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Hospital based-surveillance of cerebral palsy (CP) in Hanoi using the Paediatric Active Enhanced Disease Surveillance Mechanism (PAEDS-Vietnam): a study towards developing national hospital based disease surveillance in Vietnam

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Abstract for protocol (299 words)

Introduction: The epidemiology, pathogenesis, management and outcomes of cerebral palsy (CP) in low- and middle-income countries (LMIC) including Vietnam are unknown because of the lack of mechanisms for standardised collection of data. In this paper, we outline the protocol for developing a hospital-based surveillance system modelled on the Paediatric Active Enhanced Disease Surveillance system in Australia (PAEDS). Using PAEDS-Vietnam we will define the aetiology, motor function and its severity, associated impairments, nutritional, and rehabilitation status of children with CP in Hanoi, Vietnam. These essential baseline data will inform future health service planning, health professional education and training and family support.

Methods and Analysis: This is a hospital-based prospective surveillance of children with CP presenting to the rehabilitation, neurology and general paediatric services at the National Children's Hospital and St Paul's Hospital in Hanoi. We will use active, prospective daily case-finding for all children with CP aged <18 years who are hospitalised or present to outpatients departments. Following parental consent, data will be collected using a modified version of the Australian Cerebral Palsy Register questionnaire. The data collection form has been developed in consultation with local and international experts and translated into Vietnamese. Information collected will include demographics, maternal health and birth history, type and severity of CP, known risk factors for CP and nutrition, immunisation, education and rehabilitation status.

Ethics and Dissemination: This study was approved by the Hanoi Medical University Institutional Review Board (HMU IRB decision no. 1722) and the University of Sydney Human Research Ethics Committee (approval no. 2016/456). Establishment of PAEDS-Vietnam will enable hospital-based surveillance of CP for the first time in Vietnam. The data collected will enable estimates of the burden of CP in these Hanoi hospitals. It will identify preventable causes of CP, patient needs and service gaps and facilitate early diagnosis and intervention.

Keywords: Cerebral palsy, Childhood disability, Surveillance, Hanoi, Vietnam

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INTRODUCTION

Cerebral Palsy (CP) is the major global cause of childhood disability. Based on data from high income countries it affects up to 17 million people with a prevalence of approximately 2 per 1,000 live births.[1] The prevalence of CP in LMIC is believed to be four to six times higher however few reliable data are available.[2] In Vietnam there estimated to be 500,000 people living with CP, where CP comprises 30-40% of all childhood disability. [3,4]

The prevalence of CP likely varies between provinces in Vietnam. For example, CP prevalence was 0.6 per 1,000 in the general population in Khanh Hoa and 1.5 per 1,000 in the general population in Hatay.[5] These data are limited by methodological quality, including small sample sizes, and likely underestimate CP prevalence. In one treatment centre in Vietnam an increase in the number of cases with CP has been documented over time. In 1998 at that centre 394 (25.7%) of all children admitted had CP. This increased by more than three times to 912 (47.3%) of all admissions in 2002.[5] In Vietnam, the proportion of children with CP who receive rehabilitation services is estimated at between 30% and 74%, however this cannot be accurately determined without good epidemiological data.[5]

The Vietnamese Ministry of Health has recently recognised service delivery for CP as a public health priority.[3] Furthermore, a recent health reform in Vietnam has established universal health coverage which will provide free-of-charge treatment for children with CP who are aged 6 years or less. Children over 6 years of age who attend school are only covered by voluntary health insurance, requiring guardians to purchase treatment based on their ability to pay.[6] There are no Vietnamese data indicating the age of diagnosis of CP nor the proportion of children who attend mainstream school. In a recent study from Bangladesh found that the mean age of diagnosis of CP is 4.9 years and only 16% of children with CP attend mainstream school, the remainder having no access to education (preliminary results from the Bangladesh CP Register study).[7]

Treatment of CP in Vietnam is commonly reported to be a combination of traditional and modern medicine. Traditional medicine includes massage, reflexology, use of electrical or water magnets and stimulated ventilation with an electric current.4 Alternatively, a holistic treatment approach provided following establishment of a centre for social assistance for disadvantaged children was effective in improving quality of movement through physiotherapy in 92% of children and providing special/inclusive education.[8]

In Vietnam there is an urgent need to understand the burden of CP, patient needs and service gaps, however there is no disease surveillance, there are no universally accepted treatment guidelines, and there is no information on the uptake of evidence-based diagnostics, treatments and policy planning. The lack of rigorous epidemiological data limits capacity to plan for future disability services.

We aim to develop a hospital-based surveillance system modelled on the Paediatric Active Enhanced Disease Surveillance system operating in Australia (PAEDS). Using PAEDS-Vietnam we will define the aetiology, motor function, severity, associated impairments, and nutritional and rehabilitation status of children with CP in Hanoi, Vietnam. Collection of these essential baseline data will inform future health service planning, and need for health professional training and family support. Our experience will enable us to extend the surveillance to national level.

