	Newcastle, North Tynesi Northumberland—in 19 extended to all former Northern Health Region
		35 000	1991–1997			
3. Northern Ireland Cerebral Palsy Register	1.6	26 000	1981–1996	1991	1075	All Northern Ireland
4. *4Child*—Four Counties Database of Cerebral Palsy, Vision Loss and Hearing Loss in Children[‡]	2.6	35 000	1984–1997	1984	1348	Oxfordshire, Berkshire, Buckinghamshire, Northamptonshire (form Oxford Health Region)
5. Cerebral Palsy Register for Scotland[§]	5.1	60 000	1984–1990	1990	814	All Scotland
All registers	14.9	185 000			6910	

*These are approximate as birth rates decreased in the identified periods.

[†]Incomplete after 1990.

[‡]Formerly Oxford Register of Early Childhood Impairments: data about only those children with cerebral palsy are supplied to UKCP.

[§]Formerly Scottish Register of Children with a Motor Deficit of Central Origin.

were 4–5 years of age. From 1991, the survey was extended to the whole of the Northern Health Region, and data were collected prospectively from local convenors in each of the 16 former health districts. Data collection from 1991 births onwards has been continuous and consent obtained before notification to the survey.

Northern Ireland Cerebral Palsy Register

In 1991, the Northern Ireland Cerebral Palsy Register (NICPR)[13,14] retrospectively identified cases of CP in children up to 14 years of age and then in all newly diagnosed cases. Preliminary notifications are obtained by sending cards every month to clinicians and the gait laboratory, supplemented by regular surveys of paediatric physiotherapists, interrogation of the child health system, outpatient lists and death certificates, resulting in multiple notification for 73 per cent of cases. Follow-up clinical information is sought from the child's clinician; up to 1997, such information was available from 97 per cent of the cases.[14] When the register had required parental consent, this was gained in 60 per cent of the cases, although only 2 per cent of parents actually refused. In 1997, the advisory and ethics committee lifted the requirement for consent, allowing retrospective data completion, but the situation is again under review.

4Child—Four Counties Database of Cerebral Palsy, Vision Loss and Hearing Loss in Children

4Child—Four Counties Database of Cerebral Palsy, Vision Loss and Hearing Loss in Children [formerly the Oxford Register of Early Childhood Impairments (ORECI)]. This register began in 1984 following a pilot study in 1983.[15] *4Child* is unique in the United Kingdom in also collecting data about children with vision loss and hearing loss, irrespective of whether they have CP. Despite several NHS administrative boundary changes and now being covered by two Strategic Health Authorities, the *4Child* catchment area remains Oxfordshire, Berkshire, Buckinghamshire and Northamptonshire. Paediatricians are contacted for clinical information when children are aged 3 and 5 years. *4Child* is currently piloting a consent-based procedure. Information about *4Child* is made publicly available through annual reports and on the internet.[16]

Cerebral Palsy Register for Scotland

Cerebral Palsy Register for Scotland (CPRS) began as the Scottish Register of Children with a Motor Deficit of Central Origin. It was established by the Public Health Research Unit in Glasgow in 1990, retrospectively ascertaining cases from 1984.[17] Administration of the original register was transferred to the Information Statistics Division of NHS Scotland when

funding ceased. Data for birth years 1984–1990 are held currently by UKCP.

CPRS seeks to identify cases from 1990 births, and the register was re-launched with charity funding in 2002 as a joint venture between the NHS and Napier University, from where it is now administered. A designated paediatrician in each Health Board helps co-ordinate the local registration of cases. Parents can also register their child directly via the register's website.[18]

Parental consent is obtained, and parents of children on the former register are also contacted for permission to re-register the child. Consent includes entry into the register, obtaining clinical information from existing NHS systems and linking the child's data with data from the mother's pregnancy record. A particular strength of the Scottish register is the ability to link to routinely collected pregnancy data.

The UKCP database

The common UKCP database collates core data items from each of the five collaborating registers (Table 2). No personal identifiable information is included in the common database that is held at the National Perinatal Epidemiology Unit.

