Institution: Queen's University Belfast

Unit of Assessment: UOA 3

Title of case study: Improving healthcare for children with cerebral palsy via surveillance

Period when the underpinning research was undertaken: 2000-2020

Details of staff conducting the underpinning research from the submitting unit:

Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Dr Claire Kerr	Senior Lecturer; Manager of the NICPR (2016-)	2007-present
Dr Jackie L Parkes	Reader; Manager of the NICPR (1998-2013)	1998-2013
Dr Oliver Perra	Senior Lecturer in perinatal health and wellbeing; Manager of the NICPR (2013-	2013-present

Period when the claimed impact occurred: 2013-2020

Is this case study continued from a case study submitted in 2014? No

1. Summary of the impact

Surveillance of children with cerebral palsy (CP) and associated research undertaken by the Northern Ireland Cerebral Palsy Register (NICPR), held at Queen's University Belfast, has:

1. Enabled development of new services, **providing specialist care and targeted rehabilitation** to all children with CP in Northern Ireland (NI);

2. Developed cost-effective tools to describe CP that have been adopted across NI and internationally, **improving communication** between healthcare professionals and families and **reducing clinical assessment burden**; and

3. **Informed UK and international standards of care**, for example, NICE guidelines and a UK National Confidential Enquiry into Patient Outcome and Death (NCEPOD).

2. Underpinning research

Defining prevalence via systematic surveillance

CP is the leading cause of childhood physical disability. It is a life-long condition. Clinical presentation varies widely from mild problems to profound disability with high associated health and social care costs **(R1)**. Numbers and needs of people with CP are not captured by routine healthcare data coding **(R2)**.

As a result of improved survival of small and premature babies who are particularly at risk of CP, the Department of Health (NI) commissioned Parkes to monitor prevalence of CP to inform child health surveillance and planning of rehabilitation services. The NICPR (https://www.qub.ac.uk/research-centres/NorthernIrelandCerebralPalsyRegister/) has received continuous support since 1992 and is the only remaining CP register commissioned by the NHS **(R2)**. It is governed by an Advisory Committee that includes people with CP and its work is influenced by the NICPR's Patient and Public Involvement Committee.

The NICPR is a member of the Surveillance of Cerebral Palsy in Europe (SCPE) network, part of the European Platform on Rare Diseases Registration, managed by the European Commission's Joint Research Centre **(R3)**. The NICPR has systematically collected data on over 2,000 children with CP, including information about their birth, health and severity of impairment **(R1,3)**. Our data and research has shown that in 'high risk' infants, that is, those born prematurely or at low birthweight, prevalence of CP is decreasing **(R1,3)**.

Classifying Severity of Cerebral Palsy

As part of SCPE, the NICPR contributed to establishing consistent and objective criteria for classification of CP **(R3)**. Recognising the need for clear communication about CP severity between healthcare professionals and families, Kerr and colleagues developed and validated a robust 'family-report' version of a clinical classification tool. High levels of inter-observer agreement when using the tool were demonstrated between parents, therapists and researchers in a cohort of 184 children **(R4)**.

Assessing the Impact of Cerebral Palsy on Children and on Health Service Needs

Many children with CP require orthopaedic surgery to maintain their walking ability. Surgical planning involves lengthy, technical assessments in a hospital-based movement laboratory. This presents challenges, particularly for younger children and those with more severe disabilities. As means of quantifying walking ability in these children, Kerr and colleagues developed and validated a simple walk test **(R5)** that can be used in any clinical or community setting.

Management of CP traditionally focused on medical, surgical and therapy interventions to address specific impairments. However, as a partner in the EU-funded SPARCLE studies, that included eight research centres in six different European countries (SPARCLE 1 & 2, 2004-2012), Parkes demonstrated how quality of life, psychosocial well-being and participation of children with CP are influenced by pain, and by the child's physical, social and attitudinal environment **(R6)**. Parkes' work recommended embedding assessment of pain and participation into routine clinical practice.

As part of the recent Child Health Outcome Review Programme, commissioned by the UK Healthcare Quality Improvement Partnership, Perra and colleagues demonstrated that although children with CP aged 0-24 years represent 0.3% of the NI population, they account for 1.6% of hospital admissions and 1.6% of outpatient appointments, evidencing higher health service needs than their typically developing peers **(R2)**.