METHODS AND ANALYSIS

Aims and Objectives

The overall aim of this study is to i) implement a hospital-based surveillance system to identify children presenting with CP in Hanoi that is modelled on PAEDS; ii) collect baseline information on the known risk factors, clinical presentation (motor function/severity, associated impairments, nutritional and rehabilitation status), service use and needs of children with CP in Hanoi, Vietnam; and iii) assess the feasibility of a national hospital based paediatric disease surveillance mechanism for Vietnam.

Our specific objectives are to identify and characterise children with CP presenting to the National Children's Hospital (NCH) and St Paul's Hospitals in Hanoi, Vietnam in order to:

1. Estimate the burden of CP in the two hospitals

2. Define the aetiology of CP

3.Document the motor impairment and severity of CP using the Gross Motor Function Classification System (GMFC) and the Manual Ability Classification System (MACS)

4. Describe associated impairments in children with CP

5. Assess the nutritional status of children with CP

6. Assess the rehabilitation status of children with CP

7. Evaluate the strengths and limitations of a hospital based disease surveillance mechanism

Overview of study design

This is a hospital based, prospective cohort study among children with CP who attend the Rehabilitation, Neurology, and General Paediatric services (inpatient and outpatient) at the NCH and St Paul's Hospital in Hanoi, Vietnam.

Description of the participating hospitals

NCH is a 1,200 bed tertiary paediatric hospital that provides services for nearly 40,000 in-patients and 350,000 out-patients each year from northern Vietnam. St Paul's Hospital is a general medical facility with 150 paediatric beds. Both hospitals are located in central part of Hanoi - the capital of Vietnam.

Surveillance method/activities

We will establish a method for active, hospital-based surveillance to identify children with CP attending the two hospitals (i.e. PAEDS-Vietnam). This system will be based on the highly successful, government funded Paediatric Active Enhanced Disease Surveillance (PAEDS) System in Australian, established by the Australian Paediatric Surveillance Unit (APSU) in collaboration with the National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases (NCIRS) in 2007.[9] PAEDS is currently active in five Australian States and collects data on six conditions (i.e. acute flaccid paralysis, intussusception, varicella and herpes zoster, pertussis, febrile seizures and acute childhood encephalitis). Clinicians are appointed specifically to identify new admissions or presentations with the condition of interest on a daily basis. This is achieved by daily contact with key collaborators (e.g. directors of the rehabilitation ward) and review of hospital intake data (e.g. ward admissions). This process allows for the timely collection of clinical and laboratory data on hospitalised children and has proven invaluable for monitoring selected conditions of national interest (e.g. varicella requiring hospitalisation)[10] and responding to epidemiological emergencies (e.g. the 2009 influenza pandemic).[11,12]

Study participants

All children aged less than 18 years with CP attending as an inpatient or outpatient to one of the participating hospitals during the study period.

Case definition

We have adopted the approach used by Surveillance of Cerebral Palsy in Europe (SCPE) and the Australian Cerebral Palsy Register (ACPR) [13,14] which allows use of any definition that includes the following five key elements.[15,16,17]

Cerebral palsy:

(1) is an umbrella term for a group of disorders

(2) is a condition that is permanent but not unchanging

(3) involves a disorder of movement and/or posture and of motor function

(4) is due to a non-progressive interference, lesion, or abnormality, and

(5) the interference, lesion, or abnormality originates in the immature brain.

Inclusion/exclusion criteria

A 'case' must fulfil the criteria contained in the five definitional elements above. In children aged <5 years with a diagnosis of 'CP, the diagnosis must be confirmed when the child reaches 5 years of age. If new information becomes available for a child participating in the study their entry may be updated, which may involve inclusion or exclusion.[14]

Consent

Informed consent for inclusion in the study will be obtained from the parent/guardian of children with CP following a clear explanation of the study.

Case ascertainment

Before commencing surveillance we will provide, and train clinicians to use, internationally recognised diagnostic guidelines. Clinicians at each site will identify eligible children on a daily basis (active case ascertainment). Clinical data relevant to the study protocol will be recorded on a data collection form. We will train medical officers (paediatric doctors or

trainees) to identify and characterise cases in each surveillance hospital for the duration of the study. The medical officers will be responsible for recruiting participants from different hospital departments (e.g. rehabilitation, general paediatrics and outpatient clinics) and will be supervised by the collaborating lead investigators from the surveillance hospitals, who will verify the type and severity of CP recorded. Data quality and completeness will be checked regularly by the investigators and senior clinicians at both hospitals. Table 1 shows the components of the proposed surveillance mechanism to be used by in PAEDS-Vietnam.