Classification and definitions

The classification of CP agreed by SCPE is used, and the SCPE core data items are included in the UKCP database in addition to items unique to UK registers. Categories of definition and severity of the impairments were agreed, and these are summarized in Table 3. Most registers do not have a stated upper age limit for postneonatal cases, but in practice this age is 5 years.

All children with CP from the individual registers are included in the UKCP database, including those with CP related to a defined event occurring after the first 28 days of life associated with subsequent clinical signs of CP (postneonatal or late impairment CP).

Preliminary analyses

Data, abstracted in July 2004 about all children and held on the UKCP database for birth years 1960–1997, are used here to illustrate the range of data available. Information about all live births for the appropriate geographical areas was available only for 1976–1996, and therefore, rates per 1000 live births are presented for only those years. Proportions are used where denominator data were not available.

Table 2 Core variables held on the UKCP common database

Demographics and background	*Clinical information*
Sex	Limb function
Year of birth	Which/number of limbs affected
Month of birth	Lower limb function
Birthweight	Severe impairment of lower limb function
Gestational age	Upper limb function
Residence in area at birth	Severe impairment of upper limb function
Number of babies at delivery	Type of cerebral palsy (CP) (Surveillance of Cerebral Palsy in Europe classification[17])
Order of birth	Type of spastic CP
Mother's age	Seizures
Subject alive or dead	Congenital malformation
Year of death	Postneonatal insult
Carstairs score	Age at postneonatal insult
	Vision
	Vision impairment
	Severe vision impairment
	Hearing
	Hearing impairment
	Severe hearing impairment
	Intellectual
	Intellectual impairment (IQ < 70)
	Severe intellectual impairment (IQ < 50)
	Intellectual level

Morris R, Carstairs V. Which deprivation? A comparison of selected deprivation indices. *J Public Health Med* 1991;**13:**318–26.

Table 3 Definitions of impairments used to describe children on the UKCP database

Impairment	*Definition*
Severely impaired lower limb function	Unable to walk even with aids, uses wheelchair or is bedridden
Severely impaired upper limb function	Unable to feed or dress self
Vision impairment	Any vision impairment
Severe vision impairment	Visual acuity of 6/60 or worse in the better eye/clinical assessment where testing not possible
Hearing impairment	Clinical assessment that impairment is present
Severe hearing impairment	Severe/profound impairment or >70 dB loss in the better ear/clinical assessment where testing not possible
Intellectual impairment	Moderate or worse developmental delay/learning difficulty likely to need special education/IQ < 70
Severe intellectual impairment	Severe/profound impairment, delay or learning difficulty/IQ < 50
Seizures	Presence of seizures, either current or in the past

Characteristics of the children

There are 6910 records of children born 1960–1997 inclusive. Some children with CP die before a diagnosis can be confirmed, and historically, registers have taken different decisions about whether to record these early deaths. For consistency, the data about children who died before their first birthday are excluded from this analysis, leaving 6855 records. There were 6257 (91 per cent) children born to mothers resident at the time of delivery in the areas covered by the registers. Area of residence is unknown for 33 children (0.5 per cent), and 565 children (8 per cent) were born to mothers resident outside the register areas. The latter two groups of children were included for the purposes of the general discussion but excluded where rates have been calculated. CP rates were generally lower in the 1990s following a peak in the 1980s (Fig. 2), although mean prevalence of CP was 2.0 per 1000 live births for birth years 1986–1996 compared with 1.9 per 1000 live births for 1976–1985. Data about intellectual impairment for Scotland and vision impairment before 1975 for North of England were not systematically collected, and these centres' data are excluded from the analyses of those items.

Postneonatal causes of cerebral palsy

Five hundred and thirty-seven children (8 per cent) are known to have had a postneonatal cause for their CP. The aetiology for these cases is different to those with pre- and perinatal causes, so although their data are included for the general discussion about CP and the range of impairments, their data are excluded from the analysis of rates.

