

Title	National Standards for Public Involvement in Research
Principal investigators	Dr Claire Kerr (Queen's University Belfast, P.I.), Ms Helen Savage (NICPR Public Representative) & Dr Karen McConnell (Queen's University Belfast, Research Fellow).
Funding	Public Health Agency (PHA) & National Institute for Health Research (NIHR), 2018-19.
Outline	The Northern Ireland Cerebral Palsy Register (NICPR) was one of 10 'test-bed' projects that tested the NIHR National Standards for Public Involvement in Research. This involved working with NIHR and PHA to help establish if the NIHR standards work in practice and to share what is learnt from using the standards. As a 'test-bed' the NICPR (i) created a public involvement (PI) group (persons with CP and their family, carers and friends), (ii) collaboratively determined terms of reference, activities and training needs of this PI group, (iii) developed jargon-free communication methods to meet the needs of different audiences, and (iv) recorded, monitored and evaluated our PI activity
Publications and Outputs	Download a copy of the Standards for Public Involvement in Research.

Title	National Standards for Public Involvement in Research
Principal investigators	Dr Elena Guiomar Garcia Jalon (Queen's University Belfast, P.I.), Dr Oliver Perra (Queen's University Belfast, co-applicant) & Dr Anna Gavin, Dr Dermot O'Reilly & Prof Allen Thurston (Queen's University Belfast, collaborators).
Funding	Public Health Agency & Improving Children's Lives, 2015-20.
Outline	This study investigated the prevalence of pain in cerebral palsy using information on prescribed pain medication.
Publications and Outputs	Garcia Jalon EG, Maguire A, Perra O, Gavin A, O'Reilly D, Thurston A. Data linkage and pain medication in people with cerebral palsy: a cross-sectional study. Developmental Medicine & Child Neurology. 2021 Sep;63(9):1085-92. Available at: https://doi.org/10.1111/dmcn.14854

<i>Title</i>	Multiple birth and cerebral palsy in Europe 1990-2007: a multicentre study
<i>Principal investigators</i>	Dr Oliver Perra (Queen's University Belfast, P.I.), Prof Judith Rankin (University of Newcastle) & SCPE Network.
<i>Funding</i>	Queen's University Belfast, 2015-18
<i>Outline</i>	This study investigated the prevalence of cerebral palsy among single and multiple births between 1990-2007 using data provided by the multi-centre Surveillance of Cerebral Palsy in Europe (SCPE) network.
<i>Publications and Outputs</i>	Perra O, Rankin J, Platt MJ, Sellier E, Arnaud C, De La Cruz J, Krägeloh-Mann I, Sweet DG, Bjellmo S. Decreasing cerebral palsy prevalence in multiple births in the modern era: a population cohort study of European data. Archives of Disease in Childhood-Fetal and Neonatal Edition. 2021 Mar 1;106(2):125-30. Doi: 10.1136/archdischild-2020-318950
<i>Title</i>	Transition study – a study of how to improve the transition of young people with complex health needs from children to adult services
<i>Principal investigators</i>	Professor Allan Colver (Newcastle University, P.I.) and nine other investigators, assisted by collaborators and research associates across the UK, including Dr Mark Linden and Prof Maria Lohan (Queen's University Belfast).
<i>Funding</i>	National Institute for Health Research, Programme Grants for Applied Research scheme, 2012-17.
<i>Outline</i>	The Transition Programme was a 5-year programme of research examining how health services can contribute most effectively to the successful transition of young people with complex health needs from childhood to adulthood.
<i>Publications and Outputs</i>	Visit the Transition Study website for more information.

<i>Title</i>	A study of participation and quality of life of 8-12 year old children (SPARCLE 1) and 13-17 year old children (SPARCLE 2)
<i>Principal investigators</i>	Professor Allan Colver (Newcastle University, P.I.) with Dr Jackie Parkes (Queen's University, Local Co-ordinator), Mrs Ann Madden (Queen's University, Local Research Associate) and seven other Local Co-ordinators and Research Associates from other EU countries including France, Sweden, Italy, Denmark and Republic of Ireland.
<i>Funding</i>	EEC Research Framework 5 (Quality of Life), 2004-05 (SPARCLE 1), 2009-10 (SPARCLE 2).
<i>Outline</i>	SPARCLE 1 investigated the role of 'environmental factors' (access, transport, social policy, attitudes, and service arrangements) on participation and quality of life for 8-12 year old children with cerebral palsy of all abilities. SPARCLE 2 reassessing the same children when they were 13-17 years old.
<i>Publications and Outputs</i>	Visit the SPARCLE Study website.
<i>Title</i>	Management of the upper limb in children with cerebral palsy
<i>Principal investigators</i>	Mrs Karen McConnell supervised by Dr Claire Kerr (Queen's University Belfast) & Prof Linda Johnston (Queen's University Belfast)
<i>Funding</i>	Department for Employment & Learning, PhD studentship, 2009-12.
<i>Outline</i>	This study investigated assessment of the upper limb in cerebral palsy, upper limb problems from the perspectives of families and therapists, and use of constraint induced movement therapy to treat the upper limb in children with hemiplegic cerebral palsy.
<i>Publications and Outputs</i>	<p>McConnell K, Johnston L, Kerr C. Therapy management of the upper limb in children with cerebral palsy: A cross-sectional survey. <i>Developmental Neurorehabilitation</i>. 2012 Oct 1;15(5):343-50. Available at: Therapy management of the upper limb in children with cerebral palsy: a cross-sectional survey - PubMed (nih.gov).</p> <p>McConnell K, Johnston L, Kerr C. Upper limb function and deformity in cerebral palsy: a review of classification systems. <i>Developmental Medicine & Child Neurology</i>. 2011 Sep;53(9):799-805. Available at: Upper limb function and deformity in cerebral palsy: a review of classification systems - MCCONNELL - 2011 - Developmental Medicine & Child Neurology - Wiley Online Library</p>