Data collection, quality assurance and analysis plan

Standard data collection forms has been developed in consultation with international experts, translated into Vietnamese, and modified following review by Vietnamese investigators to ensure they are appropriate for the local setting. Data will be collected on demographics and primary health indicators, birth details of the child with CP and maternal pregnancy details, neurological and motor classifications of CP (i.e. GMFCS), associated impairments, timing of CP, immunisation, nutrition, education and rehabilitation status. Once the record form has been completed and checked by a research physician, data will be entered into the PAEDS-Vietnam electronic data repository. Cases will be de-identified and only the study investigators and nominated delegates will have access to identifiable data. The PAEDS-Vietnam secretariat and data coordinating centre will be located at the Hanoi Medical University, Hanoi, Vietnam. Internal checks for data quality and data entry errors will be performed routinely in the data coordinating centre. The completeness of ascertainment will be checked by audit of hospital records and using capture recapture methods. De-identified data will be shared regularly with the Sydney investigators using a secure portal.

Descriptive epidemiological measures, such as rate of hospital presentations and prevalence of CP will be estimated from the surveillance data. We will use the most recent national census and demographic and health survey data to calculate the denominator population and enable comparisons. Frequencies of different types of CP will be presented in percentage with 95% confidence interval (95% CI).

Confidentiality and Privacy

Coded, non-identifiable data will be stored on the PAEDS-Vietnam electronic database. The dataset will be accessible by the administrator only, with computers protected by a secure password log-on instigated after five minutes of computer inactivity. No data will be stored

on any researcher's personal or hospital computer. Only group data will be presented in reports or publications and no identifiable information will be made available or apparent through provision of specific personal or health characteristics. A non-identifiable dataset will be shared with the lead investigators in Australia for data quality assessment and advanced statistical analysis.

ETHICS AND DISSEMINATION

Ethics approval

This study was approved by the Hanoi Medical University Institutional Review Board (HMU IRB decision no. 1722) and the University of Sydney Human Research Ethics Committee (approval no. 2016/456).

Dissemination

This study will have a number of immediate social and public health benefits: 1) By identifying children with CP from participating hospitals we will increase clinician knowledge and skills and facilitate early diagnosis and intervention; 2) This prospective surveillance will provide unique baseline data on the estimated prevalence and profile of children with CP and, the aetiology and risk factors for CP in Hanoi, Vietnam; 3) This cohort could be used as a sampling frame for future research e.g. to intervention trials to evaluate cost-effective treatment strategies to promote functional abilities and limiting secondary impairments in children with CP; and 4) PAEDS-Vietnam will establish the feasibility and utility of a hospital-based, prospective, active disease surveillance mechanism in Vietnam including its strengths and limitations. Once established, this surveillance could be adapted to monitor any disease of public health importance and extended to have a nation reach.

List of abbreviations

ACPR: Australian Cerebral Palsy Register, APSU: Australian Paediatric Surveillance Unit, BCPR: Bangladesh Cerebral Palsy Register; CP: Cerebral Palsy, HREC: Human Research Ethics Committee, LMIC: Low and Middle Income Countries, NCIRS: National Centre for Immunisation Research and Surveillance, PAEDS: Paediatric Active Enhanced Disease Surveillance, SCPE: Surveillance of Cerebral Palsy in Europe

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

EE together with GK and NVB conceptualized, designed and established this research study. EE, GK, NVB also contributed to study design and were responsible for the development of the study materials. NVB developed the Vietnamese version of the data collection sheet. EE, GK and NVB were responsible for ethics applications and reporting. NVB, TQD, NTHG, CMC, NTVA, NVY will be responsible for recruitment, data collection and overall conduct of the study in Vietnam. EE, GK, NB, NVB and CMC will be providing specialist advice in this study. EE and GK drafted the manuscript with input from all the co-authors. All authors have agreed the final version of the manuscript and were involved in the decision to submit the manuscript.

All authors read and approved the final manuscript.

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Table 1: Components of PAEDS-Vietnam surveillance methods

Surveillance hospitals	NCH and St Pauls Hospitals
Surveillance Departments	Rehabilitation, Neurology, General Pediatric outpatient
Case ascertainment	Daily review of both inpatient and outpatients list
Consent and recruitment	Participating study physicians Defined inclusion/exclusion criteria's
Data quality monitoring	Named investigators at the participating institutes/departments
Data entry	Research officers/investigators entering data to Electronic data repository
Ongoing monitoring	Monthly study implementation meeting- all investigators

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INTRODUCTION

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Reported treatment of CP in Vietnam is commonly a combination of traditional and modern medicine. Traditional medicine includes massage, reflexology, use of electrical stimulation or water magnets and stimulated ventilation with an electric current.[5] An holistic treatment approach, provided following establishment of a centre for social assistance for

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METHODS AND ANALYSIS

Aims and Objectives

The overall aim of this study is to i) implement a hospital-based surveillance system to identify children presenting with CP in Hanoi that is modelled on PAEDS; ii) collect baseline information on the known risk factors, clinical presentation (motor function/severity, associated impairments, nutritional and rehabilitation status), service use and needs of children with CP in Hanoi, Vietnam; and iii) assess the feasibility of a national hospital based paediatric disease surveillance mechanism for Vietnam.