Cerebral palsy subtypes

The number of children ascertained as having CP, of any type, by each register is listed in Table 1. The type of CP is dominated by spastic CP, with bilateral and unilateral spastic CP making up 91 per cent of cases on the database (Table 4). Rates per 1000 live births, between 1976 and 1996, for each of the registers, range from 0.8 to 2.0 for spastic CP and from 0.1 to 0.3 for non-spastic CP.

Impairments

The children have a wide range of impairments and varying severity of impairments. Registers' different methods of data collection mean that some items of data are incomplete in the earlier years, for example, intellectual impairment and the presence of seizures. Where information was available, almost one-third of children had severely impaired lower limb function and nearly a quarter had severely impaired upper limb function (Table 4).

Migration

Some children will be lost to follow-up when they move out before diagnosis. UKCP does not currently hold information to analyse the proportions.

Deaths

The proportion of deaths recorded ranged from 7 to 14 per cent, although it should be noted that some registers hold data from as early as the 1960s. Over the whole database, 739 children (11 per cent) are known to have died by July 2004. Twenty-seven per cent (184/684) of deaths occurred between the ages of 1 and 4 years. Long-term survival has been extensively analysed and reported elsewhere.[19]

Discussion

Information about CP is not routinely collected in the United Kingdom. Child Health Information Systems were expected