Title The health of children with cerebral palsy and stress in their parents

Principal investigators Ms Elaine McCahey supervised by Dr Jackie Parkes (Queen's University Belfast), Dr Nichola McCullough (Ulster University), and Mrs Ann Madden (Queen's University, Local Research Associate)

Funding Department for Employment & Learning, PhD studentship, 2009-12.

Outline This study described the health of children with cerebral palsy and investigated predictors of stress in their parents.

Publications and Outputs Parkes J, McCullough N, Madden A, McCahey E. The health of children with cerebral palsy and stress in their parents. Journal of Advanced Nursing. 2009 Nov;65(11):2311-23. Available at: <https://doi.org/10.1111/j.1365-2648.2009.05089.x>

Title Locomotor Ability in Cerebral Palsy

Principal investigators Mr Aidan Cosgrove, Dr Brona McDowell, Dr Claire Kerr (Belfast Health & Social Care Trust, Musgrave Park Hospital), Dr Jackie Parkes (Queen's University Belfast)

Funding Northern Ireland Research & Development Office, in Recognised Research Group 8 (Trauma and Rehabilitation), 2002-08.

Outline This study investigated changes in the locomotor abilities of children with ambulant cerebral palsy, aged 4-16 years over time.

<i>Title</i>	LiLaC Study: Lifestyle limitations in children and young adults with severe cerebral palsy
<i>Principal investigators</i>	Mrs Collette Donnelly (Royal Belfast Hospital for Sick Children) supervised by Dr Jackie Parkes (Queen's University Belfast) & Dr Brona McDowell & Miss Catherine Duffy (Belfast Health & Social Care Trust, Musgrave Park Hospital).
<i>Funding</i>	Northern Ireland Research & Development Office, Doctoral Fellowship Scheme, 2006-10.
<i>Outline</i>	This study investigated the prevalence of orthopaedic problems (hip dislocation, pelvic obliquity, spinal deformity, orthopaedic-related pain) and their relationship with participation and health in children and young people aged 4-25 years with severe cerebral palsy (GMFCS levels IV and V).
<i>Publications and Outputs</i>	Donnelly C, Parkes J, McDowell B, Duffy C. Lifestyle limitations of children and young people with severe cerebral palsy: a population study protocol. Journal of advanced nursing. 2008 Mar;61(5):557-69. Doi: 10.1111/j.1365-2648.2007.04470.x

<i>Title</i>	Inequalities in pregnancy outcome
<i>Principal investigators</i>	Professor Helen Dolk (University of Ulster, Principal Investigator) with Dr John Jenkins in collaboration with others including UKCP partners
<i>Funding</i>	Northern Ireland Research & Development Office; Commissioned Programme – Targeting Social Need, 2004-06.
<i>Outline</i>	This study replicated a larger survey based in Great Britain exploring inequalities in pregnancy outcomes. One of the outcome measures used was cerebral palsy rates and the extent to which they varied by socio-economic indicators across the United Kingdom.

<i>Title</i>	Life expectancy in cerebral palsy
<i>Principal investigators</i>	Professor Jane Hutton (University of Warwick, Principal Investigator) with Dr Karla Hemming and UKCP partners including Dr Jackie Parkes and Professor Helen Dolk
<i>Funding</i>	Medical Research Council (MRC), 2001-05.
<i>Outline</i>	This study utilises the registry data already collected by the UKCP partners to investigate regional and clinical variations in survival among the childhood population with cerebral palsy.
<i>Publications and Outputs</i>	Available at: scope4.pdf (warwick.ac.uk)
<i>Title</i>	Use of physiotherapy & alternatives by children with cerebral palsy
<i>Principal investigators</i>	Ms Jackie Parkes, Dr Helen Dolk, Dr Nan Hill and Dr Michael Donnelly
<i>Funding</i>	Special Fellowship Royal Belfast Hospital for Sick Children; Department of Health and Social Services Northern Ireland, 1994-98.
<i>Outline</i>	This study used the NICPR as a sampling frame to survey the views and experiences of parents with a child with moderate – severe cerebral palsy.
<i>Publications and Outputs</i>	Parkes J, Donnelly M, Dolk H, Hill N. Use of physiotherapy and alternatives by children with cerebral palsy: a population study. Child: care, health and development. 2002 Nov;28(6):469-77. Doi: 10.1046/j.1365-2214.2002.00304.x