Our specific objectives are to identify and characterise children with CP presenting to the National Children's Hospital (NCH) and St Paul's Hospitals in Hanoi, Vietnam in order to:

1. Document the burden of CP in these two hospitals and estimate the prevalence of CP in Hanoi province

2. Define the aetiology of CP

3.Document the motor impairment and severity of CP using the Gross Motor Function Classification System (GMFC) and the Manual Ability Classification System (MACS)

4. Describe associated impairments in children with CP

5. Assess the nutritional status of children with CP

6. Assess the rehabilitation status of children with CP

7. Evaluate the strengths and limitations of a hospital based disease surveillance mechanism

Overview of study design

This is a hospital based surveillance study to identify a prospective cohort of children with CP who attend the Rehabilitation, Neurology, and General Paediatric services (inpatient and outpatient) at the NCH and St Paul's Hospital in Hanoi, Vietnam.

Description of the participating hospitals

NCH is a 1,200 bed tertiary paediatric hospital that provides services for nearly 40,000 in-patients and 350,000 out-patients each year from northern Vietnam. St Paul's Hospital is a general medical facility with 150 paediatric beds. Both hospitals are located in central Hanoi, the capital of Vietnam.

Surveillance method/activities

We will establish a method for active, hospital-based surveillance to identify children with CP attending the two hospitals (i.e. PAEDS-Vietnam). This system will be based on the highly successful, government funded Paediatric Active Enhanced Disease Surveillance (PAEDS) System in Australian, established by the Australian Paediatric Surveillance Unit (APSU) in collaboration with the National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases (NCIRS) in 2007.[10] PAEDS is currently active in five Australian States and collects data on six conditions (i.e. acute flaccid paralysis, intussusception, varicella and herpes zoster, pertussis, febrile seizures and acute childhood encephalitis). Clinicians are appointed specifically to identify new admissions or presentations with the condition of interest on a daily basis. This is achieved by daily contact with key collaborators (e.g. directors of the rehabilitation ward) and review of hospital intake data (e.g. ward admissions). This process allows for the timely collection of clinical and laboratory data on hospitalised children and has proven invaluable for monitoring selected

conditions of national interest (e.g. varicella requiring hospitalisation)[11] and responding to epidemiological emergencies (e.g. the 2009 influenza pandemic).[12,13]

Study participants

All children aged less than 18 years with CP attending as an inpatient or outpatient to one of the participating hospitals during the study period.

Case definition

We have adopted the approach used by Surveillance of Cerebral Palsy in Europe (SCPE) and the Australian Cerebral Palsy Register (ACPR) [14,15] which allows use of any definition that includes the following five key elements.[16,17,18]

Cerebral palsy:

(1) is an umbrella term for a group of disorders

(2) is a condition that is permanent but not unchanging

(3) involves a disorder of movement and/or posture and of motor function

(4) is due to a non-progressive interference, lesion, or abnormality, and

(5) the interference, lesion, or abnormality originates in the immature brain.

Inclusion/exclusion criteria

A 'case' must fulfil the criteria contained in the five definitional elements above. In children aged <5 years when a diagnosis of 'CP' is made, the diagnosis must be confirmed when the child reaches 5 years of age. Most children will be followed clinically in the hospital setting until therapy is established. Only those children aged less than 5 years will be specifically followed up by the investigator team to confirm the diagnosis once they are over age 5. If new information becomes available for a child participating in the study their entry may be updated, which may involve inclusion or exclusion.[15]

Children with intellectual disability of a known cause, neuromuscular disorders, genetic disorders (e.g. trisomy 21, tuberous sclerosis), a known epilepsy syndrome, progressive neurodegenerative disorders, brain malignancy or traumatic brain injuries will be excluded from this study.

Consent

Written consent for study participation will be obtained by Vietnamese Surveillance Medical Officers (i.e. third party) using participation information and consent forms written in Vietnamese. The treating physician will then complete the data collection form. The Surveillance Medical Officers will not have any role in patients clinical care, thus coercion is unlikely and participation will not influence clinical care.

Children with cerebral palsy aged less than 18 years will be recruited in this study and parental consent alone will be sought for two reasons;

a. Children with cerebral palsy often have intellectual/cognitive impairment and their ability to give informed consent is variable and uncertain.

b. Children aged less than 18 years are considered minors in Vietnam, requiring their parents/primary care givers to take full responsibility/authority for any decisions related to their medical care and participation in research.

However, children aged over 14 years and with an appropriate comprehension level will be assed for assent. To consider a child for assent the study investigators will take into account the child's age, maturity, and psychological state to determine whether the child is capable of giving a meaningful assent.