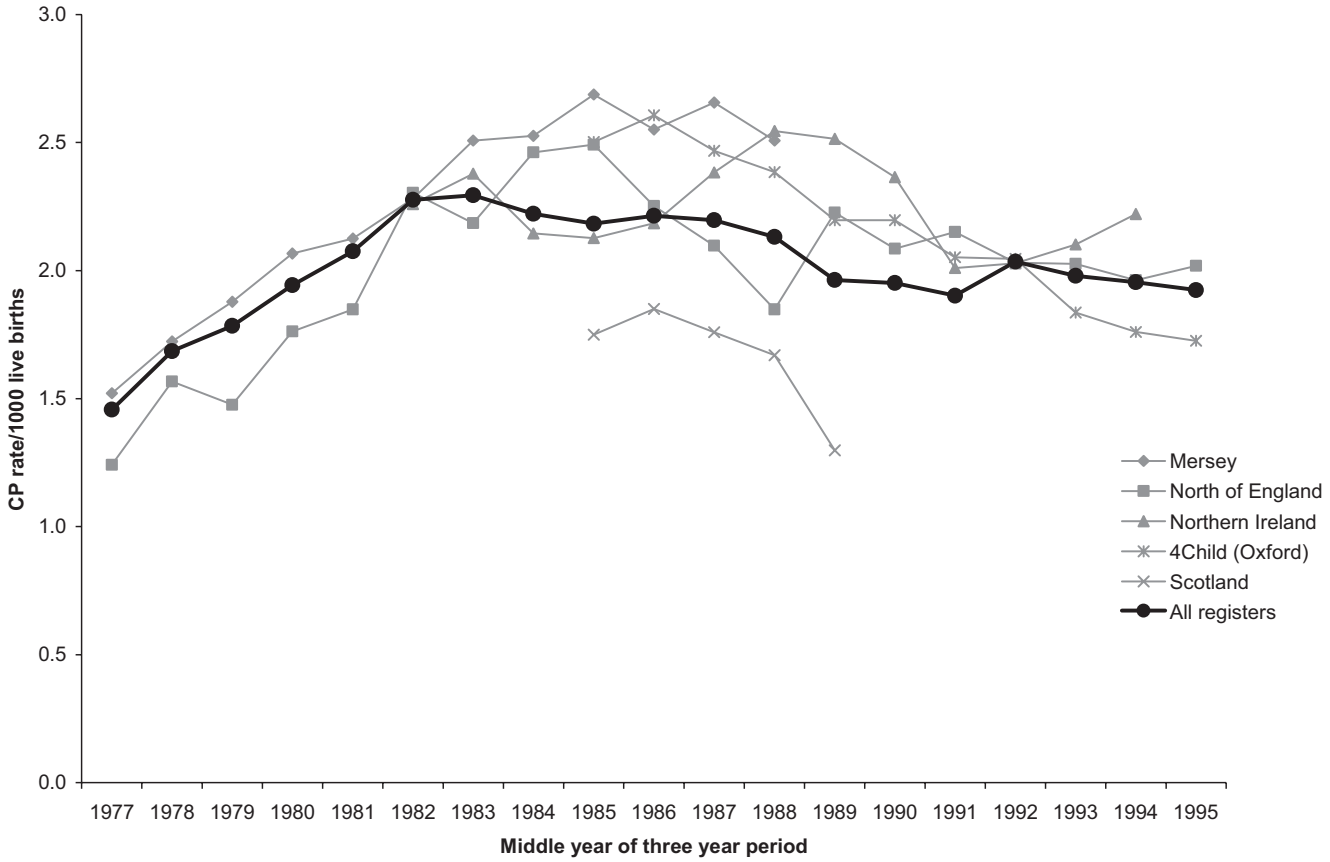

Fig. 2 Rate of cerebral palsy (CP) (3-year moving average) per 1000 live births for each register and for the UKCP combined database, excluding postneonatal CP and children born to mothers residing outside the catchment areas. Birth years of data: (i) Mersey, 1976–1990; (ii) North of England, 1976–1996; (iii) Northern Ireland, 1981–1996; (iv) Oxford (*4Child*), 1984–1996; and (v) Scotland, 1984–1990.

to deliver this important service, but despite many years of discussion,[20] little has yet been done to implement improvements to the range and quality of the data collected. For example, 52 per cent of children on the Northern Ireland CP register were not recorded as having CP on the Child Health System of the Health Board in Northern Ireland.[21] A further study,[22] showing failures of local systems, strengthened the case for specialized registers. The new NHS National Programme for Information Technology seems to promise only integration of existing systems but not improvement.[23]

The CP rate reported here of around two per 1000 live births in the United Kingdom is in agreement with earlier analyses,[24] and although CP is the commonest cause of serious motor impairment in young children, the number of children affected is not large. Although rates in particular subgroups, such as low birthweight, may be much higher, absolute numbers remain small, limiting investigation into the causes. To improve the reliability of estimated CP prevalence, rates need to be calculated from large numbers of births. Each of the registers is based in a different geographical area, and so caution is needed in interpreting the pooled data. Differing time periods, encompassing changing technologies and patterns of care, are also covered by the different registers. Pooling data can enable both differences and similarities to be investigated,[25] and currently, the only means of describing the UK picture is to refer to this pooled database.

The variable nature of CP and associated impairments means that where only small numbers of cases exist, it is difficult to adequately describe the different patterns of impairments, either in their range or in their severity. Despite decades of CP research, debate about how best to describe the severity of disability continues. Subjective terms such as mild, moderate and severe or profound are in common usage in publications of the last 20 years but rarely clearly defined. Working closely together enables researchers in different centres to arrive at a common language to describe children with CP and to compare their lives with those without CP. Other disease registers have found such collaboration to be of great benefit, for example, the United Kingdom Association of Cancer Registries (UKACR)[26] and

Table 4 Cerebral palsy (CP) subtype, indicators of severity and associated impairments

All CP cases >1 year, n = *6855*	*Total with available data*	*With this impairment*	
		Number	*% Range**
CP subtype	6595		
Spastic bilateral		3666	54–56
Spastic unilateral		2296	33–35
Spastic, laterality not known		28	0.4–0.4
Dyskinetic		362	5.3–5.5
Ataxic		243	3.5–3.7
Motor impairment			
Severely impaired lower limb function	6304	1968	29–31
Severely impaired upper limb function	6178	1448	21–23
Associated sensory impairment			
Vision impairment[†]	5748	2317	34–40
Severe vision impairment	5445	594	9–11
Hearing impairment	6026	476	7–8
Severe hearing impairment	6216	149	2.2–2.4
Associated intellectual impairment			
Intellectual impairment[‡]	5229	2663	39–51
Severe intellectual impairment	5229	1612	24–31
Other associated impairments			
Seizures	3620	1201	18–33
Congenital malformations	2757	495	7–18

Includes data from all UKCP registers, all years (as detailed in Table 1) and postneonatal CP.