3. References to the research

(R1) Perra O; Garcia Jalon EG; Cummings C; Platt MJ; Knox H. Children and young people with cerebral palsy in Northern Ireland (1981-2008): A comprehensive report from the Northern Ireland Cerebral Palsy Register, 2016. https://www.qub.ac.uk/research-centres/NorthernIrelandCerebralPalsyRegister/Filestore/Filetoupload,825660,en.pdf

(R2) Carter B; Bennett CV; Jones H; Bethel J; **Perra O**; Wang T; Kemp A. Healthcare use by children and young adults with cerebral palsy. Developmental Medicine and Child Neurology 2020 Apr 20. [Epub ahead of print] https://onlinelibrary.wiley.com/doi/epdf/10.1111/dmcn.14536

(R3) Surveillance of Cerebral Palsy in Europe (SCPE) Scientific report 1998-2018: https://eu-rd-platform.jrc.ec.europa.eu/sites/default/files/SCPE%20Scientific%20report%201998-2018.pdf

(R4) McDowell BC; **Kerr C; Parkes JL**. Interobserver agreement of the Gross Motor Function Classification System in an ambulant population of children with cerebral palsy. Developmental

Medicine and Child Neurology 2007 49(7) 528-533. https://onlinelibrary.wiley.com/doi/epdf/10.1111/j.1469-8749.2007.00528.x
(R5) McDowell BC; Humphreys L; **Kerr C**; Stevenson M. Test-retest reliability of a 1-min walk test in children with bilateral spastic cerebral palsy (BSCP). Gait and Posture 2009 29(2) 267-269. https://www.ncbi.nlm.nih.gov/pubmed/19013798
(R6) Fauconnier J; Dickinson H; Beckung E; Marcelli M; McManus V; Michelsen SI; **Parkes JL**; Parkinson K; Thyen U; Arnaud C; Colver A. Participation in life situations of 8-12 year old children with cerebral palsy: cross sectional European study. British Medical Journal 2009 Apr 24; 338. https://www.bmj.com/content/bmj/338/bmj.b1458.full.pdf

4. Details of the impact

The NICPR defines prevalence and needs of children with CP via ongoing, robust surveillance. This surveillance and associated research has:

1. Enabled review of existing services and development of new services, providing access to specialist care for all children with CP in NI. Beneficiaries include children with CP and their families who receive tailored, goal-orientated health and education, designed to meet population-level needs; and community-based healthcare staff who now have access to tertiary expertise and new clinical services. Examples of our impact on service review and development include:

(a) NICPR data and research **(R1,3)** underpinned the business case for a **tertiary paediatric neurodisability service** that was established in late 2013 and serves all of NI, providing specialised management of movement disorders to up to 600 children annually. **[S1]**

Within the neurodisability service, data provided by the NICPR provided the basis for the business case and staffing profile for the award winning **evidence-based upper limb service and pathway.** '*The upper limb service is now seen as the 'gold standard' throughout the UK and was recognised as the 'Most Effective Adoption and Diffusion of Best Practice' in the Health Service Journal (HSJ) Awards 2016.*' **[S1]**

NICPR data also informed the case for **introduction of local splinting clinics** in all five Health and Social Care Trusts (HSCT) in NI. '*This has improved access to splinting services for many children with CP (approximately 120 children per year) as there are now monthly splinting clinics in each trust, instead of having to travel to the regional centre.*' **[S1]**

(b) NICPR data **(R1)** was used to justify the creation of a new joint **Paediatric/Orthopaedic service in the Western HSCT in 2015.** The Western HSCT is geographically dispersed and most distant from the NI regional orthopaedic centre. The new dual-speciality service reduces the travel burden for 90 children/year **[S2]** and provides holistic, family-centred care. A 2017 patient satisfaction survey **[S3]** revealed 100% of respondents to be happy with the new service as '*parents value having the opportunity to see an orthopaedic surgeon about their child's CP at the same time as their paediatrician.*' **[S2]**

(c) NICPR data has been used by a NI charity (Mae Murray Foundation) that focuses on inclusion, particularly of children and young people with disabilities and their families. The charity **challenged proposals by the NI Education Authority to remove specialist education schools** for children with physical disabilities, using NICPR data to rebut the Education Authority's claim that the proposals would affect a small number of children.

The value of the NICPR data is evidenced by the following testimonial from the Chairperson of the Mae Murray Foundation: '*The evidence provided [by NICPR] allowed us to make a strong and convincing case that there is a substantial number of children and families affected by Cerebral Palsy whose rights to education, which are enshrined in the UN Convention, are at risk of being jeopardised by the proposed changes. The evidence provided by the NICPR has been also referenced in correspondence with Permanent Secretary for NI, the Children's Commissioner, the Children's Law Society, and we are also considering approaching the Human Rights Commission on this matter. I will emphasise at this point that without the data and the information that NICPR were able to provide to and organise for us, we would have had a very difficult task in rebutting the information the Education Authority was giving to parents.*' **[S4]**

2. Developed internationally-adopted, cost-effective tools to describe CP that improve communication and reduce assessment burden. Beneficiaries of these tools are children with CP, their families, and healthcare professionals, as they reduce assessment burden and provide a common language facilitating transparent communication. For example:

(a) As a partner in a European research consortium (SCPE) **(R3)**, Parkes contributed to development of decision and classification tools for CP. These harmonised definitions and tools are used internationally **improving communication about CP**. In 2018 SCPE reported that over 21,000 European children with CP have been assessed using these tools **(R3)**, including over 2,000 children from NI **(R1)**. A 2014 survey demonstrated that internationally, 63% of all CP registers use SCPE definitions **[S5]**.