Case ascertainment

Before commencing surveillance we will provide, and train local clinicians to use, internationally recognised diagnostic guidelines to make the diagnosis of CP.[19] Clinicians at each site will identify eligible children on a daily basis (active case ascertainment). Clinical data relevant to the study protocol will be recorded on a data collection form. We will train medical officers (paediatric doctors or trainees) to identify and characterise cases in each surveillance hospital for the duration of the study. Local study physicians (e.g. general paediatricians, rehabilitation paediatricians, paediatric neurologists) will make the diagnosis of CP or confirm the diagnosis on referred cases. They will be trained in recently published CP diagnostic algorithm.[19]

The medical officers will be responsible for recruiting participants from different hospital departments (e.g. rehabilitation, neurology, general paediatrics and outpatient clinics) and will be supervised by the collaborating lead investigators from the surveillance hospitals, who

will verify the type and severity of CP recorded. Clinical data on all cases identified will be reviewed by the investigator group for potential misdiagnosis. In contentious cases the opinion of a paediatric neurologist will be sought. Data quality and completeness will be checked regularly by the investigators and senior clinicians at both hospitals. Table 1 shows the components of the proposed surveillance mechanism to be used by in PAEDS-Vietnam.

Data collection and quality assurance

Standard data collection forms has been developed (Appendix A) in consultation with international experts, translated into Vietnamese, and modified following review by Vietnamese investigators to ensure they are appropriate for the local setting. Data will be collected on demographics and primary health indicators, birth details of the child with CP and maternal pregnancy details, neurological and motor classifications of CP (i.e. GMFCS), associated impairments, timing of CP, immunisation, nutrition, education and rehabilitation status. Once the record form has been completed and checked by a research physician, data will be entered into the PAEDS-Vietnam electronic data repository. Cases will be de-identified and only the study investigators and nominated delegates will have access to identifiable data. The PAEDS-Vietnam secretariat and data coordinating centre will be located at the Hanoi Medical University, Hanoi, Vietnam. Internal checks for data quality and data entry errors will be performed routinely in the data coordinating centre. The completeness of ascertainment will be checked by audit of hospital records and using capture recapture methods. De-identified data will be shared regularly with the Sydney investigators using a secure portal.

Statistical methods

Descriptive epidemiological measures, such as rate of hospital presentations and prevalence of CP will be estimated from the surveillance data. Frequencies of different types of CP will be presented as a percentage with 95% confidence interval (95% CI). An estimate of prevalence of CP in Hanoi province will be calculated per 1000 child population with 95% CI. We will estimate the prevalence based on the hospital catchment population and proportion of children with CP attending those hospital for services. This method has previously been used successfully by our group to estimate the incidence of congenital rubella syndrome in Hanoi province.[20] We will document the children's address (e.g. district, province) to enable identification and of children coming from outside the Hanoi region and their exclusion from estimates of prevalence.

We will perform one-sample binomial tests (including t-tests) to compare proportions for demographic variables in children with CP and the most recent national census and demographic and health survey data to calculate the denominator population and enable comparisons. The Statistical Package for Social Sciences (IBM SPSS® 23, Chicago, IL, USA) will be used for data handling and analysis.

Confidentiality and Privacy

Coded, non-identifiable data will be stored on the PAEDS-Vietnam electronic database. The dataset will be accessible by the administrator only, with computers protected by a secure password log-on instigated after five minutes of computer inactivity. No data will be stored on any researcher's personal or hospital computer. Only group data will be presented in reports or publications and no identifiable information will be made available or apparent through provision of specific personal or health characteristics. A non-identifiable dataset will be shared with the lead investigators in Australia for data quality assessment and advanced statistical analysis.

ETHICS AND DISSEMINATION

Ethics approval

This study was approved by the Hanoi Medical University Institutional Review Board (HMU IRB decision no. 1722) and the University of Sydney Human Research Ethics Committee (approval no. 2016/456).

Study duration

The pilot phase of the study will be for six months. During this period we will train the study investigators and participating physicians and develop the study implementation tools. Moreover, during the pilot phase we will gain a better understanding of the case load (i.e. number of children with CP seeking medical care at participating hospitals). After the pilot phase we will conduct an interim evaluation of the surveillance mechanism. Once the pilot phase is successfully implemented surveillance will be continued for another 18 months. The PAEDS-Vietnam mechanism will remain in place for potential use in other conditions.

Study limitations

Hospital based surveillance of children with CP will likely overestimate children with severe CP or with co-morbidities such as epilepsy as these children more often require hospitalization. Moreover, we would not be able to precisely estimate the prevalence of CP as it is unlikely that all the children with CP will seek medical care in the participating hospitals.

Dissemination

This study will have a number of immediate social and public health benefits: 1) By identifying children with CP from participating hospitals we will increase clinician knowledge and skills and facilitate early diagnosis and intervention; 2) This prospective surveillance will provide unique baseline data on the estimated prevalence and profile of children with CP and, the aetiology and risk factors for CP in Hanoi, Vietnam; 3) This cohort could be used as a sampling frame for future research e.g. to intervention trials to evaluate cost-effective treatment strategies to promote functional abilities and limiting secondary impairments in children with CP; and 4) PAEDS-Vietnam will establish the feasibility and utility of a hospital-based, prospective, active disease surveillance mechanism in Vietnam including its strengths and limitations. Once established, this surveillance could be adapted to monitor any disease of public health importance and extended to have a nation reach.