*The range of proportions are shown where there are missing data, for example, for severely impaired lower limb function, 1968/6855 = 29%, 1968/6304 = 31%.

[†]Cases from the North of England before 1975 were excluded because information about vision impairment was not regularly collected up to that time.

[‡]Cases from Scotland for all years were excluded because information about intellectual impairment was not systematically collected.

the British Isles Network of Congenital Anomaly Registers (BINOCAR).[27]

At the time that the collaboration began, the environment in which disease registers operate was changing. The Data Protection Act, 1998, requires that database custodians in the United Kingdom must do whatever is reasonable to ensure that subjects are aware of the likelihood of inclusion of their personal data on that database.[28] The requirement that no personal information could be released by clinicians to registers without the specific consent of the data subject prompted cancer registry custodians to suggest that data collection would become unworkable.[29] An additional clause, Section 60, was added to the Health & Social Care Act, 2001,[30] to help address this concern and led to the setting up of the Patient Information Advisory Group (PIAG).[31] All studies, research projects and registers intending to use personal identifiable information without specific consent were required to apply to PIAG for 'Section 60 support' which would allow them to carry on their work without either specific informed consent or anonymization of data for a transitional period. CP registers cannot anonymize their data, because they need to check for duplicate notifications and to follow children's development over a period of years. Register staff are unable to obtain consent directly because they do not have a direct clinical relationship with children and their families, so consent must be sought by children's clinicians. Although few parents refuse consent when approached,[13,32] difficulties arise in the process. There may be uncertainty about who should ask for consent, consent may be sought repeatedly, or where a child is seen by several clinicians, the assumption may be made that consent will have been sought earlier. The situation for UKCP registers is complicated further as the Health & Social Care Act applies to only England and Wales, and this aspect of governance is still uncertain for Scotland and Northern Ireland.

Many registers are moving towards a fully consent-based system of ascertainment, although Newton asserts that it is sometimes impractical, or even impossible, for a disease

register to gain consent from all subjects, and the resultant bias could invalidate epidemiological research.[33] Interchange of ideas through the collaboration should lead to effective ways of communicating to families the need for research into CP whilst minimizing the additional work-load on clinicians.

Funding has always been a challenge for disease registers. Whilst registers in Merseyside and Scotland continued passive accrual of new cases, ascertainment in the 1990s declined substantially because of underfunding. Long-term planning is essential for CP registers, as trends in CP rates can only be discerned when sufficient time has elapsed to allow a firm diagnosis to be made, typically around the age of 4 or 5 years. The quality of a disease register, its research output and the data collected are functions of continuity.[28] Continuity of funding is among the key characteristics required to run a successful register. Following the Newton and Garner report,[27] two of the three English CP registers received support from Department of Health funding aimed specifically at research-active disease registers. Disease research registers in England alone were estimated to number nearer to 400 than the 250 identified, and competition for funding was fierce. The UKCP collaboration receives no direct funding.

Initial UKCP collaborative work has successfully exploited facilities not available in many other areas of the world. Linkage to death notification has enabled the generation of survival data and the investigation of the relationship of survival to severity of disability.[19] Linkage to census-generated area deprivation data using postcode is currently underway and will examine the relationship between CP and socio-economic factors. Future work is being planned to investigate trends in the type of CP, the effect of CP on the participation of adolescents and the frequency and diversity of multiple impairment.

Over the past 20 years, population-based CP registers in the United Kingdom have played a key role in monitoring rates of CP over time. They have provided a framework for epidemiological and clinical research and have been a source of information to guide the planning of services for children and adults with CP.[23,24] Closer collaboration should bring benefits from the pooling of expertise, a larger database enabling research not possible with smaller databases and a supportive network of colleagues familiar with similar issues. The UKCP database is an important developing national resource for surveillance and research into the rates, causes and consequences of CP.

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