(b) The 'family report' of the Gross Motor Function Classification System (GMFCS), developed by Kerr and McDowell **(R4)**, built on the work of Palisano and colleagues (CanChild, McMaster University, Canada). The family-report '*presents an option for parent involvement in classifying children's motor abilities*' **[S6],** has been translated into 14 languages and is freely available online. A 2018 study **[S7]** reported that 71% of families, that were aware of their child's GMFCS level, found it **useful for collaborative goal-setting** with clinicians.

(c) Kerr and McDowell's 'one-minute walk test' **(R5)** is **used in routine clinical practice** by the NI Gait Analysis Service with approximately 50 children per year. The Gait Analysis Service Manager reported that it reduces assessment burden and '*provides us with reliable and meaningful results*'. **[S8]**

3. Informed UK and international standards of care that benefit service commissioners, planners and policy makers as well as clinicians and, ultimately, children and families.

(a) Thirteen publications by Parkes, and/or using NICPR data, are included in the **2017 NICE guideline on assessment and management of CP in under 25s [S9]**. NICE provide national guidance, advice, quality standards and information that are considered international 'best practice'. Parkes' contributions informed recommendations for recognising and discussing speech issues, assessment of mental health problems, and assessment and management of comorbidities in CP.

(b) The NICPR was one (of only two) representative registers contributing data to the **2018 UK National Confidential Enquiry into Patient Outcome and Death (NCEPOD) [S10].** NCEPOD reported higher rates of healthcare consultations, poor communication with patients and multi-disciplinary teams, and inadequacies in NHS data collection and

coding for children with chronic neurodisabilities **(R2).** NCEPOD made 35 recommendations for action by NHS staff, systems and services, commissioners, general practitioners, regulators, Royal Colleges and Specialty Associations, with the overall aim of improving care provided to children and young people with chronic neurodisabilities. The NCEPOD report has already prompted joint working with numerous partner organisations to ensure a consistent approach to long-term ventilation of children and young people with chronic neurodisabilities **[S10].**

Inclusion of NICPR data and research in these seminal guidelines **[S9]** and reports **[S10]** demonstrates the quality, significance and reach of the NICPR's work in care planning and policy.

5. Sources to corroborate the impact

1. Testimonial by clinical specialist occupational therapist, Paediatric Neurodisability Service, Belfast Health and Social Care Trust.
2. Testimonial by community paediatrician, Western Health and Social Care Trust.
3. Patient and carer satisfaction survey of joint orthopaedic/paediatric clinic re-audit. Western Health and Social Care Trust, 2017.
4. Testimonial by Chairperson, Mae Murray Foundation.
5. Goldsmith S; McIntyre S; Smithers-Sheedy H; Blair E; Cans C; Watson L; Yeargin-Allsopp M. on behalf of the Australian Cerebral Palsy Register Group. An international survey of cerebral palsy registers and surveillance systems. Developmental Medicine and Child Neurology 2016 58(Suppl 2):11-17. https://onlinelibrary.wiley.com/doi/epdf/10.1111/dmcn.12999
6. Family and Self-Report Gross Motor Function Classification System. CanChild. https://canchild.ca/system/tenon/assets/attachments/000/000/481/original/GMFCS_Family.pdf
7. Bailes AF; Gannotti M; Bellows DM; Shusterman M; Lyman J; Horn SD. Caregiver knowledge and preferences for gross motor function information in cerebral palsy. Developmental Medicine and Child Neurology 2018 60(12):1264-1270 https://onlinelibrary.wiley.com/doi/epdf/10.1111/dmcn.13994
8. Testimonial by clinical specialist physiotherapist, NI Gait Analysis Service, Belfast Health and Social Care Trust
9. National Institute for Health and Care Excellence. Cerebral Palsy in under 25s: assessment and management. NICE guideline [NG62] 2017. https://www.nice.org.uk/guidance/ng62/evidence (see pages 146-151, 286-290, 326-330, 361-364, 371-382 of the full guideline)
10. The National Confidential Enquiry into Patient Outcome and Death. Each and Every Need. 2018. London https://www.ncepod.org.uk/2018cn.html (see pages 3, 22-6, 86-7, 90-96)