List of abbreviations

ACPR: Australian Cerebral Palsy Register, APSU: Australian Paediatric Surveillance Unit, BCPR: Bangladesh Cerebral Palsy Register; CP: Cerebral Palsy, HREC: Human Research Ethics Committee, LMIC: Low and Middle Income Countries, NCIRS: National Centre for Immunisation Research and Surveillance, PAEDS: Paediatric Active Enhanced Disease Surveillance, SCPE: Surveillance of Cerebral Palsy in Europe

Competing interests

The authors declare that they have no competing interests.

Authors' contributions

EE together with GK and NVB conceptualized, designed and established this research study. EE, GK, NVB also contributed to study design and were responsible for the development of

the study materials. NVB developed the Vietnamese version of the data collection sheet. EE, GK and NVB were responsible for ethics applications and reporting. NVB, TQD, NTHG, CMC, NTVA, NVY will be responsible for recruitment, data collection and overall conduct of the study in Vietnam. EE, GK, NB, NVB and CMC will be providing specialist advice in this study. EE and GK drafted the manuscript with input from all the co-authors. All authors have agreed the final version of the manuscript and were involved in the decision to submit the manuscript.

All authors read and approved the final manuscript.

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Table 1: Components of PAEDS-Vietnam surveillance methods

Surveillance hospitals	NCH and St Pauls Hospitals
Surveillance Departments	Rehabilitation, Neurology, General Pediatric outpatient
Case ascertainment	Daily review of both inpatient and outpatients list
Consent and recruitment	Participating study physicians Defined inclusion/exclusion criteria's
Data quality monitoring	Named investigators at the participating institutes/departments
Data entry	Research officers/investigators entering data to Electronic data repository
Ongoing monitoring	Monthly study implementation meeting- all investigators

HOSPITAL BASED SURVEILLANCE OF CP IN HANOI, Vietnam

FOR PERSON WITH CEREBRAL PALSY (CP)

Page 1

Contact details (person with CP)

First name Middle Name Surname

Gender: ☐ Male ☐ Female DOB (DD/MM/YYYY) __ __ /__ __ /__ __ __ __

Ethnic Group: ☐ Vietnamese ☐ Tay ☐ Thai ☐ Chinese ☐ Khmer ☐ Muong ☐ Nung ☐ Hre ☐ Phu ☐ E de ☐ Dao ☐ Co tu ☐ Cham ☐ Other, please specify.....

Address

House No: Street name:

Sub-district: District: Province:

Postcode: Email: Telephone/Mobile No:

Demographics and primary health indicators (person/family of person with CP)

Type of accommodation flooring: ☐ Finished floor ☐ Rough wood/bamboo ☐ Earth, sand

Number of household member: ..... Persons; Number of rooms in the household: ..... Rooms

Source of Drinking Water: ☐ Piped water ☐ Well water ☐ Other sources (ponds, river, stream, lake)

Sanitation: ☐ Flush toilet ☐ Pit toilet ☐ No facility, bush

Monthly family income of the child with CP (in Vietnamese Dong) ..... Dong

Please complete this section if individual with CP is under 18, or older than 18 but unable to give consent.

First name Surname Type of relationship

Address

House No: Street name:

Sub-district: District:

Province: Postcode: Email:

Telephone/Mobile No:

Health Professionals details

Name

Type (e.g. Medical practitioner, Physiotherapist, Occupational therapist)

Phone/Mobile Place of work

Address

Email

HOSPITAL BASED SURVEILLANCE OF CP IN HANOI, Vietnam

FOR PERSON WITH CEREBRAL PALSY (CP)

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Birth details of person with CP and maternal pregnancy details

Birth place ☐ Hospital ☐ Health Care Centre ☐ birth centre ☐ home birth ☐ Other/Specify.....

If home birth, ☐ Unplanned ☐ Planned, Delivery attended by ☐ Skilled birth attendant/TBA ☐ Other family members ☐ Doctor/Midwife

Birth weight (in gram) _____ or ☐ Unknown Born at _____ weeks gestation

Was there any sign of birth asphyxia (e.g. very weak breathing/cry, cyanosis, bradycardia, poor muscle tone/reflexes, meconium strained liquor, seizure - circle which applies): ☐ No ☐ Yes ☐ Don't Know

Did the child show any early feeding difficulties (first month of life) manifesting as poor sucking abilities?
☐ No ☐ Yes ☐ Don't Know

Mode of delivery ☐ Spontaneous vaginal delivery ☐ Instrumental delivery ☐ Caesarean section

Any complications during child birth/labour ☐ No ☐ Yes

If yes specify (please tick) ☐ Obstructed/prolonged labour (active phase of labour >12 hours) ☐ Malpresentation
☐ Pre-eclampsia/Eclampsia ☐ Haemorrhage ☐ Premature rupture of membranes/premature labour (<37 weeks) ☐ Other complications,

If other please specify _____

Did the mother experience any febrile illness during pregnancy ☐ No ☐ Yes ☐ Don't Know

If yes, was it associated with rash? ☐ No ☐ Yes ☐ Don't Know
If yes, please specify when did the rash appear? ☐ 1-12 weeks ☐ 13-28 weeks ☐ 29-40 weeks ☐ Don't Know

Did the mother experience any febrile illness during labour/child birth? ☐ No ☐ Yes ☐ Don't Know

Did the mother receive any antenatal care during pregnancy? ☐ Yes ☐ No

If Yes, ☐ Regular ☐ Irregular (but >2 visits) ☐ Irregular (<2 visits)

Did the mother receive any nutritional supplementation during pregnancy (e.g. Iron/Folic acid) ☐ Yes ☐ No ☐ Don't Know

[If multiple hospital transfer, specify highest level]
Hospital of neonatal transfer (if applicable) _____ District of hospital _____

Received more than routine care? ☐ Yes – NICU [e.g. intubation & ventilation] ☐ Yes - special care [e.g. Phototherapy, NG feeding] ☐ No - routine care only [e.g. Observation]

If Yes, total length of stay _____ days

Was MRI completed? ☐ Yes ☐ No Which hospital? _____

Was this a multiple birth? ☐ Yes ☐ No If Yes, ☐ Twins ☐ Triplets ☐ 4 ☐ 5 ☐ 6 ☐ >6

Birth order of child with CP in the family (e.g. 2nd) _____

Was there any assistance with conception? (please tick)
☐ No ☐Yes, type unknown ☐ Yes, if known please circle which type of assistance: fertility drugs only, ovulation stimulation only, artificial insemination, ICSI, IVF, GIFT. Other

Number of previous live births to mother _____ Number of previous stillbirths (> 20 weeks gestation) to mother _____

Number of previous miscarriages (< 20 weeks gestation) to mother _____

HOSPITAL BASED SURVEILLANCE OF CP IN HANOI, Vietnam

FOR PERSON WITH CEREBRAL PALSY (CP)

Birth parent details

Mother

First name Middle Name Surname

DOB (DD/MM/YYYY) __ __ /__ __ /__ __ __ __ Mother's educational level at time of child's birth: ☐ Illiterate

☐ Primary ☐ Secondary ☐ Higher secondary ☐ Graduation ☐ Post graduation ☐ Diploma/other trade qualification

Mothers occupation at time of child's birth

Father

First name Middle Name Surname

DOB (DD/MM/YYYY) __ __ /__ __ /__ __ __ __ Father's eeducational level at time of child's birth: ☐ Illiterate

☐ Primary ☐ Secondary ☐ Higher secondary ☐ Graduation ☐ Post graduation ☐ Diploma/other trade qualification

Father's occupation at time of child's birth

Are the parents related (blood related, i.e. first cousin) ☐ Yes ☐ No

Is there any other family member with disability? ☐ Yes ☐ No

If yes, how the other disabled family members related to the child with CP? ☐ Sibling ☐ Parent ☐ Both

Please specify the disability/impairment of the other family member (s)

Clinical details of child with CP (If you are unsure about any question, please leave blank)

Age at which CP was first formally diagnosed Years Months

Type of cerebral palsy (please tick)	**Main type at initial diagnosis (<5 years)**	**Main type at or over age 5**	**Secondary type at or over age 5**
Spasticity			
Left hemiplegia / monoplegia	☐	☐	☐
Right hemiplegia / monoplegia	☐	☐	☐
Diplegia	☐	☐	☐
Triplegia	☐	☐	☐
Quadriplegia	☐	☐	☐
Dyskinesia			
Mainly athetosis	☐	☐	☐
Mainly dystonia	☐	☐	☐
Ataxia	☐	☐	☐
Hypotonia	☐	☐	☐
Resolved by age 5	☐	☐	☐
Known syndrome - not CP	☐	☐	☐
Unknown syndrome - not CP	☐	☐	☐
Unknown	☐	☐	☐

HOSPITAL BASED SURVEILLANCE OF CP IN HANOI, Vietnam

FOR PERSON WITH CEREBRAL PALSY (CP)

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Severity of cerebral palsy (please tick one) (please see GMFCS sheet for further information)	**Main type at initial diagnosis**	**at or over age 5**
GMFCS level I	☐	☐
GMFCS level II	☐	☐
GMFCS level III	☐	☐
GMFCS level IV	☐	☐
GMFCS level V	☐	☐

Comment (e.g. any difficulty in assessing the GMFCS level)

Ability to handle objects in daily life (please tick one) (please see MACS sheet for further information)	**At or over age 4**
MACS level I	☐
MACS level II	☐
MACS level III	☐
MACS level IV	☐
MACS level V	☐

Were any birth defects present? (e.g. congenital heart defect) ☐ No ☐ Yes

If yes, please give details

Is there a known syndrome? ☐ No ☐ Yes

If yes, please give details

Presence of associated impairments (please tick one for each section)

Epilepsy	☐ Yes ☐ Resolved by age 5	☐ No ☐ Unknown
Intellectual	☐ No impairment ☐ Probably no impairment ☐ Probably some impairment	☐ Mild ☐ Moderate ☐ Severe ☐ Unknown
Visual	☐ No impairment ☐ Some impairment (e.g. glasses) **Strabismus ☐ No ☐ Yes ☐ Unknown**	☐ Functionally blind ☐ Unknown
Hearing	☐ No Impairment ☐ Some impairment (includes conductive hearing loss)	☐ Bilateral deafness ☐ Unknown
Speech	☐ No impairment ☐ Some impairment	☐ Non verbal ☐ Unknown

HOSPITAL BASED SURVEILLANCE OF CP IN HANOI, Vietnam

FOR PERSON WITH CEREBRAL PALSY (CP)

Timing of cerebral palsy? ☐ **Unknown** ☐ **During pregnancy and up to first 28 days of life (pre & perinatal)** ☐ **After first 28 days of life (postnatal)**

Was there a confirmed cause of cerebral palsy?

☐ Unknown
☐ In utero cytomegalovirus
☐ Other infection (toxoplasmosis, rubella, herpes simplex virus)
☐ Other infection (please list in comments)
☐ Other (please list in comments)

Head injury
☐ Motor vehicle accident
☐ Non accidental
☐ Fall
☐ Other (please describe in comments)

Infection
☐ Unspecified cause
☐ Viral
☐ Bacterial
☐ Dehydration due to gastroenteritis

Stroke or CVA
☐ During or following surgical procedure
☐ Spontaneous
☐ Associated with other cardiac complications

Other
☐ Post seizure
☐ Near sudden infant death syndrome (SIDS)
☐ Post immunisation
☐ Near drowning
☐ Peri-operative hypoxia
☐ Apparent life-threatening event
☐ Other (please describe in comments)

Comments

Immunisation history

Is the child fully immunised? ☐ Yes ☐ No ☐ Don't know

1. BCG and HepB vaccine after Birth ☐ 2. DPT-HepB-Hib and OPV at 2 months ☐ 4 months ☐ and 6 months ☐
3. Measles vaccine 9 months ☐ 4. Measles and Rubella vaccine 18 months ☐ 5. Japanese encephalitis vaccine 12 months ☐; + 2 weeks ☐; 2 years ☐

If No, reason why the child missed immunisation?
☐ Not aware ☐ No money ☐ Transport problem ☐ Others, please specify

Is there any BCG vaccine mark? ☐ Yes ☐ No

If the child is 9 months to 15 years old, did the child receive Measles-Rubella (MR) vaccine on 2015 National MR campaign [☐ N/A] ☐ Yes ☐ No

HOSPITAL BASED SURVEILLANCE OF CP IN HANOI, Vietnam

FOR PERSON WITH CEREBRAL PALSY (CP)

Nutrition

Current weight of the child _____ in Kg

Mid arm circumference of the child _____ in cm **Head circumference** of the child _____ in cm

Height of the child _____ in cm [knee height in cm .....]

(those with deformities, estimate height using the knee height equation, Height = (2.69 x knee height) + 24.2)

Education

Is the Child Currently attending mainstream school? ☐ Yes ☐ No ☐ Not applicable

Type of School if the child is attending a school ☐ Primary ☐ secondary ☐ Vocational/Other

Is the child currently attending any special school? ☐ Yes ☐ No

If not attending any school (6+ years) reason why? ☐ Working ☐ School too far ☐ Disability not accepted by school ☐ Lack of money

☐ Parents refused ☐ Other reason, specify _____

Rehabilitation

Has the child ever received any rehabilitation service or other related support ☐ Yes ☐ No

What type of support was received?

☐ **Assistive/adaptive device** ☐ Surgery ☐ Therapy exercises ☐ Advice ☐ Other, Specify _____

If Assistive/adaptive device is ticked, please specify which applies;

☐ Wheelchairs ☐ Standing/walking aids (walker/frame) ☐ Strollers ☐ Orthotics (AFO/KFO) ☐ Specialised seating (corner chair) ☐ Mealtime Aids ☐ Communication Aids, Other ☐, Please specify.....

What was the type of location for accessing these rehabilitation services?

☐ Home based ☐ NGO centre ☐ Hospital ☐ Private clinic

Age at when the child first received any rehabilitative services _____ (in years)

Reason why child NEVER received rehabilitation?

☐ Not aware ☐ No money ☐ Transport problem ☐ Others, please specify _____

General health

Number of hospitalizations for chest infections/respiratory infections in the past 6 months: ..... times

Does the child have any swallowing difficulty? ☐ Yes ☐ No ☐ Unknown

Does the child have reflux (gastro-oesophageal reflux disease – GORD)? ☐ Yes ☐ No ☐ Unknown

The above information has been collected by _____ on __ __ /__ __ /__ __ __ __

who is a (please tick) ☐ Medical practitioner ☐ Physiotherapist ☐ Occupational therapist ☐ Speech pathologist